THE EFFECTIVENESS OF JOINT CRISIS PLANS IN REDUCING HOSPITAL ADMISSIONS FOR ETHNIC MINORITY SERVICE USERS WITH SEVERE MENTAL ILLNESS – FINDINGS OF THE CRIMSON TRIAL

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

2013

GILLIAN BROWN

SCHOOL OF MEDICINE
## Contents

List of Tables .................................................................................................................. 8
List of Figures .................................................................................................................... 11
Abstract ............................................................................................................................. 12
Declaration .......................................................................................................................... 13
Copyright Statement ......................................................................................................... 13
Acknowledgements ........................................................................................................... 14
About the Author ............................................................................................................... 14
  The author’s original contribution to research beyond CRIMSON ................................. 15
Chapter 1: Introduction .................................................................................................... 17
  Overview ......................................................................................................................... 17
  Prevalence of mental illness ....................................................................................... 18
  Breakdown of ethnic groups in the UK .................................................................... 19
  Higher rates of non-psychotic illness in ethnic minority groups .......................... 20
  Higher rates of psychosis in ethnic minority groups ............................................... 21
  Race, culture and ethnicity ......................................................................................... 23
    Race ............................................................................................................................. 23
    Culture ........................................................................................................................ 23
    Ethnicity and ethnic groups .................................................................................... 24
    Ethnic versus cultural factors in ethnic minority mental health ........................ 25
    Pitfalls of ethnic categorisation ............................................................................. 26
    Difficulties with collecting ethnic minority mental illness data ........................ 28
  Aims of this review ....................................................................................................... 28
  Higher hospital admission rates for ethnic minority groups .................................. 29
    Trends in compulsory hospital admissions in the UK ...................................... 32
  Consequences of compulsory hospital admissions ............................................... 34
  Explanations for disproportionate hospital admission rates .................................. 36
    1. Higher rates of psychosis .................................................................................... 36
2. Seeking help too late .................................................................................................................. 38
3. Refusing to be treated on a voluntary basis ........................................................................... 39
4. Being more likely to be sectioned ........................................................................................... 40

Summary of explanations for disproportionate compulsory hospital admissions ........... 44

Questions arising from this chapter ......................................................................................... 46

Chapter 2: Inclusion of ethnic minority groups in psychiatric research ................................. 47

Overview .................................................................................................................................... 47
Rationale for this review .............................................................................................................. 48
Background .................................................................................................................................... 48
Methodology .................................................................................................................................. 49
Results .......................................................................................................................................... 50
Participant related barriers.......................................................................................................... 56
Practical issues ............................................................................................................................... 60
Family/ community related ........................................................................................................... 63
Health service related .................................................................................................................. 64
Research process .......................................................................................................................... 66
Discussion ..................................................................................................................................... 69
Limitations of applying US data to a UK population ................................................................. 72
Conclusion ..................................................................................................................................... 74
Implications for this thesis ........................................................................................................... 75

Chapter 3: Systematic review of the effectiveness of helping people with mental illness
specify how they would like to be treated in a crisis ................................................................. 76

Overview ..................................................................................................................................... 76
Background ..................................................................................................................................... 77
Terminology used in crisis planning interventions ................................................................. 78
Objectives ..................................................................................................................................... 80
Methods ........................................................................................................................................ 80
Criteria for considering studies for this review ................................................................. 80
Search methods for identification of studies ........................................................................... 81
Recruitment of eligible service users................................................................. 127
Informed consent.................................................................................................. 129
On-going trial promotion ...................................................................................... 129
Research assessments used .............................................................................. 130
Service user data collection .............................................................................. 130
Socio-demographic information ......................................................................... 130
Adult service use schedule .............................................................................. 132
Hospital admissions .......................................................................................... 133
Joint crisis plan usage questionnaire ................................................................. 137
Focus groups .................................................................................................... 137
Care Coordinator data collection ...................................................................... 138
Socio-demographics .......................................................................................... 138
Working alliance inventory (WAI) clinician version .......................................... 141
Focus groups .................................................................................................... 141
Researcher ....................................................................................................... 142
Randomisation of participants ........................................................................ 142
Blinding and concealment of allocation ............................................................ 143
Training and supervision process ..................................................................... 143
The joint crisis plan intervention ..................................................................... 145
Maintaining contact with participants throughout the trial ......................... 146
Summary of how CRIMSON has addressed the limitations of previous research.............................................................................................................. 146
Power calculation ............................................................................................. 147
Analysis Plan for CRIMSON .......................................................................... 148
Chapter 6: Methodology for this thesis within CRIMSON ............................... 149
Overview .......................................................................................................... 149
Rationale for this thesis .................................................................................... 149
Defining ethnicity .............................................................................................. 150
Ethnic minorities in this thesis ......................................................................... 151
Summary of reasons for inclusion of south Asian and black service users only... 153
Studies within this thesis ................................................................. 154

1. The effectiveness of joint crisis plans ........................................ 154
2. The recruitment of ethnic minorities in Manchester/Lancashire ....... 158
3. Joint crisis plans culturally relevant statement analysis ............... 163

Chapter 7: Results ............................................................................. 164

Overview ........................................................................................... 164

Findings of the CRIMSON trial ......................................................... 165

Primary outcomes analysis ............................................................. 166
Subgroup analysis ............................................................................ 169
Secondary outcomes analysis ......................................................... 171

Study 1: The effectiveness of joint crisis plans ............................... 173
Purpose of this study ....................................................................... 173
Study trial diagram .......................................................................... 173
Reasons for non-completion of joint crisis plans by site ............... 175
Primary outcomes analysis ............................................................. 175
Results by hypotheses ..................................................................... 180

Study 2: Recruiting ethnic minorities into the CRIMSON trial ........ 189
Purpose of this study ....................................................................... 189
Number of south Asian participants recruited ............................. 189
Results from diary entries ............................................................. 189

Study 3: Joint crisis plan culturally relevant statement analysis ...... 203
Purpose of this study ....................................................................... 203
Numbers of south Asian and black participants who made a culturally relevant statement within their joint crisis plan.. 203
Content analysis of joint crisis plans ............................................... 205
Summary of results ......................................................................... 208

Chapter 8: Discussion – Differential effect of joint crisis plans, yet positive implications for ethnic minority trial recruitment ........ 209

Overview ........................................................................................... 209

Study 1: Strengths, limitations and implications ......................... 210
Final word count: 79655
List of Tables

Table 1: UK population by ethnic group: January-December 2010 .................................................. 20
Table 2: Number of people admitted to hospital and those with compulsory admissions, by ethnic group.................................................................................................................. 31
Table 3: Number of people with compulsory hospital admissions, by ethnic group from 2007-2011 ................................................................................................................................. 33
Table 4: Number of people using secondary mental health services and those on Care Plan Approach, all by ethnic group........................................................................................................ 43
Table 5: Rejected search results showing reason for exclusion ............................................................... 52
Table 6: Table of included studies ........................................................................................................... 53
Table 7: Frequency of barriers across included studies ....................................................................... 55
Table 8: Key terms relating to planning for a crisis .............................................................................. 79
Table 9: Excluded search results with reason for exclusion ................................................................. 84
Table 10: Summary table of included studies ....................................................................................... 87
Table 11: Summary table of interventions designed to help service users document their treatment preferences ................................................................................................................. 90
Table 12: The three recruitment sites in the trial, the NHS trusts involved and the areas covered................................................................................................................................. 114
Table 13: Breakdown of top ethnic populations across the south London recruitment areas .......................................................... 117
Table 14: Ethnic breakdown of the population in Birmingham ............................................................. 120
Table 15: Breakdown of ethnic groups in east Lancashire .................................................................. 122
Table 16: Breakdown of ethnic minority groups in Manchester ......................................................... 123
Table 17: Service user outcome measures for the CRIMSON trial....................................................... 130
Table 18: Care coordinator outcome measures for the CRIMSON trial ............................................. 132
Table 19: How barriers were addressed within the trial ..................................................................... 158
Table 20: Baseline demographics by randomisation arm for the CRIMSON trial............................. 165
Table 21: Proportions admitted by trial arm ......................................................................................... 167
Table 22: Logistic regression, joint crisis plan vs. control group ......................................................... 168
Table 23: Summary of number of days admitted (including formal and informal sections) by trial arm ................................................................................................................................. 168
Table 24: Linear regression of number of days admitted, robust standard errors, joint crisis plan vs. control group ................................................................. 168
Table 25: Summary of number of admissions during follow-up period by trial arm .......... 169
Table 26: Comparison of admission by randomisation arm for black subgroup ............... 169
Table 27: Logistic regression, joint crisis plan vs. control group for black subgroup ......... 170
Table 28: Summary of number of days admitted (under formal or informal section) by randomisation arm for black subgroup ................................................................. 170
Table 29: Summary of number of admissions in follow-up period by randomisation arm for black subgroup .................................................................................................................. 171
Table 30: Summary of secondary outcomes and t-test by randomisation arm ............... 171
Table 31: Individual linear regression models of outcomes by randomisation arm ......... 172
Table 32: Number of completed joint crisis plans for south Asian and black and white British participants .................................................................................................................. 175
Table 33: Summary of reasons for non-completion by ethnic group.............................. 175
Table 34: Baseline demographics by randomisation arm ................................................ 175
Table 35: Baseline characteristics associated with missing outcome data ...................... 176
Table 36: Ethnic breakdown of full sample by trial arm including missing data ............. 178
Table 37: Number of south Asian and black participants admitted by trial arm ............ 179
Table 38: Logistic regression, intervention group versus the control group for formal admissions adjusted by site (n=176) ........................................................................................................... 182
Table 39: Sensitivity analysis: Logistic regression, intervention group versus the control group for formal admissions adjusted by site .................................................................................................................................. 182
Table 40: Logistic regression, intervention group versus the control group for formal admissions for white British participants (n=307) and south Asian and black participants (176), adjusted by site ........................................................................................................ 183
Table 41: Table to show proportions admitted by trial arm ........................................ 184
Table 42: Logistic regression, intervention groups versus the control group for mixed admissions, adjusted for by site (n=176) .................................................................................................................................. 185
Table 43: Sensitivity analysis: Logistic regression, intervention group versus the control group for any admissions adjusted by site .................................................................................................................................. 185
Table 44: Logistic regression, intervention group versus the control group for any admissions for white British participants (n=307) and south Asian and black participants (176), adjusted by site .................................................................................................................................. 185
Table 45: Summary of unadjusted working alliance scores and t-test by randomisation arm (n=139) ................................................................. 186

Table 46: Linear regression model of working alliance inventory scores adjusted by site and baseline working alliance scores (n=139) ................................................................. 187

Table 47: Sensitivity analysis: Linear regression model of working alliance inventory scores adjusted by site and baseline working alliance scores .................................................. 187

Table 48: Linear regression model of working alliance inventory scores adjusted by site and baseline working alliance scores for white British (n=249) and south Asian and black (n=139) participants .................................................................................................................. 187

Table 49: Socio-demographics of south Asian participants ................................................................. 191

Table 50: Number of people who made cultural references ................................................................. 203

Table 51: Number of participants included within content analysis, their ethnicity and sections of the joint crisis plan they made cultural references within ............................................. 204

Table 52: Identification of barriers and recommended activities to overcome them................. 234
List of Figures

Figure 1: Prevalence of common mental health problems in UK ........................................ 19
Figure 2: Common mental disorders by ethnicity and gender ........................................... 21
Figure 3: Positive psychosis screening questionnaire item by ethnicity and gender .............. 22
Figure 4: PRISMA diagram to show process of study selection ........................................ 51
Figure 5: PRISMA diagram to show process of study selection ........................................ 83
Figure 6: Map to show non-white population by area in the UK ....................................... 115
Figure 7: Map of London, showing the south London and Maudsley foundation trust teams from which participants were recruited ................................................................. 116
Figure 8: Map of London to show non-white population .................................................. 117
Figure 9: Map of Birmingham, showing the Birmingham and Solihull mental health NHS foundation trust teams from which participants were recruited and the population of ethnic minority groups ................................................................. 119
Figure 10: Map of Lancashire, showing the Lancashire care foundation trust teams from which participants were recruited ................................................................. 121
Figure 11: Map of Lancashire to show the Non-White population ..................................... 121
Figure 12: Map of Manchester, showing the Manchester mental health and social care trust teams from which participants were recruited and the population of non-white residents by area ................................................................. 123
Figure 13: Diagram describing the process of recruitment ................................................ 124
Figure 14: Recovery style questionnaire (RSQ) ................................................................. 133
Figure 15: Treatment experience survey (TES) ................................................................. 134
Figure 16: Working alliance inventory (WAI) client version ............................................ 135
Figure 17: Global assessment of functioning (GAF) .......................................................... 136
Figure 18: Engagement and acceptance scale (EAS) ......................................................... 138
Figure 19: Service engagement scale (SES) ................................................................. 140
Figure 20: Map of south Asian countries ........................................................................ 152
Figure 21: Map of the world to show Africa and the Caribbean ....................................... 152
Figure 22: Trial consort diagram ..................................................................................... 174
Figure 23: Flowchart to show the recruitment of south Asian participants from the Manchester/Lancashire site ................................................................. 190
Introduction: This thesis contains three studies which are embedded within the larger CRIMSON trial: an individual level, randomised control trial comparing joint crisis plans with treatment as usual for people with severe mental illness. This thesis presents sub-analysis from CRIMSON, testing hypotheses about ethnic minorities only within the context of the wider trial. Recruitment and utilisation of the intervention by ethnic minorities is also investigated.

Methods: The joint crisis plan intervention documented the service users’ treatment preferences for the event of a future crisis. The plan was formulated collaboratively by the service user and their clinical team and was negotiated by an independent facilitator. The settings for the trial were community mental health teams across three sites in England. The hypotheses tested were that compared to receiving treatment as usual, the intervention group would experience fewer compulsory hospital admissions, fewer psychiatric hospital admissions and an improved working alliance with their care coordinator. Following a systematic review, strategies were implemented to overcome barriers to recruiting ethnic minorities into the CRIMSON trial. Diary entries were maintained in the Manchester/Lancashire site detailing attempts to overcome barriers encountered with the recruitment of ethnic minorities. Content analysis was carried out on the completed joint crisis plans to assess culturally relevant statements made regarding service users’ mental health and future treatment.

Results: In the sub-analysis 182 participants were randomised (94 experimental, 88 control group). No evidence of treatment effect was seen for compulsory hospital admissions (OR 0.87, 95%CI 0.43-1.77, p=0.71) any psychiatric admissions (OR 1.18, 95%CI 0.62-2.24, p=0.62) or service user rated working alliance (B=2.69, 95%CI -2.95-8.32, p=0.35). Additional sub-analysis found differential effects of the intervention on specific ethnic groups, with a reduction in overall admissions observed for black participants and an increase in admissions for south Asian and white British service user on any admission. Strategies for reducing barriers to participation into the research from ethnic minorities were implemented and 50% of south Asian and black service users who were eligible for CRIMSON were recruited. 28% of south Asian and black participants made culturally relevant statements within their joint crisis plans. This figure was significantly higher for south Asian (44%) compared to black (20%) participants (p=0.03).

Conclusions: This thesis suggests that joint crisis plans may have a differential effect on people from different ethnic groups, for reasons that at present we do not understand. This is interesting because it emphasises the importance of analyses that look at ethnic minorities and the way that they may help elucidate the effects of complex interventions. It also suggests that different ethnic minorities may react in different ways. This thesis certainly supports the value of efforts to recruit ethnic minorities. It is recommended that future work around joint crisis plans should take a qualitative approach to aid the understanding of what lies behind these apparent differential effects.
Declaration

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

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 she 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://www.campus.manchester.ac.uk/medialibrary/policies/intellectual-property.pdf), 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

My thanks to the CRIMSON team for providing me with the fantastic opportunity to contribute to the trial. In particular I would like to thank Simone Farrelly for her support and encouragement throughout, and Clare Flach for her guidance with the statistical analysis in this thesis. I am grateful to Max Marshall and Waquas Waheed for their supervision over the past four years. I have greatly benefited from sharing their wealth of knowledge whilst developing as an independent researcher.

About the Author

The author graduated with BSc (Hons) Psychology from the University of Liverpool in 2003. She worked as a psychological assistant within the prison service, progressing to forensic psychology training in 2005 and completing and MSc in forensic Psychology in 2007; prior to becoming a chartered psychologist.

From 2007 she was associate lecturer at Manchester Metropolitan University and taught on the Psychology programme. She left the prison service in 2008 to work as a researcher at the University of Manchester on the CRIMSON trial, which forms the basis of this thesis.

In 2011 the author became a full time lecturer at Edge Hill University, teaching across the applied health and social care portfolio.

The author made the following contributions to the running of the CRIMSON trial.

- She was the full time researcher on the trial across the north-west site which covered East Lancashire and Manchester.
- She developed relationships with key professionals in the community, including modern matrons of psychiatric wards, police liaison officers and GPs.
- She devised and delivered presentations to mental health teams and managers to promote the trial across the Manchester/Lancashire recruitment area.
- She contributed to the preparation and distribution of posters across mental health settings as well as distributing promotional materials (pens, post-its, mugs and leaflets) to community mental health teams.
- She contributed to the preparation and delivery of a presentation of the research to a North West area crisis conference.
- She arranged meetings with individual care coordinators to further discuss the trial and plan appropriate strategies to disseminate information to service users.
- She met with eligible service users to gain informed consent.
- She devised local newsletters for community mental health teams and service users. These were disseminated individually and also placed in the local trust magazine.
- She set up and maintained local databases for the recruitment site and maintained full trial databases.
- She conducted 130 assessments for service users at both baseline and follow-up stages.
- She attended all local research meetings, monthly access grid meetings with the research teams across the UK and attended required training sessions run by the trial scientific coordinator.
- She developed links with interpreters across the NHS trusts and arranged for their involvement within the trial.
- She set up focus groups for service users and clinicians in Lancashire and contributed to their facilitation.
- She was co-author on 2 papers that have been submitted from this project to date and is first author on an additional 2.

The author's original contribution to research beyond CRIMSON

The CRIMSON trial forms the basis for this thesis and details are provided within Chapter 5. The methodology described within this thesis was pre-defined prior to the author's involvement in the trial. A summary of the findings from CRIMSON is provided at the beginning of Chapter 7, although the remainder of this thesis is the work of the author. The studies presented within this thesis have been designed within the implementation of CRIMSON to maximise the opportunity that this trial presents to meet the author’s aims.

This thesis reports on three studies which are embedded within the wider CRIMSON trial. The author has shown an original contribution to research throughout the thesis in the following ways. A systematic review was completed on the barriers to recruiting ethnic minority service users into psychiatric research. This is documented in Chapter 2 and has been adapted by the author and accepted for publication within the International Journal of Methods in Psychiatric Research. A systematic review was completed on the
effectiveness of helping people with mental illness specify how they would like to be treated in a crisis (Chapter 3). This has been completed to build on an existing Cochrane review and serves the purpose of updating the search and widening the criteria. This review gives consideration to the inclusion of ethnic minority service users when testing the effects of the interventions, adding to the existing literature within this area.

The author puts forward an innovative method of applying the findings from the systematic review from Chapter 2, through keeping research diaries relating the experiences of recruiting south Asian service users into the trial. The author gained the support of colleagues, including interpreters and the principal investigator within the recruitment area, who agreed to maintain a research diary to support their own diary entries. Through such qualitative research methods, the author was able to mitigate limitations from the systematic review and examine the emerging themes which supported those previously extracted from existing literature, considering the implications for future research and practice. This qualitative study has been written up for publication and the author is awaiting feedback.

The author builds on a secondary outcome from the CRIMSON trial, which completed pre-defined sub analysis on black (African and Caribbean) participants. The author develops this by including south Asians within this analysis and testing for the effects of joint crisis planning on services users' hospital admission (compulsory and mixed) and working alliance. This analysis provides the opportunity to explore the effects of the intervention for different ethnic groups. Furthermore, this thesis uses the joint crisis plans developed within the trial to complete analysis on the documents created by black and south Asian service users. This analysis is informed by the literature documented throughout the thesis and allows for exploration of the service users' preferences. The three sub studies documented within this thesis are the original work of the author and were not pre-specified within the CRIMSON trial.

The author has completed additional work over the duration of this trial that has not focussed on ethnic minorities and hence is excluded from this thesis. Such work has added to the author's understanding of the intervention and provided a broader perspective of the concept of empowerment and autonomy of service users, which is relevant to this thesis.
Chapter 1: Introduction

Overview

It is widely accepted that people from ethnic minorities in the UK have higher rates of mental illness than the white indigenous population. Evidence suggests that whilst general mental illness is at a pronounced rate for ethnic minorities\(^1\)-\(^4\), a particular cause for concern is the elevated prevalence of psychosis for minority groups\(^5\)-\(^7\). The high prevalence of psychosis results in higher rates of hospital admissions for ethnic minority groups when compared to their white counterparts\(^8\) and this is particularly true of their increased rates of compulsory hospital admissions\(^9\)-\(^14\).

Compulsory hospital admissions have many negative connotations, on an individual and a societal level. Such admissions have a high financial cost, placing an economic burden on services\(^15\);\(^16\) and more importantly they can cause the service user and their families stigma and humiliation\(^17\) as well as future practical problems such as financial, housing and employment issues\(^18\)-\(^21\). Whilst some compulsory hospital admissions are necessary for the safety of the individual and others, there is some evidence to suggest that such high rates of admissions may have negative effects for the service users\(^22\);\(^23\); as they seem to arise from problems with service users engaging with health services. Negative connotations for service users may result in them disengaging from future treatment with services\(^24\).

As research suggests that people from ethnic minority groups may be more likely to delay help-seeking, become disengaged\(^25\) and be less trusting of services than white patients\(^22\);\(^26\);\(^27\), it is important to consider interventions that may promote engagement with treatment. One solution to this problem of engagement may be some form of joint crisis planning, whereby the service user is encouraged to have more active involvement in their future care and be given the opportunity to work collaboratively with their clinical team to highlight their treatment preferences for the event of a future crisis. This chapter will conclude with the rationale for the CRIMSON trial\(^28\).
Prevalence of mental illness

The prevalence of mental illness\(^1\) internationally is high, with figures estimating that about 14\% of the global burden of disease is attributable to mental illness\(^{29,30}\). It has been reported that around 450 million people worldwide suffer from a mental or behavioural disorder\(^{31}\), although it must be noted that these figures date back to the last decade and their accuracy at this time is unknown. The World Health Organisation have explored global mental health resources and produced an estimate of prevention and treatment resources that are available worldwide in the Atlas report\(^{32}\). Within the UK it is estimated that approximately one in four British adults experience at least one diagnosable mental health problem in any one year, and one in six experiences this at any given time\(^{33}\). It is important to consider the prevalence figures available in the UK population for both common mental disorders and psychotic illnesses.

It is reported that 9.7\% of people in England experience depression with anxiety and 2.6\% experience depression without anxiety\(^{34}\). The results of surveys are illustrated below in Figure 1, which shows the prevalence of common mental health problems across the UK\(^{35}\).

\(^{1}\) The World Health Organisation describes mental illness as “any of various psychiatric conditions, usually characterised by impairment of an individual’s normal cognitive, emotional, or behavioural functioning, and caused by physiological or psychosocial factors”. 
It is also important to consider current statistics for psychotic illness in the UK. The most prevalent psychotic mental illnesses are schizophrenia and bipolar disorder\textsuperscript{33}. The point prevalence rate for schizophrenia in the UK has been estimated at 5 per 1000 of the population or 0.5\%\textsuperscript{33}. The equivalent prevalence for bipolar disorder is slightly higher than for schizophrenia and has been reported to be 1\% of the population\textsuperscript{33}.

**Breakdown of ethnic groups in the UK**

Prior to commencing discussions around the prevalence of mental illness for ethnic minorities, it is valuable to consider the breakdown of the population in the UK by ethnic group. The census data available at this time is from 2001, as the 2011 data is yet to be published. Therefore data is presented in Table 1 below, from the Office for National Statistics Annual Population Survey from 2010\textsuperscript{36}. 

©MIND
Table 1: UK population by ethnic group: January-December 2010

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Numbers</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td></td>
<td></td>
</tr>
<tr>
<td>British</td>
<td>49,277,000</td>
<td>82.7</td>
</tr>
<tr>
<td>Other</td>
<td>3,336,000</td>
<td>5.6</td>
</tr>
<tr>
<td>Mixed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td>236,000</td>
<td>0.4</td>
</tr>
<tr>
<td>White and Black African</td>
<td>114,000</td>
<td>0.2</td>
</tr>
<tr>
<td>White and Asian</td>
<td>205,000</td>
<td>0.3</td>
</tr>
<tr>
<td>Other Mixed</td>
<td>181,000</td>
<td>0.3</td>
</tr>
<tr>
<td>Asian</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td>1,319,000</td>
<td>2.2</td>
</tr>
<tr>
<td>Pakistani</td>
<td>1,054,000</td>
<td>1.8</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>434,000</td>
<td>0.7</td>
</tr>
<tr>
<td>Other Asian</td>
<td>577,000</td>
<td>1.0</td>
</tr>
<tr>
<td>Black</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>633,000</td>
<td>1.1</td>
</tr>
<tr>
<td>Black African</td>
<td>919,000</td>
<td>1.5</td>
</tr>
<tr>
<td>Black Other</td>
<td>65,000</td>
<td>0.1</td>
</tr>
<tr>
<td>Chinese</td>
<td>271,000</td>
<td>0.5</td>
</tr>
<tr>
<td>Other</td>
<td>946,000</td>
<td>1.6</td>
</tr>
<tr>
<td>Total*</td>
<td>61,378,000</td>
<td></td>
</tr>
</tbody>
</table>

Higher rates of non-psychotic illness in ethnic minority groups

Whilst the prevalence of non-psychotic mental illness is under researched compared to the prevalence of psychosis in ethnic minorities, disparities in the figures have emerged\(^1\text{-}^3\). A comprehensive review of mental illness across ethnic minority groups is provided within the EMPIRIC study\(^4\). Within this study, disparities across mental illness for ethnic minority groups were shown with statistically significant variations in the prevalence of common mental disorders across ethnic groups.

---

*This total includes all those who did not report their ethnicity and also includes those in Northern Ireland who stated that their ethnicity was white (3.2% combined). The percentage has been calculated from the total number of people with completed ethnicity data."
Figure 2, below, depicts the scores from the administered Revised Clinical Interview Schedule (CIS-R)\textsuperscript{37} which is used to screen for common mental disorders\textsuperscript{iii}. It highlights gender differences as more females scored higher on the schedule than males, with the exception of Bangladeshi women. This also shows much higher percentages of common mental disorder in all groups other than Bangladeshi women when compared to the white group. When the figures were adjusted for age it was concluded that middle aged Pakistani men and older Pakistani and Indian women were shown to have higher incidence rates of common mental disorders than white groups\textsuperscript{4}.

**Figure 2: Common mental disorders by ethnicity and gender**

![Prevalence of CIS-R score of 12 or more, by sex and ethnic group](image)

© Crown copyright

**Higher rates of psychosis in ethnic minority groups**

Psychotic symptoms in the general population of England have also been reported to be more common in people from ethnic minorities, being twice as high in black Caribbean people than white people\textsuperscript{5,6}. It has been reported that African-Caribbean people living in UK are at a higher risk of developing schizophrenia than the white indigenous population\textsuperscript{38}. The figure of incidence rates for psychotic disorders in service users from

\textsuperscript{iii} Common non-psychotic mental illnesses include depression, anxiety, obsessive compulsive disorder, phobias, personality disorders and eating disorders.
ethnic minorities greatly varies. In a review of ethnic disadvantage and schizophrenia, 17 studies (15 from UK and 2 from Netherlands) were used to estimate relative risks of incidence. The relative incidence figures ranged from 1.7 to 13.2. Such variation in the figures demonstrates the difficulties of producing an accurate representation, although the elevated figure for ethnic minority groups when compared to whites is not disputed. Figure 3 below shows the scores from the Psychosis Screening Questionnaire (PSQ) which was used to assess psychotic symptoms in the EMPIRIC study. It is clear that there are a higher percentage of people from black African, Pakistani and Indian groups that have a positive score on any PSQ item, compared to the white group. This is not true of the Bangladeshi group, of which a smaller percentage scored positively on any item, compared with the white group.

Figure 3: Positive psychosis screening questionnaire item by ethnicity and gender

© Crown copyright 2012

The literature shows that all mental illnesses are more common in ethnic minorities compared with white groups. Whilst this increase is evident in terms of common mental disorders, the increased rates are more pronounced for psychotic illnesses and psychosis seems to be a particular problem for ethnic minority groups in general, with some inter-group variations evident.
Race, culture and ethnicity

Within the introductory text and statistics, the prevalence of mental illness has been discussed for ethnic minorities and the term ethnicity has been used with the absence of contextualisation. Therefore, prior to progressing with this chapter, it is important to define the key terms of race, culture and ethnicity which are often deemed to be controversial variables, poorly described and have multiple interpretations. Within research it is not uncommon to find the above terms used interchangeably or used as synonyms for each other\(^2\). Following some exploration into these terms, consideration will be given to the complexity of ethnic categorisation.

**Race**

Whilst there is variance within definitions that attempt to encapsulate the meaning of race, common elements of its definition include ancestry, descent and heredity\(^4\). The term race can have paradoxical purposes; to either highlight common genetic characteristics or alternatively to distinguish categorical differences between people. Race was traditionally best understood as relating to a person’s biological and therefore their genetic heritage\(^4\) and categorisation was commonly based on physical characteristics\(^4\) or some shared biology within groups of people\(^4\). Studies of racial variations in health make an assumption that it is the genes determining race that determine health\(^4\). The use of the term race has evolved from being a purely biological categorisation system to being more commonly seen as part of a social process, whereby people are organised into social groups\(^4\). Consequently more modern definitions of race emphasise social rather than biological origins within UK and international literature\(^4\). In Europe the term race has become somewhat redundant in favour of the term ethnicity which will be explored in more detail below.

**Culture**

Whilst there are many definitions provided which attempt to capture the essence of culture, there is consensus within each that it is not fixed and is a dynamic and fluid concept\(^4\). Perhaps one of the most all-inclusive definitions is presented by the United Nations Educational, Scientific and Cultural Organisation (UNESCO) who describe culture as
‘the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs’

Other definitions refer to culture as being difficult to pin down, due to its dynamic nature; these descriptions recognise the need for systems of identification to be flexible to define aspects of peoples’ identities and how they live. Definitions of culture place emphasis on social factors, stating it can be socially transmitted as is closely linked to language. These classifications explore how cultures dictate rules and convention in terms of organisation of behaviour, they also refer to cultures as being cognitive structures within a network of social relationships. When people enter a host country they start acculturating and, as people acculturate at different rates, frictions within families may emerge. Lack of acculturation has been studied within the context of women from Pakistani residing in the UK having increased rates of depression.

Ethnicity and ethnic groups

‘Ethnicity’ is frequently reported across healthcare documentation and research, with little explanation as to its meaning. The word ethnicity is derived from the Greek word ‘ethnos’ which has been translated to mean nation. It commonly relates to the group to which people belong to, or are perceived to belong to, based on shared characteristics. These include geographical origins, ancestral origins and cultural traditions and language. Therefore, like culture, ethnicity is a dynamic concept and assumptions about its stability over a length of time should not be assumed.

This word ethnicity is used to encapsulate ancestry, heritage, religion, culture, nationality, language and religion. Ethnicity currently implies at least one of the following: shared origins, shared social background, shared culture and tradition and it refers to the maintenance between generations which promotes a sense of identity and common language or religious tradition. It is important that the word ethnicity is not confused with nationality or migrant status, which often will not represent the ethnic identity of the individual. As with definitions of culture, exploration of ethnicity has emphasised social factors, with culture being linked to the social group that a person belongs due to various cultural factors. These include language, diet, religion, ancestry and some physical characteristics which have been associated with race.
Given the above explanations it follows that people with the same ethnicity would form an ethnic group, which has been described as being a ‘collectivity’ within a wider population, based on common ancestry and with a shared cultural focus, as described through the various factors cited above\textsuperscript{54}. Due to the number of factors to be considered within assigning an ethnic group category, ethnic group requirements within research usually consist of juxtaposing categories of colour and nationality. The phrase ethnic minority group is commonly used, but not exclusively, to describe a non-white population. It has been argued that it is more accurate to use the phrase minority ethnic group, although the two expressions are used synonymously\textsuperscript{53}.

\textbf{Ethnic versus cultural factors in ethnic minority mental health}

Following the previously presented definitions of culture and ethnicity it is valuable to differentiate between cultural and ethnic factors within ethnic minority mental health. It is proposed that ethnic factors take a more traditional biological approach to considering risk factors which lead to the development of illness. These factors give consideration to genetics and prevalence of illness within second generation populations. Ethnic factors also include the pharmacology of taking medicine and how the service users respond to medicine, with exploration into the side effects for different ethnic groups. Cultural factors differ from the above as they take a different perspective, emphasising the wide array of factors that have been described above under the wider umbrella of culture. Such factors include religion, rituals, beliefs, concepts about illness, engagement with services, help seeking and satisfaction.

It has been argued that socio-economic status is a stronger determinant of health outcome than ethnicity or race, as when this has been controlled for in studies, evidence suggests that any race effect may in fact vanish\textsuperscript{55}. This gives some support for the argument that ethnicity may be a proxy for socio-economic and cultural influences, although the extent to which this is a true proxy is questionable. This view would make the rigid assumption that people from certain ethnic groups will always be economically deprived or always affluent, failing to account for change or indeed inter group variability. Similarly, as described above culture is a dynamic concept and even when coupled with socio-economic status, the wide variation and acculturation within ethnic groups does not directly equate to the concept of ethnicity.
Pitfalls of ethnic categorisation

Whilst it is argued that terminology with regards to race, culture and ethnicity should reflect the hypothesis that is being tested, there is recognition that at the initial stages it is difficult for researchers to ascertain whether it is ethnicity race or culture that is important in relation to their research and so specific classifications within hypothesis may not be accounted for\(^{47}\). It is however clear that in order to allow for comparison between studies, a well-defined framework is needed for the classification of ethnic groups. Classification allows data to be arranged according to common features, results to be reproduced and should allow comparison over time and between different sources.

Ethnic identification can create challenges within research as membership to a particular group is self-defined and, as highlighted above, ethnicity is dynamic and terminology and groups are constantly evolving\(^{56}\). Assumptions about the stability of ethnic groups cannot therefore be made; due to political changes and changing fashion in terminology it is unlikely that an agreed classification can be achieved. Peoples' ethnic identity is subject to change and they may record themselves as one ethnic group at one time and another on a subsequent occasion.

Whilst some appeals to promote an international vocabulary for ethnic categorisation systems have been voiced\(^{43}\) there are clear differences between the meanings of ethnic categorisation language used across different countries. For example, whilst the terms Asian usually refers to people from south Asian origin when used in the UK, in the US, Asian is commonly understood to mean people from far Eastern Asian populations\(^{53}\). It has been proposed that rather than trying to find a catch all name for ethnic groups, it is better to define the exact group of interest using a more descriptive title\(^{47}\).

Office for National Statistics categorisation system

Ethnic categorisation systems used in the UK are frequently based on the Office for National statistics (ONS) guidelines\(^{57}\). The purpose of the publications by ONS is to produce information about Britain that can be used for social and economic policy-making\(^{58}\); this also makes some comparison with other societies and economies possible. As such categorisation systems were not designed for medical research, questions can be raised about the appropriateness of utilising this borrowed system in health research.
A further limitation to classification systems of ethnicity relates to the inevitable problem that no one label will be able to capture variability between differences within that group. For example, the term south Asian is commonly used in the UK to refer to people of south Asian origin, although there is great variability between people within this group, based on characteristics previously discussed including country of origin, language and religion. For example, within health research Bhopal warns of the dangers of combining Bangladeshi men (who have a high prevalence of smoking) with other groups of south Asian men who have a low prevalence of smoking. Any such differences will therefore be lost if the data is combined under the broader category of south Asian.

Whilst the above argument undermines the use of the ONS categorisation system, there is merit in its application within health research with respect to its categorisation of ethnic minorities. In more general terms the grouping of ethnic minorities is necessary within research as without this there would be too many categories, containing low numbers of participants which would make the findings less meaningful in two respects. Firstly, small sample sizes would make this true at a statistical level. Secondly, if researchers do not cluster smaller groups then it is argued that the focus can become too narrow and may be of limited interest to the wider readership and indeed to the future transferability of findings to health care services.

Different researchers have different ideas on which categorisation systems should be used, if all of these were implemented it would create complications. Whilst the criticism of the ONS categorisation based on its origin has been voiced, this system has the backing of the Government and tends to be followed within both research and health care services in the UK. The value of this unified system allows comparability of data and research findings over time and across health care interventions.

In response to concerns about the differences between subgroups being lost when broader categories of ethnicity are used when combining groups under broader headings, it important to note that whilst this is valid in some instances, and when reviewing certain conditions it is likely to be a more serious concern than when reviewing others. For example, whilst there are clear differences between different south Asian subgroups (eg Bangladeshi, Pakistani, Indian) it could be argued that in a more general sense, the historical origins of such groups are similar, hence many cultural similarities will remain.
Difficulties with collecting ethnic minority mental illness data

There are difficulties in ascertaining an accurate representation of the prevalence of mental illnesses in ethnic minorities in the UK and the process of obtaining data is complex and relies on cultural understanding. This is due to the data collection methods, with the majority of data captured at a national level coming from surveys; western psychiatric practice is possibly more appropriate for some ethnic groups than others. There are also cultural differences in the way that mental illness is experienced by people and indeed in the way that it manifests itself. Such obstacles in both self-reporting and diagnosis of mental illness may account in part for discrepancies with the statistics presented to describe prevalence of illness for ethnic minorities.

Aims of this review

This review aims to present literature which addresses the disproportionate hospital admissions for people from ethnic minority groups in the UK compared to white British people. In line with the general consensus of the term ‘ethnic minority group’, it will be used to describe any ethnicity other than white-British within the UK.

This review relies on the categorisation systems employed by the researchers. The terms and ethnic minority groups will therefore be reported on, in a way consistent with the primary research. Some authors may use broader categories than others, for example reporting on Asian rather than south Asian, or an even more descriptive category within the wider south Asian group such as Pakistani. Where literature is included from outside the UK to support some of the explanations for disproportionate admissions, is it necessary to adopt caution and consider its application within the UK population. The data presented within the introductory section regarding prevalence of mental illness has provided statistics including the following ethnic groups in line with the ONS categories: white British, white other, mixed white and black Caribbean, mixed white and black African, mixed white and Asian, other mixed, Asian Indian, Asian Pakistani, Asian Bangladeshi, Asian other, black Caribbean, black African, black other, Chinese and other. It is important to note that with the categories of ‘other’, a free text option is required within research tools to try and understand who is included within this category and the wide variation within this group often provides a sample which is too diverse to make any sensible conclusions from.

Throughout this review, all ethnic minorities are of interest and hence no specific groups are omitted. It is intended that this literature review will be inclusive. Also, the following two
chapters will add to this and assist to formalise the ethnic minority groups, which will be included within the testing of the intervention later within this thesis.

**Higher hospital admission rates for ethnic minority groups**

As psychotic illnesses are a pronounced problem for ethnic minority groups in the UK (non-white British) and such illnesses lead to high admission rates; it is important to give consideration to the figures for both voluntary and compulsory hospital admissions and the explanations offered for such disparities in the data. The literature concurs that compulsory admissions are more common for people from ethnic minority groups than white people. One study found that the pooled odds ratio for compulsory admissions for black patients, when compared to white patients was 4.31 (95% CI 3.33-5.58). Another study found that black patients were more likely to be involuntarily detained than white, with a difference being notable between the odds ratios (when compared to white) for black Caribbean (adjusted OR=3.67, 95% CI, 2.07-6.50) and black African patients (adjusted OR=2.88, 95% CI, 1.04-7.95). Audini and Lelliott standardised rates of sectioning, as number per unit of ethnic specific populations and reported that black patients were 6 times more likely to experience compulsory admission than white patients (450 vs 68 per 100,000 population).

Literature concerned with service users experiencing their first episode of psychosis replicated the above findings; African-Caribbean and black African service users were more likely to have compulsory admissions that their white counterparts, with African-Caribbean men having the highest admission statistics (OR= 4.75, 95% CI, 2.41-9.38). It is of interest that these findings were disputed by Burnett et al. who did not find such differences for people with a first episode of psychosis. They found that the proportion of African Caribbeans experiencing compulsory detainment was 14/86 (16%), compared to 49/270 (18%) for white patients ($\chi^2=0.16$, df=1, $p>0.1$). Another study explored the referral frequency from GPs and from the criminal justice sector, reporting that GP referral was less frequent for African Caribbeans compared with white British (OR= 0.48, 95%CI, 0.25-0.90) and more common from criminal justice sector compared to white British (OR= 1.98, 95%CI, 1.04-3.77).

Systematic reviews consistently show a large and significant difference in voluntary admissions and compulsory admissions between black and white service users. Singh et al. completed a systematic review around ethnicity and detention under the Mental Health Act in the UK, to explore differences in explanations offered. Using robust
methodology, the review included 49 studies, with only 19 of these containing raw data to allow for the completion of meta-analysis. It was found that using overall pooled odds ratios that compared with white patients, black patients were 3.83 times (95% CI= 3.05-3.73), black and minority ethnic patients 3.35 (95% CI= 3.42-4.29) times and Asian patients 2.06 (95% CI= 1.60-2.65) times more likely to be detained under the Mental Health Act in the UK.

Whilst the literature concurs that ethnic minority groups have higher rates of detention than white patients and the evidence of this disparity is compelling, the statistics are greatly varied. Higher rates of admissions such as those discovered by Audini and Lelliott10 have been criticised as being sensationalised64 with suggestions that the figures produced are overestimates which arise from; the lack of correct adjustment of statistics, unrepresentative samples (taken from inner-city areas), inconsistent recording of ethnicity and failure to account for repeat admissions64. The authors10 also documented the limitations to their work, stating that they used an opportunistic methodology, relying on previously existing research studies. The one thing that stands true is that there is persuasive evidence to support increased rates of detention for ethnic minorities compared to white patients across the literature. It is the extent to which these rates differ that is currently less clear.

The findings from research studies are broadly reflected in official statistics, as shown in Table 2 below. The fifth annual report on NHS adult specialist mental health services and their users was published in 2011, covering the previous five years and reporting on hospital care and community delivered services65. These statistics count people only once per year regardless of how many admissions or contact with services they made over that period. These figures report that the number of people accessing mental health services in England from 2010 to 2011 increased to 1,287,730 (2.8% of the population). Whilst this figure had risen from previous years, the figures report that the proportion of service users admitted to hospital had decreased, which is consistent with the reduction in the number of NHS beds available66.

Figures from 2011 admissions are provided below in Table 2, which detail both voluntary and compulsory admissions data and are taken from official statistics from the mental health minimum dataset65. The admission data is split further into the ethnic groups of service users and the percentage figure has been calculated for each type of admission to show the percentage of admissions by that particular ethnic group. The final column of Table 2 is taken directly from Table 1 and this shows the estimated percentage
breakdown of population in the UK by ethnic group. This population breakdown figure can be compared to those admission figures to suggest that the admission rates are comparatively higher for some ethnic minorities than for white patients.

Table 2: Number of people admitted to hospital and those with compulsory admissions, by ethnic group

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Number of people admitted to hospital (%</th>
<th>Number of people with compulsory hospital admission (%)</th>
<th>Percentage of the total population (from Table 1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>79,190 (77.7)</td>
<td>29,567 (70.3)</td>
<td>82.7</td>
</tr>
<tr>
<td>Irish</td>
<td>1,456 (1.4)</td>
<td>574 (1.4)</td>
<td>-</td>
</tr>
<tr>
<td>Any other White background</td>
<td>5,435 (5.3)</td>
<td>2,349 (5.6)</td>
<td>5.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P&gt;0.05</td>
<td>P&gt;0.05</td>
</tr>
<tr>
<td>Mixed White and Black Caribbean</td>
<td>677 (0.7)</td>
<td>387 (0.9)</td>
<td>0.4</td>
</tr>
<tr>
<td>White and Black African</td>
<td>228 (0.2)</td>
<td>140 (0.3)</td>
<td>0.2</td>
</tr>
<tr>
<td>White and Asian</td>
<td>298 (0.3)</td>
<td>140 (0.3)</td>
<td>0.3</td>
</tr>
<tr>
<td>Any Other Mixed Background</td>
<td>615 (0.6)</td>
<td>340 (0.8)</td>
<td>0.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P&gt;0.05</td>
<td>P&gt;0.05</td>
</tr>
<tr>
<td>Asian or Asian British</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td>1,517 (1.5)</td>
<td>763 (1.8)</td>
<td>2.2</td>
</tr>
<tr>
<td>Pakistani</td>
<td>1,433 (1.4)</td>
<td>841 (2.0)</td>
<td>1.8</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>578 (0.6)</td>
<td>368 (0.9)</td>
<td>0.7</td>
</tr>
<tr>
<td>Any Other Asian Background</td>
<td>1,305 (1.3)</td>
<td>734 (1.7)</td>
<td>1.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P&gt;0.05</td>
<td>P&gt;0.05</td>
</tr>
<tr>
<td>Black or Black British</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td>2,795 (2.7)</td>
<td>1,862 (4.4)</td>
<td>1.1</td>
</tr>
<tr>
<td>African</td>
<td>2,347 (2.3)</td>
<td>1,567 (3.7)</td>
<td>1.5</td>
</tr>
<tr>
<td>Any Other Black Background</td>
<td>2,017 (2.0)</td>
<td>1,422 (3.4)</td>
<td>0.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P= 0.036</td>
<td>P=0.005</td>
</tr>
<tr>
<td>Other Ethnic Groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>303 (0.3)</td>
<td>181 (0.4)</td>
<td>0.5</td>
</tr>
<tr>
<td>Any Other Ethnic Group</td>
<td>1,684 (1.7)</td>
<td>805 (1.9)</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P&gt;0.05</td>
<td>P&gt;0.05</td>
</tr>
<tr>
<td>Total</td>
<td>104,645</td>
<td>42,818</td>
<td></td>
</tr>
</tbody>
</table>

Table 2 provides a snapshot of admissions and ethnic representativeness and is not as comprehensive as the longitudinal research studies or systematic reviews as their methodology is more robust. There are limitations in terms of drawing firm conclusions from this overview as it provides a different reflection of reality than in previous reviews\textsuperscript{14}. The figures in bold indicate higher admission figures than the ethnic groups’

\textsuperscript{14} Ethnic group subtotals do not add up to total number of people included, because this total figure includes all those for whom ethnicity was invalid or missing. The total number of people with completed ethnicity data has been calculated and it is this figure from which the ethnic subgroup percentages have been calculated.
representativeness within the UK population would suggest. This table suggests that voluntary hospital admissions are over representative for the following ethnic groups: white and black Caribbean; other mixed backgrounds; any other Asian background; black Caribbean; black African; other black background and ‘any other’ ethnic group. In terms of compulsory hospital admissions the figures are higher for the groups previously highlighted and also for the following groups: white and black African; Pakistani and Bangladeshi. The subgroups of the five categories (white, mixed, Asian, black, other) were combined and the statistical significance of differences between voluntary and compulsory admissions compared with the population breakdown percentage was analysed. The only group to have statistical significance in the difference between the proportions of people admitted (true for both voluntary and compulsory admissions) was the black group (including Caribbean, African and any other black background). The significance is in bold in the table and this figure is two-tailed.

This table of statistics has its limitations and the way in which the data is presented could be criticised. There are several issues with using the data in this way, the first being that people are counted only once in any year regardless of the number of times they are admitted. The quality of the hospital ethnicity data is questionable as the data is provided from numerous sources, including independent sectors. Other limitations include the age structure of the population and the simplicity of calculating differences between the admission percentage and the percentage of the ethnic group within the UK population.

The positive element of the presentation of this data is that it provides an up to date summary account of admissions data, so is not reliant on dated figures, as some of the previous literature is.

**Trends in compulsory hospital admissions in the UK**

Whilst recent admission rate statistics have been presented above, it important to document any trends in compulsory admissions across previous years and to consider trends within those proportions of ethnic minorities that are involuntarily detained. Figures showing compulsory admissions by ethnic group from 2006-2011 are provided below in Table 3, and are taken from official statistics from the mental health minimum dataset. The figures are presented for broad ethnic groups and then smaller subgroups, with the actual number of admissions and then percentages presented for each figure against the total number of admissions that year. This allows comparisons of percentages to be made with different ethnic minority groups across this five year period.
Table 3: Number of people with compulsory hospital admissions, by ethnic group from 2007-2011

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Number of people admitted to hospital (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>20309 (72)</td>
</tr>
<tr>
<td>Irish</td>
<td>400 (1)</td>
</tr>
<tr>
<td>Any other White background</td>
<td>1580 (6)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>22289 (80)</td>
</tr>
<tr>
<td>Mixed White and Black Caribbean</td>
<td>251 (1)</td>
</tr>
<tr>
<td>White and Black African</td>
<td>100 (0)</td>
</tr>
<tr>
<td>White and Asian</td>
<td>100 (0)</td>
</tr>
<tr>
<td>Any Other Mixed Background</td>
<td>152 (1)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>603 (2)</td>
</tr>
<tr>
<td>Asian or Asian British</td>
<td>434 (2)</td>
</tr>
<tr>
<td>Pakistani</td>
<td>513 (2)</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>145 (1)</td>
</tr>
<tr>
<td>Any Other Asian Background</td>
<td>350 (1)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1442 (5)</td>
</tr>
<tr>
<td>Black or Black British</td>
<td>1219 (2)</td>
</tr>
<tr>
<td>African</td>
<td>888 (3)</td>
</tr>
<tr>
<td>Any Other Black Background</td>
<td>654 (2)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2761 (10)</td>
</tr>
<tr>
<td>Other Ethnic Groups</td>
<td>110 (0)</td>
</tr>
<tr>
<td>Any Other Ethnic Group</td>
<td>464 (2)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>574 (2)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>28149</td>
</tr>
</tbody>
</table>

Table 3 above shows that compulsory admissions have increased over the five year period when total admissions are compared at an annual level. This is also true when ethnic minority groups are considered individually, as the figure increase is in proportion with the overall total of admissions, hence there are no particular ethnic minority groups where the increase is specifically elevated. It is therefore concluded that based on this

---

*Ethnic group subtotals do not add up to total number of people included, because this total figure includes all those for whom ethnicity was invalid or missing.*
dataset, the trends in increase in compulsory hospital admission are consistent, regardless of the ethnic group under consideration. The same concerns and limitations that have been explained previously in relation to applying findings from this dataset are present.

Whilst a number of factors have been prosed for such an increase in admission rates, there is little empirical evidence for many, such as illicit drug or alcohol use. It is noted that the increase in compulsory hospital admissions has occurred at the same time as a reduction in mental illness beds, which has prompted investigation into such associations\(^{67}\). Research found that when a one year time period lag was introduced, bed reductions preceded compulsory hospital admissions (Cross correlation -0.69, 95%CI= -1.06 to -0.15)\(^{66}\). This research concluded that the reduction in two mental illness beds through closure may lead to one additional compulsory hospital admission in the next year. It is also notable that this increase in compulsory treatment is despite an increase in community based services; it is argued that such services reduce voluntary admissions yet have little impact on reducing involuntary admissions.

**Consequences of compulsory hospital admissions**

Following the review of increased detention rates for ethnic minority groups, it is important to consider the consequences of such admissions, on both an individual and wider level. The burden of compulsory admissions has far reaching effects. Measures of burden have included the following descriptors; estimates of prevalence, mortality associated with the disorders, disabilities and impairments related to the disorders, and costs\(^{68}\). The burden is higher for psychotic illnesses than common mental disorders in the UK, with suggestions that the economic burden associated with schizophrenia accounts for between 1.5 and 3% of all health care costs\(^{16}\). This has been attributed to the recurrence of episodes\(^{69}\) as well as the cost of hospital admissions and treatment across services\(^{15}\).

Compulsory admissions inevitably have negative connotations for the service user, as well as the individual concerned losing their liberty, there is the stigma and humiliation associated with the hospitalisation\(^{17}\). Research suggests a mixed response from service users who have experienced compulsory treatment. A review of quantitative literature\(^ {22}\) including 18 studies revealed that, following compulsory admissions, between 33% and 81% of service users regarded the admission as justified and/or the treatment as beneficial. Whilst the top end of these figures is favourable, they suggest that a substantial proportion of service users viewed their admission as being neither justified nor beneficial.
This review also found that between 6% and 33% of service users perceived no benefits or even felt harmed by their treatment\textsuperscript{22}. This support the rather bleak picture that Gilbert et al. painted with regards to service users reporting negative experiences within their admissions\textsuperscript{23}. In addition service users have stated that their experience of detention in hospital was a violation of their autonomy and restricted their liberty\textsuperscript{70}; they also noted the emotional impact and disruption to their lives\textsuperscript{71}.

Following discharge from admission and the section being rescinded, the experience and sense of shame can damage future relationships and have an impact on the entire family unit, with normal life being disrupted and a burden placed on families\textsuperscript{72}. Following detention, people may be rendered homeless, which may add to the negativity that the community already feels towards them\textsuperscript{18,19}. Literature suggests that having been sectioned can affect service users’ future employment\textsuperscript{20,21}, although this notion is challenged as it is argued that fitness to work is the crucial factor regardless of any compulsory hospital admissions\textsuperscript{73}. One further implication of having had a compulsory hospital admission is that it may restrict service users’ ability to get visas\textsuperscript{74}. These and other consequences may result in long term loss of faith in services by patients, causing a subsequent failure to engage with future treatment\textsuperscript{24}.

Whilst there are many negative connotations following a person being detained under the Mental Health Act, this process is often necessary and it can undoubtedly save lives and be the only appropriate action available to help people at that time. As previously stated, a review of compulsory hospital admissions showed mixed findings. Taking some of the most positive findings, it is suggested that service users showed clinical improvements following compulsory admissions and that between 39 and 75% of patients rated their admission as being positive following the event\textsuperscript{22}. Furthermore, Quirk and Lelliott\textsuperscript{75} have placed importance on some of the positive experiences that service users have reported based around their communication and constructive relationships developed during their admission. It is plausible that some of the negative effects of compulsory admissions are particularly problematic in ethnic minorities where, for example, mental disorders may attract particular stigma. In summary, it is reasonable to state that compulsory treatment should to be used judiciously and avoided when possible, using alternative treatment where detention is not necessary.
Explanations for disproportionate hospital admission rates

Evidence supporting the disproportionate admission rates for ethnic minority groups is widespread, so it is important to give consideration to the offered explanations for such differences. Four main explanations have been advanced for the high rates of compulsory admissions and these will be explored in turn below. These categories are by no means exhaustive, nor are they mutually exclusive, but provide broad umbrella terms to discuss some of the reasons for this phenomenon. These four explanations centre on actual behaviours that lead to people being sectioned under the Mental Health Act and are categorised as: 1) higher rates of psychosis, 2) seeking help too late, 3) refusing voluntary admissions and 4) being more likely to be sectioned.

1. Higher rates of psychosis

The disparity in the prevalence of psychosis in ethnic minority groups and white patients has been previously discussed\textsuperscript{5-7,13,38}, with the caveat that exact figures are difficult to determine. The apparent higher rates of psychosis in ethnic minorities could be explained by one of two schools of thought, the first being that the rates are actually higher and the second that the higher rates can be attributed to misdiagnosis. If the first argument is correct and incidence rates for ethnic minorities are indeed higher, it is important to consider reasons that have been offered to account for this.

Deprivation of ethnic minorities may be a contributing factor, as it has been argued that the socio-economic position of ethnic minorities may be the root cause of the differences in prevalence of psychosis and consequently in admission rates\textsuperscript{76,77}. Socio-cultural factors such as education, unemployment, single-parent families and less social support have been offered for the disproportionate rates of compulsory admissions for ethnic minority groups\textsuperscript{13}, although such explanations have largely been untested. Cooper et al.\textsuperscript{6} concluded that perceived disadvantage by black service users could be offered as an explanation to account in part for the excess of psychosis in this group of people. This perceived disadvantage could arguably have an adverse effect on service users’ engagement with their treatment. Whilst socio-cultural factors may have some bearing on admission rates, they do not account for variations that have been reported between different ethnic groups, where little variation in socio-economic disadvantage is likely\textsuperscript{78}. It is also interesting that in a study within the UK, ethnic density has been shown to be inversely related to psychosis incidence at a local level\textsuperscript{79}. 
Dein et al.\textsuperscript{13} explored ethnic biases in the application of the Mental Health Act and reported a number of environmental factors which may be associated with increased rates of psychosis in black service users. Such factors include late presentation to services, migration and mistrust of services. This presents an interesting argument that these seemingly excessive diagnoses of psychotic disorders in black service users are in many respects preventable, if early intervention is applied appropriately.

Whilst it is difficult to refute the increased rates of psychosis in ethnic minority groups, the true extent of the existence of psychosis is unknown. The second, and opposing, argument relates to potential misdiagnosis of psychosis in ethnic minorities with research suggesting there may be communication problems between clinicians and patients\textsuperscript{80}. Beyond misdiagnosis by psychiatrists, the insight displayed by ethnic minorities into their own mental health has come under scrutiny, with an unwillingness to recognise psychiatric illness being suggested. Some researchers have reported that a lack of knowledge could result in those from ethnic minority groups over-generalising or oversimplifying symptoms and mental illness as a whole\textsuperscript{81}, potentially leading to misdiagnosis.

Sharpley et al. found that as well as African-Caribbean people in the UK having higher risk of developing schizophrenia than white people in the UK, this higher risk was also evident when compared to the population in their country of origin\textsuperscript{38}. This may be attributable to culturally acceptable behaviour, in terms of hallucinations and paranoid ideas, suggesting that adaptation to the assessment tool may be necessary for the African-Caribbean population. However, evidence suggests that when given case studies to diagnose, British psychiatrists did not over-diagnose schizophrenia in African-Caribbean people\textsuperscript{82}, indicating that misdiagnosis is far from conclusive. To further support the above argument, evidence to refute the suggestion of misdiagnosis as an explanation is taken from findings from the AESOP study; this concluded that diagnosis does not explain the high levels of compulsory admissions among African Caribbean and black African service users\textsuperscript{11}. When pathways to care were further explored, ethnic variation in such pathways were also not explained through differences in diagnosis\textsuperscript{12}. Further work sought to examine the relationship between indicators of social disadvantage and psychosis, and variations by ethnicity, finding strong links\textsuperscript{83}. It is argued that independent social risk factors, such as those explored, may contribute in part to the reported higher rates of psychosis in the black Caribbean population. Therefore, whilst the explanation of misdiagnosis is regularly referred to throughout the literature, the evidence to support it is limited.
2. Seeking help too late

This explanation for higher compulsory admission rates relates to people from ethnic minorities’ delayed help-seeking. This could potentially result in them being less cooperative when mental illness is detected and may be linked to deprivation, mistrust or stigma. Social deprivation has been alluded to within the previous explanation, the argument being that the late presentation to services by black males may be due to social deprivation, leading to more social isolation. The explanations of mistrust and stigma will now be explored in relation to how these issues may delay the help-seeking process for ethnic minority groups.

Research has indicated that ethnic minority groups have limited trust in healthcare professionals, much of which is rooted in a deep historical context. Mistrust may also arise from service users’ suspicion about services. The view that psychiatrists are ‘like policemen’ suggests that African American encounters with them are often followed by involuntary hospitalisation and some suspicions of the perceived profit motive of pharmaceutical companies are reported.

Stigma attached to mental health has been offered as a reason to explain differences in admission rates in ethnic minority groups. A difference in stigmas associated with different illnesses has been observed, for example depression is generally less stigmatised than psychosis. Stigma towards mental health seems to be particularly pronounced in Asian American communities and many older members of minority groups may be more concerned with the impact a psychiatric diagnosis will have on their family’s reputation. The stigma that some African Americans attach to the concepts of mental health and illness makes engagement in treatment that much more problematic. Stigma emerges from research in different ways, with one author referring to people using the words; crazy, scary, weakness, helpless, hopeless and irresponsibility to describe the stigmas associated with mental health. This cited literature in relation to stigma has been taken from the US. As previously highlighted, caution is needed when generalising this to a UK setting due to the differing composition of ethnic minorities, terminologies and historical contexts. Whilst stigma is unarguably a relevant factor for people with mental illnesses internationally, the form which this takes and the historical reasons for the emergence of such beliefs have different underpinnings. Such differences will be explored in greater detail within Chapter 2.
Literature from the UK has also highlighted stigma experienced by service users with mental illness and the wider effects for their families and communities. This is compounded when service users experience a compulsory hospital admission, which can cause the service user and their families stigma and humiliation\textsuperscript{17,18}. Qualitative research has offered explanations to account for the differences in admissions between ethnic groups. Here, the views of service users are obtained in order to analyse themes and trends in their own experiences. The literature pertains to ethnic minority groups in England reporting unfavourable experiences of mental health services, with the most adverse reactions being verbalised by African-Caribbeans\textsuperscript{86}. These perceptions of experiences may account for why such groups are hesitant to seek help from services when required. This explanation will be further explored when considering why ethnic minority groups may refuse voluntary treatment that is offered to them.

3. Refusing to be treated on a voluntary basis

This explanation relates to evidence that suggests people from ethnic minority groups may refuse treatment that is offered to them on a voluntary basis. This may be attributed to the factors of stigma and mistrust of services that have been previously explored and may lead to more relapses and the necessity for future compulsory treatment.

Research suggests that south Asian service users\textsuperscript{87} and black service users\textsuperscript{88} were reportedly dissatisfied with services, with the former analysis emphasising the importance of socio-economic exclusion being a primary factor in shaping black service users’ experiences (as referred to in explanation 1). In addition to this perception of socio-economic exclusion, cultural and institutional exclusion were present for south Asians. Service users in these groups reported that despite efforts following past recommendations, their voice is still not being heard and this makes engagement with the health care providers more difficult. This is substantiated within a literature review regarding disengagement from mental health services\textsuperscript{89} and due to the above mentioned factors, disengagement may result in the necessity for future coercion\textsuperscript{90}.

Service users from ethnic minorities have also been shown to terminate their treatment early\textsuperscript{91-93}. Such supporting evidence is far from conclusive and in a more recent survey, ethnicity had a negligible effect on service users’ experience in comparison to numerous other variables\textsuperscript{94}. Here, Asian service users were most likely to report negative experiences, with black service users no more likely to do so than white service users. It is reported that some ethnic groups have voiced their perception of more coercive
treatment, which may link to the dissatisfaction they feel towards services, potentially resulting in their refusal of treatment on a voluntary basis. This avoidance of services along with negative perception of services may account in part for increased rates of compulsory admissions.

4. **Being more likely to be sectioned**

People from ethnic minority groups may be more likely to be sectioned than white patients and it is argued that this is because of a) some form of institutional racism or b) due to the route by which they present to services (their pathway of care). These two explanations will be explored in turn.

**a) Institutional racism**

One explanation offered to account for admission rates of ethnic minority patients is that of institutional racism. The most commonly accepted definition for this term is that set out by Sir William Macpherson in the Stephen Lawrence enquiry, “Institutional Racism is the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping, which disadvantage minority ethnic people”. Perhaps the most relevant case to consider in this context is the independent investigation into the case of David Bennett, following his death at a Norfolk Mental Health Care Trust clinic. This inquiry was called for to investigate the care and treatment that the deceased received and review allegations of institutional racism within the clinic. The verdict of accidental death aggravated by neglect was reached and the conclusion included the statement that “at present people from the black and minority ethnic communities, who are involved in the mental health services, are not getting the service they are entitled to”. The inquiry resulted in a total of 22 recommendations which included; cultural awareness and sensitivity training; training to tackle overt, covert and institutional racism as well as ministerial acknowledgement of institutional racism in the mental health service and a commitment to eliminate it.

This links in with arguments that services may be less sympathetic towards people from ethnic minority groups or indeed view them as being more dangerous, resulting in being frightened of them. These issues have been highly publicised with the headline ‘Big, black and dangerous’, with particular criticism that previous inquiries into deaths of
patients from ethnic minorities in mental health service have not been learned from. Despite these views the evidence to support institutional racism as a reason for higher rates of compulsory treatment is limited at present. Health Care providers are experienced in working with service users from different ethnic groups and cultural awareness training is provided. In addition, a high percentage of health care provider clinicians are from ethnic minority groups themselves, weakening the argument for institutional racism accounting for the disproportionate number of admissions. That said, it is considered that by inappropriately focussing on service users’ ethnicity, poorer care may be offered due to less sound clinical judgment^{99}; suggesting a strong balance of cultural competence and clinical practice is needed to avoid unwitting racism.

**b) Pathways to care**

The second explanation presented for the increased compulsory admission rates of ethnic minority groups referred to a delay in help-seeking and the implications that this may have for their future health care. This explanation highlights the importance of exploring the pathways into treatment for ethnic minority service users^{11;12;78;100;101}, which inevitably has strong links with their delay in accessing services. Literature recognises that factors contributing to compulsory admissions are likely to be having an effect prior to the first episode, with black service users’ treatment being more likely to be directed by non-health professionals (eg. Criminal justice agencies) compared to white service users’ treatment^{8;12;100}. It is therefore necessary to consider the trends of mental health admissions relating to forensic services^{11}. Whilst African-Caribbeans are at an increased risk of imprisonment, Coid et al.^{102} concluded this group of offenders showed less psychiatric morbidity than white prisoners, with black prisoners less likely to have undergone psychiatric treatment than white prisoners^{103}. This finding is disparate with the disproportionately high number of African-Caribbeans detained in secure hospitals^{104}. The implications of such literature suggest that the relationship between a forensic admission and mental illness in black service users is both complex and inconclusive.

It is important to consider the influence of religion on pathways to care, as south Asians’ journeys to mental health treatment is increasingly including the input of an Imam^{105}. Singh et al.^{106} reported the tendency for people from British-Pakistani backgrounds to approach faith institutions for help with their symptoms. This suggests a time factor associated with accessing appropriate medical health care and a possible delay in the pathway, as documented in the second explanation. This implies potential for deterioration in mental
health by the time the patient is assessed and treated by the professional; requiring a greater level of treatment than may have been necessary had they presented earlier.

It is important that the arguments within the literature around help-seeking and pathways to care are compared with the official statistics that are available at time of writing, with regards to ethnic minorities accessing services. The figures to show both people using secondary mental health care as well as those on Care Programme Approach (CPA), using official statistics from the mental health minimum dataset65 are provided. Table 4 shows the number and percentage of people using secondary mental health care and those under CPA, compared with the percentage of the overall UK population each ethnic group represents (from Table 1). The figures in bold indicate those that are higher than the percentage of ethnic breakdown in the UK (from Table 1). The findings shown in the table are mixed, with most of the ethnic groups having proportionate representation within secondary services. Any differences between the percentage of those accessing secondary mental health care and proportion of population for each ethnic group are not statistically significant. This is also true of any differences between the percentage of those on CPA and percentage of UK population.
Table 4: Number of people using secondary mental health services and those on Care Plan Approach, all by ethnic group

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Percentage of the total population (from Table1)</th>
<th>Number of people using secondary mental health service (%)</th>
<th>Number of people on CPA (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>82.7</td>
<td>965,383 (83.3)</td>
<td>203,076 (79.3)</td>
</tr>
<tr>
<td>Irish</td>
<td>-</td>
<td>14,057 (1.2)</td>
<td>3,554 (1.4)</td>
</tr>
<tr>
<td>Any other White background</td>
<td>5.6</td>
<td>55,106 (4.8)</td>
<td>10,473 (4.1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mixed White and Black Caribbean</td>
<td>0.4</td>
<td>5,174 (0.4)</td>
<td>1,582 (0.6)</td>
</tr>
<tr>
<td>White and Black African</td>
<td>0.2</td>
<td>1,663 (0.1)</td>
<td>494 (0.2)</td>
</tr>
<tr>
<td>White and Asian</td>
<td>0.3</td>
<td>2,463 (0.2)</td>
<td>734 (0.3)</td>
</tr>
<tr>
<td>Any Other Mixed Background</td>
<td>0.3</td>
<td>4,990 (0.4)</td>
<td>1,359 (0.5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian or Asian British</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td>2.2</td>
<td>16,300 (1.4)</td>
<td>4,391 (1.7)</td>
</tr>
<tr>
<td>Pakistani</td>
<td>1.8</td>
<td>14,133 (1.2)</td>
<td>4,357 (1.7)</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>0.7</td>
<td>5,299 (0.5)</td>
<td>1,952 (0.8)</td>
</tr>
<tr>
<td>Any Other Asian Background</td>
<td>1.0</td>
<td>12,239 (1.1)</td>
<td>3,253 (1.3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or Black British</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td>1.1</td>
<td>17,091 (1.5)</td>
<td>7,570 (3.0)</td>
</tr>
<tr>
<td>African</td>
<td>1.5</td>
<td>11,472 (1.0)</td>
<td>4,630 (1.8)</td>
</tr>
<tr>
<td>Any Other Black Background</td>
<td>0.1</td>
<td>11,400 (1.0)</td>
<td>4,509 (1.8)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Ethnic Groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>0.5</td>
<td>2,204 (0.20)</td>
<td>666 (0.3)</td>
</tr>
<tr>
<td>Any Other Ethnic Group</td>
<td>1.6</td>
<td>20,021 (1.7)</td>
<td>3,438 (1.3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total number of people included</td>
<td>1,285,594</td>
<td>263,203</td>
<td></td>
</tr>
</tbody>
</table>

It would seem from this cross sectional snapshot above, that black Caribbean groups have a higher representation (although not significant) within secondary health care and CPA. Alternatively, the representation of Asian Indian and Asian Pakistani service users in secondary services and under CPA is lower than their ethnic representation in the UK.

---

*Ethnic group subtotals do not add up to total number of people included, because this total figure includes all those for whom ethnicity was invalid or missing. The total number of people with completed ethnicity data has therefore been calculated and it is this figure from which the ethnic subgroup percentages has been calculated.*
would suggest. The figures are interesting to consider and, whilst they do not provide information about the pathway that people took to accessing the services, they show that they are being accessed. The national EDEN trial\textsuperscript{107} will add new insights into this area as it is an on-going national evaluation of early intervention for psychosis services and will include a review of pathways to care, giving consideration to the ethnicity of service users.

Whilst Table 4 above presents the utilisation of community services data, it does not allow inferences to be made regarding the time that it takes for people to access services or the route that they present through. What it does do is provide evidence to suggest that they are accessing services and from that assertion, it is important to consider the possibility that the picture of ethnic minorities accessing services might be changing over time. With such changes, it is therefore possible that through presenting in a different way, the obstacle of delayed pathway and help-seeking behaviour may now be considered a historic problem which has partially reduced.

It can be argued that historically people from ethnic minority groups may have been less likely to seek help, causing a delay in their pathway to accessing services, compared to the route taken by white service users. The literature around pathways suggests that this is a reasonable assumption to make\textsuperscript{11;12;78;100;101}. It should not however be assumed that behaviour and health intervention between society and ethnic groups is fixed, as changes in the service is inevitable, as shown by changes within the NHS over the years. It is clear that people from ethnic minorities are accessing services and this could be due to a cultural change, with the involvement of their families increasing. There is also the possibility that the behaviour that ethnic minorities present with when ill may manifest itself differently than it has done in the past. They may behave less respectfully and their symptoms may be apparent more quickly, for example through violence, causing the family to feel stigma at an early stage. It can be argued that through actively addressing the stigma experienced at an earlier stage by getting help from professional services, greater stigma from future deterioration of health may be reduced. Therefore, once ethnic minorities have sought help it is important that the stigma they feel is reduced and that the interventions they receive are the most appropriate to their needs and help them to remain engaged with their clinical teams.

**Summary of explanations for disproportionate compulsory hospital admissions**

Whilst the explanations discussed for the increased detention rates for ethnic minorities do generally account for the disparities, it is clear that they do not hold not true across all
ethnic groups. This links with the differences between ethnic minorities detention under the mental health act that have been reviewed. Therefore there is an argument that these admission rates are not solely due to the higher prevalence of psychosis within ethnic minorities, but more the higher prevalence combined with an increased likelihood of being admitted and detained under the Mental Health Act. The reasons explored above are therefore not mutually exclusive and need to be treated as collaborative explanations, with each having an influence on the others.

The common theme that emerges from this overview of the literature is non-engagement with services by ethnic minority groups; whether that is due to mistrust, perceptions of discrimination or ethnic minorities displaying fewer help-seeking behaviours. In summary, there are many reasons offered that attempt to account for the disproportionate number of admissions for ethnic minority groups compared to white service users. Whilst the true reasons are still uncertain this thesis is based on the assumption that institutional racism does not account for the observed lack of engagement from service users. It is widely reported that other explanations are offered and a systematic review suggested that those studies that reported on racism based explanations provided no primary evidence to confirm such explanations. Additionally, with multi-cultural health care clinicians who are trained and experienced in working with people from different ethnic groups, this is likely to have minimal impact on the rates of compulsory treatment.

The conclusions that can be drawn from the review of explanations are firstly that, in general, mental illness and more specifically, psychosis, is more common in people from ethnic minorities. Secondly, patients from ethnic minority groups are not very happy or engaged with their psychiatric care; this is true both before admission and in relation to the after-care received. So the two main themes emerging are; frequency of psychosis and engagement. Whilst there is not much that can be practically done at this stage to reduce the frequency of diagnoses, there is something that can be done to explore engagement, as this is a key modifiable factor. There is a whole field of literature and research around improving people’s involvement in psychiatric care and it would seem appropriate to consider how these existing interventions can benefit people from ethnic minorities who are most at risk of being readmitted to hospital.
Questions arising from this chapter

The questions that arise from this chapter are:

- Is it possible to get service users from ethnic minority groups more involved with their care through involvement with their clinicians?
- If so, how would this affect their engagement with their clinical team?
- Would greater involvement in their care in the community prevent future hospital admissions?

In summary, engagement of patients is a key modifiable factor in reducing compulsory hospital admissions and this is particularly important for people from ethnic minorities. The following two chapters will build on these findings, giving consideration to the evidence of engagement with research by ethnic minorities and interventions that reduce admission rates.
Chapter 2: Inclusion of ethnic minority groups in psychiatric research

Overview

The first chapter of this thesis placed emphasis on the disproportionate number of psychiatric hospital admissions for ethnic minority groups when compared with their white counterparts. Whilst ethnic minorities are over-represented when it comes to compulsory hospital admissions, they are under-represented in research that aims to prevent admissions and indeed in psychiatric research as a whole. This chapter presents a systematic review, exploring studies which consider the barriers to recruitment and attempt to increase the recruitment of ethnic minority participants into psychiatric research.

Nine studies met the review's inclusion criteria and the barriers to recruitment of ethnic minorities into the studies were reported under five headings, with thematic analysis revealing a number of subcategories of barriers; these are denoted in brackets: participant related, practical, family/community, health service related and research process related. Each of the barriers is presented as a narrative review within this chapter as results are based on the authors' and service users' experiences of recruitment into psychiatric research.

The key lesson from this systematic review is that the majority of barriers identified are modifiable and can be overcome to enhance the participation of ethnic minority groups into research. Facilitators to overcoming such barriers should be considered and implemented as a pre-emptive measure in any future psychiatric research. The learning from this review will be applied to the CRIMSON trial (to be discussed in Chapter 5) as it is important that, where possible, barriers to participation are overcome for ethnic minority groups. CRIMSON provides the opportunity to apply this learning and assess whether it is possible to engage ethnic minorities into a mental health trial.
Rationale for this review

Compulsory hospital admissions are increasing\(^\text{114}\) and this is driven, in part, by high admission rates for ethnic minorities\(^{9-14}\). Interventions that are designed to reduce admission rates need to be evaluated in randomised control trials, such as CRIMSON (the subject of this thesis). It is important that the CRIMSON trial includes large numbers of people from ethnic minorities, because they have a disproportionate impact on admission rates. It is widely reported that ethnic minority groups have low representation in mental health research and it is argued that they are harder to recruit into randomised control trials, which is potentially problematic for CRIMSON. The next stage of this thesis will therefore examine why recruitment into psychiatric research may be lower for ethnic minorities and what can be done to address this. The learning from this review will then be applied to the CRIMSON study to ensure that, where possible, barriers to participation in the trial from ethnic minority groups are removed.

Background

Most developed countries have a substantial number of ethnic minorities\(^{115,116}\). People from these minorities have comparatively higher rates of: depression\(^{117,118}\), schizophrenia\(^{119,120}\), suicide\(^{121,122}\) and self harm\(^{123}\), with large variation in rates between ethnic minorities and countries of residence. However, ethnic minorities are less likely to take part in mental health research\(^{124,125}\). This lack of participation inhibits service development for ethnic minorities in developed countries.

In the United States, where National Institute of Health (NIH) guidelines mandate the inclusion of ethnic minorities in clinical trials, minority participation is better than in Europe\(^{126}\). In the absence of a similar policy in the UK, it is important to consider other ways of improving participation\(^{127}\).

In general there are two ways to improve the participation of minorities in clinical research. The first way is to ensure that ethnic minorities are proportionately represented in clinical studies. The second is to conduct studies specifically on ethnic minority populations. The first approach is suitable when the study asks a question that is relevant to the general population, such as whether or not a treatment works. The second is appropriate when the study asks a question specific to the ethnic minority, for example, how far a particular approach improves access to care.
To date there have been no reviews (systematic or non-systematic) of recruitment of ethnic minorities to mental health research. Whilst observations made in non-mental health studies may be relevant to mental health, there are likely to be barriers that may be unique to those participants with mental illness, one example being the issue of stigma\textsuperscript{17}. It is suggested that the issues for ethnic minority groups highlighted in Chapter 1, that may account for disproportionate hospital admissions (disengagement\textsuperscript{89}, delayed help-seeking\textsuperscript{8} and mistrust\textsuperscript{26,27}), may also act as barriers to participation in mental health research.

This review will therefore summarise and evaluate papers that describe attempts to increase recruitment of ethnic minority participants to clinical studies relating to mental health. The aim of the review is to describe the barriers to recruiting ethnic minorities, at community and individual levels. Although there is existing research in other disease categories\textsuperscript{112}, when looking into these barriers, it is necessary to explore them specifically in relation to mental health; as the nature of mental illness and needs of the patients are different from physical health categories. A distinction has been made above between studies of interventions that include ethnic minorities and studies on ethnic minorities. This review will not differentiate between the two types of research and both will be included.

Methodology

Eligible studies described the experiences of researchers who had attempted to increase recruitment of people from ethnic minorities to clinical studies (trials and non-trials) of mental health problems. The following were included: (a) descriptions of experiences based on specific studies and (b) descriptions of experiences based on an overview of several studies.

The search strategy was devised after examining similar reviews\textsuperscript{112,128} in other medical specialities. Based on this information key words were set for three domains. The search terms were selected and each term was entered into the database. (1) Participation or recruit or retain (2) ethnic minorities (this term was exploded) or culture; and (3) research or trial. The key words within each of the three domains were combined using ‘OR’ and ‘AND’ between all three domains. Four databases (inception dates in brackets) were searched: Medline (1950), Embase (1980), PsycINFO (1806) and Cinahl (1981) up to March 31\textsuperscript{st} 2012. No date limits or language restrictions were set for the search. All titles and abstracts were available in English and so no translations were necessary when selecting for this review. No mental health related search terms were used in the search.
strategy as it was felt that this might decrease the yield of the search, but only studies relating to mental health problems were selected for the review.

The search results were imported into Reference Manager 12\textsuperscript{129} and duplicates deleted. Mental health studies were identified by reading titles and abstracts. A data extraction form was designed a priori and pilot tested. Barriers to participation were listed on the form based on the author’s knowledge of the literature. Information was extracted on: study authors, publication year, and setting and design; specifically distinguishing between the overall design of the study and the means in which barriers to participation data was obtained. Data were coded by two independent reviewers and discrepancies were discussed and finalised in the presence of a third reviewer. Whenever a new category of barrier was identified, it was added to the extraction form in an evolving process that captured the breadth of the reported data. This exploratory work collapsed the reported barriers into groups that consisted of: person related barriers, practical issues, family/community barriers, health service related barriers and research process barriers. These groupings were not mutually exclusive, which makes some repetition within the review necessary.

Results

The PRISMA diagram of study selection is provided in Figure 4 below. The initial search strategy identified 10,089 papers, of which 10,066 were excluded as not relevant to the recruitment of ethnic minorities into mental health studies. Duplicates were not removed at the initial search stage, as normal procedure would dictate, due to the large number of hits, which the search software could not rearrange. Therefore hand searching was completed on all 10,089 papers, which included numerous duplicates.
Following the rejection of papers at the abstract stage, 23 papers, relating to 23 studies, remained. The full text versions of the remaining 23 studies were obtained; of these 14 were excluded. The reasons for the exclusion of the 14 references were as follows: policy review article (1), not documenting barriers to recruitment in research (3), not focussing on ethnic minorities (4) and not specifically focussing on mental health (6). The references for excluded studies and reason for exclusion are shown in Table 5 below.

The reference list for each of the 9 included papers and the 14 excluded papers was hand searched to check for any more relevant papers that may not have been retrieved from the initial database search. No additional studies for inclusion were found from this reference search. In total therefore, nine studies were included in the review. All were available in English and, as all the required information was available, there was no need to contact the original authors.
Table 5: Rejected search results showing reason for exclusion

<table>
<thead>
<tr>
<th>Title of paper</th>
<th>Reasons for exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Introduction to the special section on recruiting and retaining minorities in psychotherapy research</td>
<td>Review article</td>
</tr>
<tr>
<td>2 Minority ethnic community participation in needs assessment and service development in primary care: perceptions of Pakistani and Bangladeshi people about psychological distress</td>
<td>Not barriers to recruitment in research</td>
</tr>
<tr>
<td>3 Threats to applicability of randomised trials: exclusions and selective participation</td>
<td>Not focussing on ethnic minorities</td>
</tr>
<tr>
<td>4 Minority populations and psychophysiological research: Challenges in trust building and recruitment</td>
<td>Not focussing on mental health</td>
</tr>
<tr>
<td>5 Ethnic representation in a sample of the literature of applied psychology</td>
<td>Not barriers to recruitment in research</td>
</tr>
<tr>
<td>6 Transcultural psychiatry: some social and epidemiological research issues</td>
<td>Not focussing on ethnic minorities</td>
</tr>
<tr>
<td>7 Including Culturally Diverse Samples in Health Research: A Case Study of an Urban Trial of Social support</td>
<td>Not focussing on mental health</td>
</tr>
<tr>
<td>8 Social Capital, Participation and the Perpetuation of Health Inequalities: Obstacles to African-Caribbean Participation in 'Partnerships' to Improve Mental Health</td>
<td>Not barriers to recruitment in research</td>
</tr>
<tr>
<td>9 Self-Assessment of Cultural Attitudes and Competence of Clinical Investigators to Enhance Recruitment and Participation of Minority Populations in Research</td>
<td>Not focussing on mental health</td>
</tr>
<tr>
<td>10 Understanding African American participation in a behavioural intervention: results from focus groups</td>
<td>Not focussing on mental health</td>
</tr>
<tr>
<td>11 Promoting cultural proficiency in researchers to enhance the recruitment and participation of minority populations in research: Development and refinement of survey instruments</td>
<td>Not focussing on mental health</td>
</tr>
<tr>
<td>12 Features associated with the non-participation and drop out by socially-at-risk children and adolescents in mental-health epidemiological studies</td>
<td>Not focussing on ethnic minorities</td>
</tr>
<tr>
<td>13 An examination of community members’, researchers’ and health professionals' perceptions of barriers to minority participation in medical research: an application of concept mapping</td>
<td>Not focussing on mental health</td>
</tr>
<tr>
<td>14 Mental health professionals' perceived barriers and benefits, and personal concerns in relation to psychiatric research</td>
<td>Not focussing on ethnic minorities</td>
</tr>
</tbody>
</table>

All nine included studies were from the USA, as indicated in Table 6 below. Researchers’ narratives were qualitatively described, none of the studies reported on any quantitative barrier related data. The barriers to recruitment identified by the studies are summarised in Table 7 below under five headings: participant issues; practical issues; family/community issues; health service related issues and research process issues.
<table>
<thead>
<tr>
<th>Title</th>
<th>Setting</th>
<th>Ethnic group</th>
<th>Diagnostic category</th>
<th>Description</th>
<th>Design</th>
<th>Source of data reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miranda et al. (1996)</td>
<td>San Francisco, USA. Hospital</td>
<td>Latino</td>
<td>Depression</td>
<td>Experiences from four different trials.</td>
<td>2 preventative and 2 treatment studies</td>
<td>Authors' own experiences of recruitment to trials.</td>
</tr>
<tr>
<td>Thompson et al. (1996)</td>
<td>Detroit, Michigan, USA. Hospital</td>
<td>African American</td>
<td>Schizophrenia or mood disorder</td>
<td>A study on the influence of ethnicity on diagnosis in psychiatric inpatients.</td>
<td>Cross sectional Study</td>
<td>Direct interview with participants. &amp; authors experiences.</td>
</tr>
<tr>
<td>Arean et al. (2003)</td>
<td>San Francisco Bay, USA Community clinic</td>
<td>African American</td>
<td>Depression or anxiety</td>
<td>Traditional methods of recruitment versus consumer-centred approach in elderly.</td>
<td>Comparative observational studies</td>
<td>Authors’ own experiences of recruitment in two trials.</td>
</tr>
<tr>
<td>Meinert et al. (2003)</td>
<td>Cleveland, Ohio, USA Community</td>
<td>African American</td>
<td>Depression</td>
<td>Mental health conference based on NIH guidelines on the inclusion of minorities</td>
<td>Intervention study</td>
<td>Participants views of barriers.</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Population</td>
<td>Condition</td>
<td>Study Description</td>
<td>Study Type</td>
<td>Authors' Contribution</td>
</tr>
<tr>
<td>-----------------------</td>
<td>----------------------------------------</td>
<td>------------</td>
<td>--------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td>----------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Gallagher-Thompson et al. (2004)</td>
<td>Community, San Francisco Bay USA</td>
<td>Latino</td>
<td>Dementia</td>
<td>Comparison of 3 recruitment strategies (non-professional, professional and advertisements)</td>
<td>Cross-sectional Nested study</td>
<td>Authors' observations from the trial.</td>
</tr>
<tr>
<td>Chen et al. (2005)</td>
<td>Manhattan, New York City, USA Neighbourhood health centre</td>
<td>Asian American</td>
<td>Depression</td>
<td>Description of building research programmes in the community.</td>
<td>Review article</td>
<td>Authors' experiences with engaging the Asian American in research.</td>
</tr>
<tr>
<td>Aliyu et al. (2006)</td>
<td>South Eastern USA Multiple academic medical centres,</td>
<td>African American</td>
<td>Schizophrenia &amp; Schizoaffective disorder</td>
<td>Procedure for maximising recruitment and retention &amp; forging community ties.</td>
<td>Description of a protocol</td>
<td>Authors' experiences &amp; literature review to enhance recruitment procedures in their study.</td>
</tr>
<tr>
<td>Loue &amp; Sajatovic (2007)</td>
<td>San Diego County, California and North East Ohio, USA</td>
<td>Latino</td>
<td>Schizophrenia, bipolar disorder or major depression</td>
<td>Overview of author’s own experience from several studies</td>
<td>Review article</td>
<td>Authors’ own experiences of recruiting.</td>
</tr>
<tr>
<td>Barrier</td>
<td>Miranda</td>
<td>Thompson</td>
<td>Le</td>
<td>Arean</td>
<td>Meinert</td>
<td>Gallagher-Thompson</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------</td>
<td>----------</td>
<td>----</td>
<td>-------</td>
<td>---------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Participant Related Barriers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explanatory models of illness</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Help-seeking/ negative attitude to psychotherapy</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Religious beliefs</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Stigma</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Gender</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>* Psychopathology/Substance misuse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of being reported to immigration</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practical Issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of childcare</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Transport provision</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial constraints</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Culturally inappropriate incentive</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>* Medical insurance</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of time</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Location of interview</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family/Community</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husbands’ influence</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family perspectives</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Stigma for family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Service Related</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>* Underutilisation of mental health services</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Language of professional/intervention</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Lack of communication and cultural awareness between staff and participants</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff personal attributes</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research Process</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited willingness and enthusiasm of researchers</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Understanding the need for ethnic participation</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paucity of resources available</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Appropriateness of assessment tools</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-availability of translated materials</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Lack of culturally competent staff</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of culturally matched staff</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under representation of ethnic minorities at recruitment sites</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Understanding of consent process</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Key: * indicates those barriers that are not modifiable within the scope of the study
The results are shown below in their barrier groupings following analysis of the 9 papers included in the review.

**Participant related barriers**

*Explanatory model of illness*

One study made reference to explanatory models of mental illness acting as a barrier to recruitment. In a study of depression\(^1\), authors reported denial to be a typical response, with patients not considering depressed moods as a medical condition requiring treatment. The authors also reported that a lack of knowledge could result in people over-generalising or oversimplifying symptoms\(^1\).

*Help-seeking/ negative attitudes to psychotherapy*

Three studies made reference to help-seeking preferences and attitudes towards psychotherapy as potential barriers to recruitment of ethnic patients. The authors suggested recruitment of African Americans in Detroit was hindered by negative attitudes toward psychotherapy in that community\(^2\). The authors stated that many African Americans with emotional problems prefer alternatives to mental health services or do not seek help at all\(^2\). Another study\(^3\) described how African Americans placed emphasis on the role of prayer and spirituality and referred to spiritual support organisations “the unique role of mutual support available within Sister circles in local communities”\(^3\). Authors report\(^2\) that many in their sample would be unlikely to seek professional help and people felt that receiving psychotherapy meant seeking assistance outside the family. Another included paper\(^4\) referred to “help-seeking” being a barrier, although did not elaborate on this comment. The recruitment study in Detroit concluded that the above findings “often result in small pools of African Americans from which to sample”\(^2\).

*Language*

Six studies highlighted language related barriers to recruitment\(^5;6;7;8;14;144;146\). These papers cover a diverse range of ethnic minorities, including Latinos, African Americans and Asian Americans. The authors of one paper wrote, “the issue of communication between the provider/care network staff and the patient with serious mental illness was seen as a potentially overwhelming barrier in many clinical settings”\(^6\). One study, which recruited from a low income Latino population in San Francisco\(^7\), found that it was critical to develop culturally sensitive language instruments, highlighting lack of
availability of appropriate questionnaires as a barrier to recruitment. Another study recruiting from Latino communities in San Diego, Ohio and Puerto Rico, found that potential participants were often monolingual in Spanish or preferred to speak in Spanish. A further study, focusing on the recruitment of Asian Americans highlighted the effect of low literacy levels, stating that, “Asian American immigrants, especially elders, have also relatively lower literacy levels.

It is not only using the correct language that is important, but also being culturally sensitive within that language. For example, one paper found that at times “the required language and phrases stipulated by institutional review board, when translated into Spanish, may contain a number of specific words and phrases that were alarming to our target population” (in this case Latinos in Washington DC and Mexico City). Another study concluded that by listening to the views of African American women they had “acquired a greater sensitivity to the language and common expressions of African Americans”. A fifth study included language as a barrier to recruitment but did not elaborate further.

Religious beliefs

Four studies identified religion as a barrier to recruitment. The first focused on recruiting and retaining low-income Latinos in San Francisco. The authors reported that “many Latinos are Catholic and, whilst authors recognised that alternative treatments and folk beliefs about psychiatric symptoms are unlikely to interfere with their participation in research, these issues may affect diagnoses and exclusionary criteria”. For example, they made the proposition that some Latinos may present with beliefs that can appear psychotic out of context, despite being culturally appropriate. Other studies found that religion can lead to seeking help from sources outside the normal health service. For example, some African Americans, who have faith in prayer and spirituality may seek help from religious leaders rather than health care professionals. This study referred to “the unique role of mutual support available within Sister circles in local communities”. Whilst this contribution was offered by African American women attending a conference to promote mental health studies in Cleveland, it may not be generalisable to other African American communities. Other studies reported that awareness of religious holidays must be incorporated into recruitment efforts, and that competing obligations, such as attendance at church functions, can affect potential participants’ willingness to engage in research.
Seven studies identified the importance of mistrust as a factor that inhibited recruitment. Four were concerned with the recruitment of African Americans. In three, this mistrust was traced to a legacy of unethical research conducted by white researchers on African Americans, such as the Tuskegee Scandal, (in which black men were not offered efficacious treatments for syphilis). One paper stated that, “Understandably, African Americans tend to distrust research in general and research conducted by whites in particular.” As a result of the Tuskegee study, one paper commented that, “some African Americans believe that their race are used as guinea pigs in medical research and inevitably, willingness to participate in clinical trials involves a strong element of trust.”

Another element of mistrust as a barrier is evident from observations about potential participants’ suspicion about services. In one paper, some African American women voiced suspicion about mental health services. The authors reported that their fear of physicians (especially psychiatrists), was based primarily on the previously mentioned syphilis study. The authors wrote that, “the view that psychiatrists are like policemen suggests that African American encounters with them are often followed by involuntary hospitalization.” The same study also commented that “participants also identified their suspicion of the perceived profit motive of pharmaceutical companies.”

Another study, concerned with the recruitment of members of the Latino community also referred to the issue of trusting professionals, stating that Latinos “traditionally have tended to be wary of professionals who they do not know.”

A study of Asian Americans described how they viewed the consent process and legal documents with suspicion. Finally, two studies described strategies to mitigate participant fear and distrust in African Americans and Latinos.

**Stigma**

Seven studies identified stigma as a barrier to recruitment, in the sense that stigma relating to mental health is a greater problem in some ethnic minorities than it is in the white population.

Three studies reported that the stigma attached to mental illness was a particular problem in African American communities. One study referred to African American women using the words “crazy, scary, weakness, helpless, hopeless, irresponsibility,”
and stigma" in association with mental health research\textsuperscript{26}. The authors reported that "one participant noted that she was taught to keep personal issues in the family and deal with them by keeping a stiff upper lip"\textsuperscript{26}. Another study focussing on the recruitment of African Americans commented that "the stigma associated with psychiatric illnesses might be magnified and misused in the context of research involving members of a minority group"\textsuperscript{145}.

A study of recruitment from the Latino community noted that "fear of being stigmatized as a result of study participation or being recognised as mentally ill"\textsuperscript{146}. The fear of being labelled mentally ill was particularly pronounced in Asian American communities, despite their limited exposure to research\textsuperscript{81}. Authors of one paper report that, "the stigma concerns of older people from ethnic minorities may be different than those of older whites. Whereas many older white patients may be concerned with what others will think of them if a mental health diagnosis is uncovered, many older minorities may be more concerned with the impact a psychiatric diagnosis will have on their family's reputation"\textsuperscript{85}.

One study\textsuperscript{27} referred to stigma as being a barrier to participating in mental illness research but did not elaborate on how stigma interferes with the recruitment process.

\textit{Gender}

Three studies, all concerned with recruiting from Latino communities, mentioned gender as a barrier to recruitment. One reported that females were unable to participate due to their husbands' disapproval of the research and recommended that the "man of the family" be included in discussions before the wife was recruited\textsuperscript{143}. The woman's traditional role in Latino culture was discussed in another study from Washington DC and Mexico City. This study reported that "a woman’s traditional role as a good housewife and mother-prominent among the less educated suggests that participating in competing activities may seem too selfish"\textsuperscript{144}. An additional barrier that may take up time and resources was reported on by authors\textsuperscript{144} who found that women were often uncomfortable about refusing to participate, and so provided passive assent to appointments. This may be due to the woman wanting to respond in a socially desirable manner and not to disappoint research staff. Inevitably this led to withdrawals or non-engagement within the research process. Another study reported that relationship issues, such as partner violence, were a barrier to recruitment in their study\textsuperscript{146}. 

59
Psychopathology/substance misuse

One study on recruitment and retention in Puerto Rican and Mexican women found that high levels of psychopathology and/or use of substances, was a barrier to recruitment\textsuperscript{146}. The authors reported that three Puerto Rican women and two Mexican women were lost to follow-up due to the severity of their psychopathology or substance use. In these women, increased drug use had led to unreliability in attending scheduled appointments and even raised questions as to the participants’ capacity to continue with the research. The study did not state whether this issue was more pronounced in ethnic minority than white participants, nor whether it was more pronounced in women.

Fear of being reported to immigration

Two studies reported that people had expressed fear of being reported to immigration if they consented to participating in the research. Authors\textsuperscript{144} reported that phrases on the consent form raised concerns about possible deportation in some women with undocumented immigration status. Another study reported that a large proportion of Mexican participants were not legally present in the United States and expressed concern about the possibility of deportation\textsuperscript{146}.

Practical issues

Lack of childcare

Five studies commented on childcare as a barrier to recruitment. One study concerned with recruitment from the Latino community found that people from ethnic minorities reported more practical barriers to mental health care, such as child care, than whites\textsuperscript{143}. Another found that childcare issues were frequently given as reason for not participating in research by members of Latino communities\textsuperscript{144}. The same study also reported that mothers were unable to come to a clinic because of child care issues. A study of depressed African American women found that some could not access treatment because of child care responsibilities\textsuperscript{26}. A study of Asian Americans suggested that elders in this community may be unable to commit to research studies because they often have childcare responsibilities. One study raised the possibility that childcare issues may be an effect of poverty rather than ethnicity as such\textsuperscript{146}. 

60
Transport provision

Six studies referred to lack of transport as a barrier to recruitment. One reported that Latino mothers were unable to come to the research site because of transportation limitations. Furthermore a study of Latinos in San Francisco Bay reported that difficulties with transportation to clinical centres deterred participation. Five of the six papers described attempts overcome this obstacle. One referred to the “financial considerations that impacted the individuals’ ability to pay for transportation costs”, suggesting that this barrier may be caused by poverty, rather than ethnicity as such.

Financial constraints

Seven studies commented on participants’ financial position as a barrier to recruitment. People of low socio-economic status report more barriers to obtaining mental health care, than white higher income individuals do. African American patients from inner-city, low-income areas expressed more reluctance to participate in research studies in major medical centres. Immigrants on low incomes may hesitate to incur the additional expense of medical services in their host country, and may believe that participation in a treatment study is likely to incur costs. One study suggested that elders from ethnic minorities may have particularly limited resources and therefore be particularly deterred by financial issues. Two studies offered solutions to overcoming financial barriers to recruitment.

Culturally inappropriate incentives

It was common for studies to offer incentives to recruitment. However, two studies pointed out how certain incentives could have a negative impact on recruitment. For example, one study found that some people did not want to be pressured by the extra obligation caused by money, and others were embarrassed because they felt they should be paying for services, not the other way round. Another study found that some Asian elders did not feel comfortable accepting money as an incentive, and felt that their information was being sold as part of a cheap material exchange.
Medical insurance

Two studies identified lack of medical insurance as a barrier to recruitment\textsuperscript{26,143}, reporting that some depressed African American women did not have access to treatment because of inadequate health insurance\textsuperscript{26}.

Lack of time

Five studies reported lack of time as a barrier. In one study concerning Latinos, the authors reported that the most common reason for not participating was “lack of time/too busy”\textsuperscript{144}. Lack of time was a factor that was cited across age groups, but was particularly common in adults from ethnic minorities who were often experiencing multiple psycho-social stressors and limited resources\textsuperscript{81,85,143}. One study highlighted time constraints as being a barrier to recruitment of Latinos and described the efforts they employed to overcome this barrier\textsuperscript{146}.

Location of interview

Five studies referred to the location of the research interview/intervention as a barrier to recruitment, and all studies described it as a potential barrier\textsuperscript{26,27,85,143,146}. One commented that “paranoia, could interfere with individuals’ willingness and ability to present at a less familiar location and result in their withdrawal from the study”\textsuperscript{146}. The same study suggested that people from ethnic minorities with less severe mental illness might be more reluctant to participate if they had to attend mental health treatment facilities, where they might be identified by other members of their community.

Employment status

One study cited conflict with employment or study as to the most common reason for Latinas not participating\textsuperscript{144}.
Family/ community related

Husbands’ influence

Two studies on Latino populations commented on prohibitions by husbands or partners as a barrier to recruitment of women from ethnic minorities\textsuperscript{143;144}. One even suggested that it might be beneficial to include the woman’s husband in discussions before she was recruited into a study\textsuperscript{143}. Some women may accept a submissive role and comply with their partners’ prohibitions against their active participation in the interventions; this has been a barrier for a small minority of participants\textsuperscript{144}.

Family perspectives

Seven studies, across African American, Latino and Asian American samples, referred to the family as a barrier to recruitment. Two studies\textsuperscript{143;144} involving Latinos recorded how strong traditional family values, could make recruitment difficult. One stated that “adherence to traditional gender roles” and “respect towards elders may be unique facilitators or barriers for recruiting Latina participants into intervention research”\textsuperscript{144}. Conversely, this paper also suggested that families can assist with the recruitment process as well as hindering it, if appropriate cultural considerations are taken into account. Another study, again involving Latinos, referred to the need to educate family members to help them identify mental health symptoms\textsuperscript{27} and another reported on how family commitments affected a participant’s recruitment into the study\textsuperscript{146}. One study\textsuperscript{26} concerned with African Americans reported that people were deterred from seeking treatment because it represented a failure to keep problems in the family. The authors reported that participants “felt that receiving psychotherapy meant seeking assistance outside the family”\textsuperscript{26}. One study\textsuperscript{146} focussing on Asian Americans recognised that family members could also contribute to the process should a participant wish to withdraw from a study. They documented that family members could assist with clarification of concerns and the withdrawal procedure. They noted that whilst this involvement may still lead to the withdrawal, it might also encourage the participant to continue.

Stigma for the family

Three studies referred to stigma in the family context as a barrier to recruitment. These studies focussed on recruitment of African Americans\textsuperscript{85;145} and Asian Americans\textsuperscript{81}. One study reported that some elder African Americans were more concerned with the
impact a psychiatric diagnosis would have on their family’s reputation than on themselves. One study concerned with Asian Americans reported that “a difference between stigmas associated with different illnesses was observed, for example depression is generally less stigmatizing than psychosis. The less stigma that is linked to a project, the more support a community is likely to give.” This study found that most Asian community leaders appeared to be understanding and sympathetic regarding the mental health aspects of research projects, which seems to contradict what is reported above. The authors reported that the leaders “all agreed with the need for services but also believed that the stigma would potentially obstruct the project.” As stigma for families and communities is a concern with regards to the recruitment of ethnic minorities into mental health research, one study focussed on recruiting African Americans endeavoured to use a “model that forges ties with Community Health Advisors to educate and gain the trust of African American communities”.

**Health service related**

*Under-utilisation of mental health services*

One study concerning the recruitment of Latinos, suggested that under-recruitment was due to low levels of engagement with mental health services. Since the study recruited from the pool of existing mental health service users, it was almost inevitable that ethnic minorities would be under-represented as they under-utilised these services.

*Language of professional/intervention*

Four studies made reference to the importance of the language of the intervention and researcher. One study focussing on Latinos stated, “providing services in Spanish is essential for recruiting monolingual Spanish-speaking Latinos.” Within this study the authors reported that, “bilingual-bicultural staff were able to maintain Latino patients in treatment at the same rate as our non-Latino sample” and all treatments in this trial were conducted in Spanish. The other three studies documented the importance of having bilingual and bicultural staff to assist their recruitment of participants, with one study stating that “the use of bicultural research staff and clinic staff (Mary’s Centre site, Washington DC) increased the number of screening interviews conducted in the US study”. This study used family support workers which included “one European-American worker who spoke Spanish fluently,
the remaining five were immigrants from various Latin countries, including Bolivia, El Salvador, Chile, Uruguay and the Dominican Republic. One study concerned with the recruitment of Latinos in the San Francisco Bay area documented the ways in which bilingual and bicultural staff were employed. They had involvement in: developing a standardised screening process in the language of the participant’s choosing, appearing at health fairs and ethnic-specific community festivals and acting as consultants to improve the relevance of outreach materials.

Lack of communication and cultural awareness between staff and participants

Three studies referred to the importance of communication between research staff and participants. The need to show respect toward male figures, as well as older adults in general, were highlighted as important aspects of Latino culture that needed to be taken into account in three studies that recruited Latinos into mental health research. Latinos are expected to be warm and personal in their interactions with others, a concept known as simpatía. Important aspects of this personal approach include the use of formal language (Usted, Señor, Señora, etc.), as well as formal greetings, in professional relationships. The studies highlighted here show the importance of being culturally aware when approaching participants and their families.

Staff personal attributes

Two studies commented on the importance of personal attributes in recruitment of ethnic groups. Latinos were said to respond well to the Simpatía and Personalismo of others and one study reported that, “traditional approaches to recruiting participants into treatment outcome studies may be perceived as both too informal and too cold for many Latinos”. This study surmised that “the success in retaining the subjects is attributed to a careful individualised approach” and the researcher’s ability to remember details of the participants’ family situations and develop personal rapport was highlighted. Furthermore this study stated that the researcher was “warm, friendly and interested in their [participants’] well-being”. The personal attributes of these staff were essential to the recruitment process.
Research process

Limited willingness and enthusiasm of researchers

Three studies, across African American, Asian American and Latino samples, reported lack of enthusiasm from researchers as a barrier to recruitment. One paper, detailing the recruitment of African American participants, reported that by “failing to understand the specific culture of the target population, they had inadvertently distanced themselves from the community and the gate-keepers, doing little to overcome attitudes about research and mental health”. Belatedly, the authors recognised that their research strategy had, to its detriment, been “minimally informed by the culture of the community we were working with”. It is unclear whether this limited willingness of the researchers was due to their restricted cultural competence, in that a lack of knowledge and skills may have contributed to their failure to understand the culture of interest. Alternatively it may simply be a rigidity in researchers’ attitudes, which has led to their reluctance to overcome such barriers.

On the other hand, one study recruiting Latino participants reported that “professional referrals were the most successful recruitment method, far more so than media efforts and non-professional referrals”. The enthusiasm of researchers to develop strong working relationships with professionals in the recruitment area was vital to successful recruitment. One study concerned with the recruitment of Asian Americans expressed the need for “research staff to stress the uniquely potential impact of certain elements of the study on both the medical staff and the patients”. Within this paper the authors stressed the need for researchers to “emphasise the cultural competence elements of the study”.

Whilst enthusiasm to promote the research study is highly important, when recruiting from ethnic minority communities, the authors also referred to the importance of considering how the service providers’ will is conveyed in action, stating, “overemphasising the academic needs of research could be interpreted as a sign of self-serving intent that is irrelevant to a community’s need”. The literature would suggest that it is particularly important to overcome this barrier where the ethnicity of research staff is different from that of the professionals/communities in the service from which the patients are recruited.
Understanding the need for ethnic participation

One study, focussing on African American participants, commented that service providers not feeling the need to include ethnic minority groups in their psychiatric research was a huge barrier to recruitment\textsuperscript{25}. The authors stated that “African American patients are frequently considered to be a research risk because they are less likely to be found or to participate for the duration of the study”\textsuperscript{25}. In addition they wrote that, “African American men are sometimes viewed as violent and threatening. These factors undoubtedly contribute to the fact that many researchers may be reluctant to conduct research focused specifically on African Americans”\textsuperscript{25}.

Paucity of resources available

Eight out of the nine included studies referred to study resources as barriers to recruitment. These studies also documented measures taken to utilise resources to maximum effect. One study, concerned with Latinos, stated that lower participation rates may be due to not providing culturally and linguistically appropriate staff\textsuperscript{143}. Other authors\textsuperscript{81} emphasised the importance of having culturally appropriate interviews and scales with accurate translations.

In addition to appropriate research materials and staff, studies highlighted the importance of the resources needed from recruitment sites. One stated that, “studies that must be done in clinical settings inevitably cause a certain degree of intrusion or interruption to the normal clinical flow”\textsuperscript{81} also “it is important to be aware of the existing workload of clinical staff and the extra burden the research process will add”\textsuperscript{81}. One study, focusing on the recruitment of African Americans, concluded that “sufficient time and money should be allocated during the research planning stage to develop culturally sensitive strategies that incorporate the reactions of African American patients into the preparation and implementation process”\textsuperscript{25n}. Several studies described the importance of spending time and resource prior to recruitment on developing partnerships between research staff and gatekeepers to the community\textsuperscript{85,144-146}. One study stated that “Latinos are more likely to enrol in research when recruitment sources derive from collaborative relationships with Latino-specific community agencies”\textsuperscript{27}.

Appropriateness of assessment tools

One study highlighted that assessment tools used could act as a barrier to recruitment\textsuperscript{25}. The potential participants were predominantly African Americans of low
income who had little knowledge of clinical research and poor literacy. As a preliminary to the study the authors had reviewed a number of diagnostic research instruments and shown that these instruments were problematic with similar client groups. From their work the authors of this paper stated that, “a more flexible approach to diagnostic assessment is often needed to prevent such barriers being in place”\textsuperscript{25}. In addition, limited availability of assessment tools in their native language was observed.

**Non-availability of translated materials**

Five studies commented on study materials acting as a barrier to recruitment. One study on the recruitment of Latinos reported, “many commonly used instruments in psychotherapy research have not been translated into Spanish or validated on Spanish-speaking populations”\textsuperscript{143}. Even when written materials have been translated into the participants’ preferred language, there is a risk that some directly translated words may be perceived as stigmatising or simply confusing\textsuperscript{144}. Other issues may be presented when materials have been translated, such as character names and descriptions used, so it is necessary for materials to be culturally appropriate, beyond simple language translations\textsuperscript{81} The final two studies that reported on translated materials described which study materials they had translated\textsuperscript{27,146}.

**Lack of culturally competent staff**

Three studies commented on the importance of culturally competent staff in recruiting ethnic minorities\textsuperscript{25,85,146}. These studies employed staff who were experienced in working with people from the ethnic minorities they were targeting for recruitment. This did not mean that staff were ethnically matched with the participants, but rather that they had the skills, experience and cultural awareness to engage the target population.

**Lack of culturally matched staff**

Three studies referred to matching the ethnicity of research workers and potential participants. Perhaps surprisingly, one study recruiting African American participants found that matching had no noticeable influence on refusal rates\textsuperscript{25}. This was supported by another study concerned with African Americans\textsuperscript{85} that found that “experience was more important than ethnic matching” when it came to recruitment rates. By “experience” the authors meant previous experience of recruiting and retaining participants from the target population. One study focusing on the recruitment of Asian Americans suggested that the critical factor was not ethnic matching per se but that the
research worker was a culturally competent person\textsuperscript{81} who could build trust with potential participants.

\textit{Under-representation of ethnic minorities at recruitment sites}

Six studies referred to the importance of considering the area from which to recruit participants. These studies described the steps they had taken to ensure they were targeting the most appropriate recruitment sites. Two studies, recruiting Latino participants, selected their recruitment sites to maximise the number of Latinos they could access. One study recruited through a medical setting, serving the Mission District, which is a Latino area of San Francisco\textsuperscript{143} and the other through the Providence Hospital in Washington DC, where patients are 60\% Latinas\textsuperscript{144}. The other studies\textsuperscript{25;26;145;146} referred to the selection of recruitment areas to reach the target ethnic minority groups, and to the dissemination of information about the studies to the appropriate communities\textsuperscript{146}.

\textit{Understanding of consent process}

Two studies referred to obtaining consent as a barrier to recruitment\textsuperscript{81;144}. One study, focusing on Asian Americans in New York, found that “Asian Americans are not accustomed to the process of giving written informed consent for treatment, and they are relatively inexperienced in participating in research trials, which they may view with suspicion”\textsuperscript{81}. Another study described an issue that arose in recruiting a Latina sample in the U.S.(but not in Mexico), which was that great care had to be taken to ensure they fully understood the intent and contents of the research consent forms\textsuperscript{144}. Explaining study procedures can be difficult as it is hard to frame randomisation in a manner that is understandable and acceptable to potential participants\textsuperscript{81}. In addition, consent forms may lead to immigrant adults refusing to participate in a study because of a suspicion of any legal documents\textsuperscript{81}.

\textbf{Discussion}

This review is the first systematic attempt to identify barriers that hinder recruitment of ethnic minorities to mental health studies. The main benefit of this review is that it provides a compilation of important barriers to recruitment. Researchers who are aware of these barriers may modify their research design accordingly in order to facilitate recruitment of people from ethnic minorities. The review suggests a key factor in under-
recruitment of ethnic minorities is simply low rates of participation in the health services in which the research is conducted.

Subsequently, once a research study is rolled out there is interplay of various barriers with a large overlap. Many of these barriers are not specific to ethnic minorities and are clearly encountered when working with majority populations that are often Caucasians, particularly of low socio-economic status. For example, child care may be a barrier for both Caucasian and ethnic minority participants, although the options available to address this issue show wide variation. Employing a paid child-minder is widely practiced in white households, whereas this concept is alien to the majority of ethnic minorities, who are more dependent upon their friends and families. Likewise, lack of health insurance acts as a barrier as there are fewer ethnic minority patients who are insured, thus reducing their chances of being recruited from treatment facilities. It is important to bear in mind that culture still plays an important part in the genesis of these problems and though the presenting nature may be the same, there are culture-specific intricacies that need special handling and will not be overcome just by employing simple solutions for the whole sample.

It is clear from the results that some of the barriers are easier to address than others and can be overcome after due interventions; meaning that the barriers can be eliminated. Fear of being labelled as mentally ill by the researchers may be an even greater deterrent to people from ethnic minorities than to people from the majority population, because of the additional fear of families being stigmatized. Working with local ethnic community organisations and involving local media can help to facilitate recruitment. This collaboration also helps when families may need to be involved in the recruitment process. But there could be an issue with this involvement as it may reinforce traditional power relationships that are associated with the oppression of women. This raises questions about confidentiality, particularly when the subjects are stressed due to problems within the families or when they do not want to share their medical issues, such as a history of self-harm.

It is here that the cultural competence of the main investigators and the field research workers in particular becomes critically important. Financial constraints and availability may not allow cultural matching of research staff yet training on how to approach, invite and recruit ethnic minority subjects is extremely important. Extra human and financial resources will be needed and must be provided in advance. This will help in preparing multilingual study materials and tailoring interventions to the needs of ethnic subjects.
The systematic review highlights the recurring issue cited in research of African Americans being viewed as threatening; with this stereotype frequently reported, although rarely substantiated with evidence. This issue contrasts with the evidence presented around ethnic matching, as it was suggested that cultural competence is as equally valid as cultural matching in terms of recruiting minority participants into research. Whilst cultural competence is important and should be the first thing to be ensured, on some occasions cultural matching may also be considered beneficial. Service users may, for example, build up more trust, more understanding and it may lead to a reduction in problems. They may deem that they have commonalities with the matched staff member and it could be valuable for both service user and staff. The argument against this viewpoint is that, if matched, the service user may have concerns around confidentiality and the issue of stigma may be present. If, for example, they are from the same community as the staff member then they may fear that the staff member will somehow make their situation known to the community, which could lead to the community stigmatising them.

As the process of recruiting ethnic minorities into mental health research is multi-factorial, no matter what investigators do, there will always be certain barriers that will be difficult to overcome. Psychopathology/ substance misuse, domestic violence, lack of insurance and underutilisation of mental health services (as shown in Table 7 above, with asterisk) are those difficult to modify factors. It can be said that, for the remaining barriers, making a few small changes in recruitment methods and extra provisions can have a beneficial impact on ethnic minority recruitment. It is also evident that the barriers are interrelated; therefore it may be necessary to address several barriers in order to get desired results. Alternatively, it could be argued that it is more likely that making adjustments to overcome one barrier may be sufficient to positively affect multiple barriers.

The review has provided a framework of barriers that is more sensitive to the needs of mental health research, based on the premise that the issues are different to those affecting other health and social research. This will hopefully help in generating tailor-made solutions for mental health research related barriers. Researchers have already reviewed existing barriers to research in general health conditions and also described, to an extent, possible solutions. That review has generated over-arching broad categories of barriers and possible solutions. In contrast, the present review provides in-depth detailed sub-categories and has attempted to categorise the barriers to better understand the process and enable exploration of solutions to the barriers. This resulted in generating as
many barriers as possible rather than amalgamating them, so that future researchers have a larger framework from which to highlight barriers and come up with pre-emptive solutions. It is hoped that in this way the framework will be transferable and applicable to other ethnic groups outside of the US. It should be reiterated that the categories used in this review are not mutually exclusive nor ethnic specific, they are dependent upon each other which accounts for some repetition. There is undoubtedly an overlap in the barriers, whilst they remain distinct in their own description.

Limitations of applying US data to a UK population

Whilst the author had aimed to review international literature in addition to UK literature, it is noticeable that only nine papers met the inclusion criteria for the systematic review and are all from the United States, with participants that were migrants typical of the US. Therefore it is important to give consideration to the limitations of applying US data to a UK population, given how the two healthcare systems differ and the composition of ethnicity and definitions of ethnic categories within each country.

There are differences in the history and the context of healthcare between the US and UK healthcare systems. Whilst the National Health Service covers all UK residents, is funded through tax and centrally governed, the US health service is reliant on funding through public and private insurers and hence imposes fees on users. This has led to criticism of the US service as being inequitable. Whilst financial support is offered through subsidised health care for those people will lower incomes, it would follow that those with less financial resources may feel excluded from accessing healthcare through lack of insurance. This key difference between US and UK health care raises the issue of generalisability of findings to the UK health care settings. As this systematic review does not specify where the research is completed (community/health care services), the nine studies are taken from mixed contexts. It is therefore argued that the differences between health care systems are more worthy of consideration when participants were recruited from health care services, as factors such as accessibility of services and financial implications for some ethnic minority groups should have prominence. Alternatively, in those studies where participants were recruited from community settings, then the differences between health care systems has less relevance as the financial implications have been to some extent mitigated, with research itself incurring no financial costs to the participants.
Chapter 1 introduced a discussion around the pitfalls of ethnic categorisation and gave consideration to the terms used in different countries. Such differences in classification terms used for ethnic subgroups can be accounted for by the ethnic composition of countries and the minority groups that are typical of that population. Table 1, which was presented in the previous chapter, showed the UK population by ethnic groups\textsuperscript{36}, with the majority of people being white British (82.7\%) or White other (5.6\%). The other main ethnic groups, in order of proportion of the population are: Asian Indian (2.2\%), Asian Pakistani (1.8\%), Black African (1.5\%), Black Caribbean (1.1\%) and Asian Bangladeshi (0.7\%).

The ethnic composition of the US differs greatly from that of the UK, with data from the 2010 Census\textsuperscript{149} reporting the largest minority groups to be Hispanic or Latino (12.5\% of the total population). This Census produced a highly descriptive ethnic minority breakdown using comprehensive systems, although for the purpose of this brief comparison, a summary of the main broader categories is produced in order of size within the population: white (75.1\%), black or African American (12.3\%), Asian (3.6\%), American Indian and Alaska native (0.9\%). As previously reported, caution is necessary when comparing the composition as the term Asian within US literature usually refers to people from Eastern Asian populations, rather than south Asians as in UK literature.

This review also raises some questions regarding the role of the researcher in both international settings and how they are viewed. The literature review documents the historical mistrust of research from African Caribbeans in the US following the Tuskegee study. Whilst there is no equivalent scandal within the UK relating to the mistreatment of ethnic minority participants, there has historically been under representation of people from ethnic minorities in clinical trials. A systematic review focussed on the barriers within mental health research design that prevented the inclusion of ethnic minority participants, was presented at the mental Health Research Network (MHRN) National Scientific meeting\textsuperscript{150}. This review was concerned with mental health studies which were recruiting within the UK on 23.11.12 as recorded by the National Institute of Health Research portfolio. Findings revealed that 64\% of recruiting studies at that time excluded participants unable to communicate in English and reasons cited for this were lack of available funding for interpreters (23.9\%) and written materials (21.7\%). Other reasons provided by trialists related to the catchment area of the recruitment site, assessment tools not having been validated in other languages and no consideration being given to ethnic minority recruitment within the grant application process. Such failure to expend
efforts to recruit ethnic minorities into research will likely impact on how research, and indeed researchers are viewed by people from minority groups.

**Conclusion**

Whilst sensible concerns have been raised above regarding the direct generalisability of findings from US data to UK settings, it is noticeable that the barriers which emerged were common across many of the studies and the issues that arose are universal and issues that would be applicable elsewhere. Although there are no studies from Europe, researchers can use these categories as a framework to explore possible barriers to any other ethnic population and generate solutions based on clinical and research experience.

Under-recruitment of ethnic minorities has an obvious implication for the generalisation of research findings, subsequent provision of health services and the utilisation of them by these ethnic groups. Within western countries, including US and UK, there are large ethnic populations. By excluding them the pool of eligible participants that can be recruited is dramatically reduced leading to under-recruitment and, more importantly, samples become non-representative with reduced generalisability of the results.

There is a need to incorporate facilitators to recruitment by organising researcher training and resource allocation; so that this becomes a pre-emptive measure to counteract barriers rather than a post-event reflection on what the barriers were. It is important to be aware of the barriers at protocol stage and have the technical and financial resources in place. Once the project is underway staff training, community engagement and intervention adaptation will need to be implemented. The effects of these on recruitment rate should be regularly reviewed and if these facilitators make an insufficient effect on recruitment rates and new barriers are encountered, this needs to be investigated in order to generate solutions.

Another important finding for future research is that the systematic literature search did not find any trials that tested interventions for recruitment of ethnic groups into mental health research. Such nested studies within randomised control trials would be valuable in assessing the effect of different recruitment methods and would help develop successful strategies to increase recruitment of ethnic groups into future research.
It is difficult to ascertain the extent to which prejudices do exist and how they affect recruitment either arising from researchers of from clinical services. It can be concluded that it is takes extra efforts to recruit participants from ethnic minorities and with this comes additional costs to the research. It is therefore important that researchers take this into consideration within the planning stages and financial costing of the research.

**Implications for this thesis**

The findings from this systematic review are important for the thesis as the learning can be applied to the CRIMSON trial. As the trial is concerned with testing the effectiveness of an intervention that is designed to reduce hospital admissions, it is important that participants from ethnic minorities are recruited into the study; as these groups are more likely to experience compulsory treatment under the Mental Health Act.

Through the compilation of barriers relating to the recruitment of ethnic minorities into mental health research, facilitators can be put in place to eliminate those obstacles that are avoidable. These facilitators have been considered in the planning and implementation of the CRIMSON trial, so that potential problems could be addressed as a pre-emptive measure, rather than be reported on as a post-trial limitation. This in-depth consideration regarding recruitment into the trial forms an important objective of this thesis, which will be documented in Chapter 4. The methodology of the CRIMSON trial is presented in Chapter 5 and Chapter 6 will highlight how the methodology in this thesis is distinct from the main trial. This will describe the strategies employed to ensure that such noted barriers to recruiting ethnic minorities would be diminished or eliminated.
Chapter 3: Systematic review of the effectiveness of helping people with mental illness specify how they would like to be treated in a crisis

Overview

Chapter 1 highlights the problem of engagement with services from ethnic minority groups\textsuperscript{22,25-27}, which is a key modifiable factor that if improved may reduce the high levels of compulsory hospital admissions reported\textsuperscript{9-14}. We also saw in Chapter 2 that the problem of engagement with ethnic minorities extends beyond their treatment to their inclusion within psychiatric research. This presents a problem for the CRIMSON trial as it is important that ethnic minorities are included, as these groups are more likely to receive compulsory treatment, which the trial aims to reduce.

The purpose of this chapter is to review the evidence from interventions that aim to reduce admission rates, which is the rationale underpinning the CRIMSON trial. This chapter presents a systematic review on the effectiveness of interventions designed to help people with mental illness specify how they would like to be treated in the event of a crisis. Five studies met the inclusion criteria and they relate to the effectiveness of different interventions to help service users to document their future treatment decisions.

Findings are presented from the following interventions: crisis cards\textsuperscript{151}, psychiatric advance directives\textsuperscript{152}, facilitated psychiatric advance directives\textsuperscript{153,154} and joint crisis plans\textsuperscript{155-158}. Evidence is presented to suggest that the use of such advance planning interventions may reduce hospital admissions\textsuperscript{151}, reduce coercion\textsuperscript{154}, improve service user control\textsuperscript{151,158} improve working alliance\textsuperscript{153} and reduce financial costs\textsuperscript{156}. Evidence is far from conclusive, with contradictory findings presented\textsuperscript{152}. More work is needed to fully understand the mechanisms of such interventions. The review revealed that across the included studies, little consideration was given to the effectiveness of the interventions with people from ethnic minorities. No additional efforts were made to enhance recruitment of these groups into the research and no subgroup analysis was completed.
Following the review, this chapter will give consideration to the merit of incorporating joint crisis plans into current practice within the NHS and how the intervention may be particularly beneficial for service users from ethnic minorities.

**Background**

As compulsory hospital admission rates are rising\(^\text{114}\), there are negative consequences for service users, their families and society. Chapter 1 concludes with the rationale for this review placing emphasis on increasing service user engagement with their treatment.

**Description of the condition**

This review will focus on people with a diagnosis of psychotic illness. Prevalence of psychosis and the particular concerns about elevated rates for ethnic minority groups have been explored in Chapter 1.

**Description of the intervention**

The interventions included will be those that provide the service users with the opportunity to document their future treatment preferences in any form of written crisis plan.

**How the intervention might work**

Chapter 1 explores the shift in services to promote service users taking more control in their own health care provision and it is proposed that by helping people with mental illness specify how they would like to be treated in a crisis, it may improve the individual’s sense of control. It is argued that, by improving this control, service users will become more involved in their treatment and reduce their perceived coercion\(^\text{159}\). It is also proposed that such involvement may facilitate help-seeking by service users at an earlier stage.

**Why it is important to do this review?**

As engagement is a key factor that is modifiable, it is important to explore interventions designed to increase engagement between service users and healthcare services, with
a view to considering their effectiveness in reducing compulsory hospital admissions. One previous Cochrane review, by Campbell and Kiseley\textsuperscript{160}, has been completed in the specific area of advance treatment directives (see Table 8 below for definitions of terminology) in 2010. This was limited to the inclusion of randomised control trials, involving adults with severe mental illness; comparing any form of advance directive with standard care for health service and clinical outcomes. This review included only two trials under the criteria\textsuperscript{152,155} and found no significant differences in outcomes, although reported it is difficult to make definitive conclusions due to the limited number of trials. The aim of this current review is to broaden these criteria to look at other interventions which were investigated by other methodologies than randomised control trials. This present review aims to modify the Cochrane review in three ways; by expanding the search, updating the search and by including a wider range of studies.

**Terminology used in crisis planning interventions**

Before continuing with the review, it is important to provide definitions of key terms that are used across the literature in this area. These terms relate to statements within the different types of intervention that are used to assist service users with planning for their future treatment in the event of a crisis. Three terms are explored which are; advance statements, psychiatric advance directives and advance agreements. Table 8 below provides a description of the three terms and aims to highlight the main differences between them concerning their legal standing and contribution by health care services.
<table>
<thead>
<tr>
<th>Term</th>
<th>Background</th>
<th>Aim</th>
<th>What does it do?/ Description</th>
<th>Who is involved?</th>
<th>Legally binding?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance statement</td>
<td>Self-reported directives show a shift from the traditional medical model to the informed choice model. Follows the Patient Self-Determination Act of 1991.</td>
<td>*To give the patient increased input into future treatment plans, which consequently may reduce perceived coercion. *To promote self-advocacy. *To reduce adverse outcomes.</td>
<td>Documents patients’ treatment preference for the event of a future mental health crisis. Within the UK, the term ‘advance statement’ is more commonly used more broadly to cover all self-preference statements reported by service users in both the context and absence of legislation.</td>
<td>The emphasis is on patient choice; there is little input, if any, from clinician. Advance statements can be written by anyone regarding future treatment in any context. They are becoming increasingly utilised with service users with mental illness to reduce compulsory admissions.</td>
<td>No</td>
</tr>
<tr>
<td>Psychiatric advance directive</td>
<td>Emerged from America as a legal instrument for service users to document treatment preferences.</td>
<td>*To empower service users to take more control of their treatment. *To reduce coercive treatment.</td>
<td>They are used by individuals who want to plan their own future health care and form a legal document.</td>
<td>*The service user makes the instructions and health care power of attorney is appointed. *No involvement is necessary from the health care provider. *A lawyer may be involved, as may an independent facilitator.</td>
<td>Yes for health care professionals unless it goes against standards of care. This is not legally binding on the service user.</td>
</tr>
<tr>
<td>Advance agreement</td>
<td>The term was introduced by the English Mental Health Act Legislation Scoping Review Study Committee.</td>
<td>*To empower service users to take control of their treatment. *To reduce coercive treatment. *To identify triggers to relapse and relapse prevention. To consider medication. *To reduce hospital admissions and adverse outcomes.</td>
<td>This term is specifically used with reference to a patient’s preference for future treatment made in conjunction with their health care provider. For it to be an advance agreement, the healthcare team must agree.</td>
<td>The service user and the health care provider. People nominated by the service user may be involved and an independent facilitator may be present.</td>
<td>No</td>
</tr>
</tbody>
</table>
Objectives

To evaluate the effects of interventions that help people with a diagnosis of psychotic illness specify how they would like to be treated in a crisis.

Methods

Criteria for considering studies for this review

Types of studies

The methodology of studies will not be a limiting factor in this review. Therefore all randomised control trials, non-randomised trials and before and after designs will be included.

Types of participants

This review is concerned with adults with a diagnosis of psychotic illness. This is not limited to schizophrenia and bipolar, as any illness with psychotic features is satisfactory for inclusion. Studies in which there is a mixture of diagnostic groups will also be included.

Types of intervention

Any type of intervention whereby the service user is helped to document their treatment preferences should be included. The level of involvement from their clinical team will vary across studies but this should not discount them. Therefore all research interventions which facilitate the production of advance statements, advance directives and advance agreements (as described previously in Table 8) will be considered for inclusion.

Types of outcome measures

Outcomes of interest, which will therefore be included within this review, are as follows:

1. Compulsory hospital admissions
2. Voluntary hospital admissions
3. Admitted or not
4. Number of bed days
5. Perceived service user coercion
6. Service user engagement measures
7. Therapeutic relationship measures: service user and clinician
8. Economic costs

Exclusion criteria

Any intervention which does not help services users with a diagnosis of a psychotic illness to document their future treatment preferences through a crisis planning process will be excluded from this review. Relevant studies that are on-going will not be considered for inclusion.

Search methods for identification of studies

Electronic resources

As there is little merit in providing a replica of the Cochrane review\textsuperscript{160}, it was important that the criteria were widened in order that the different interventions that have been tested could be explored. The intervention terms were adapted in line with a published typology of advance statements in mental health care\textsuperscript{166}. Based on this information, key words were set for 1) psychiatric and advance and directive 2) advance and agreement 3) advance and statement 4) joint and crisis and plan 5) crisis and card 6) wellness and recovery and action and plan 6) psychiatric and treatment and care and plan 7) research or trial. Key words were combined using ‘OR’ between each domain. Medline, Embase, PsycINFO and Cinahl were searched up to 30\textsuperscript{th} March 2012. No date limits or language restrictions were set for the search. Whilst mental health research was an essential inclusion criteria for the review, mental health related search terms were not generally used as it was felt that this might decrease the yield of the search and it would be beneficial to have a larger outcome set at the initial stage. The exceptions to this are the search terms ‘psychiatric advance directive’ and ‘psychiatric treatment care plan’. When ‘advance directive’ and ‘treatment care plan’ were used independently, they produced thousands of results and the vast majority were not relevant in a mental health setting. Therefore the search terms were limited within the context of psychiatry in these cases, with no diagnosis specified, as this review would accept dual diagnosis and so once again did not want to potentially exclude studies that may be relevant.
Once the studies were obtained, the patient information was checked for diagnosis of psychotic illness.

Searching other resources

All references from the trials that were included in this review were hand searched to check for relevant trials. The search was checked by comparing the citations with the excluded studies from the Cochrane review. This proved a good match and only 4 references that had been excluded were not identified in this current search. Those studies were not eligible under the criteria in this current review, as they referred to Ulysses directives (which was a search term in the Cochrane review) and did not have outcomes of interest.

Data collection and analysis

Selection of studies and data extraction

All citations from the search were exported into Reference Manager 12 and duplicate results were deleted. Studies were selected by two independent reviewers to allow for reliability checks. All citations that were produced by the search were considered and then the sources were acquired in full where relevant. All outcome data that was required was available within the studies, hence there was no need to contact authors directly. The data was extracted independently on a priori designed data extraction form and quality assessment of studies was completed.

Analysis

There are several types of interventions that help service users to document their treatment preferences (as presented later within this chapter in Table 11) and, as all are so different and focus on different outcomes, there is little merit in completing meta-analysis on findings. These interventions will be explored in a hierarchy of service user empowerment and a narrative review will be presented to provide a coherent argument around their effectiveness. It is intended that the results will be presented and discussed in the category of intervention tested within the study.
Results

Figure 5 below shows the process of study selection for inclusion in the review, highlighting the stages at which search results were rejected.

Figure 5: PRISMA diagram to show process of study selection

Results of the search

The searches from electronic databases identified 888 references. From these 56 relevant references were obtained for scrutiny, 48 of these were rejected as they did not meet the inclusion criteria that has been previously highlighted. Three of these
references were relevant in terms of the intervention, although they were only protocols at this time, so no data was available for inclusion in the review. All of the papers were available in English so there was no need for any translations. Table 9 below shows the 48 studies that were considered for eligibility after the exclusion by abstract stage.

Table 9: Excluded search results with reason for exclusion

<table>
<thead>
<tr>
<th>Author</th>
<th>Reason for non-inclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amering167</td>
<td>No intervention</td>
</tr>
<tr>
<td>Atkinson168</td>
<td>No intervention</td>
</tr>
<tr>
<td>Backlar169</td>
<td>No intervention</td>
</tr>
<tr>
<td>Blewett170</td>
<td>No intervention</td>
</tr>
<tr>
<td>Campbell160</td>
<td>Systematic review (all references searched)</td>
</tr>
<tr>
<td>Cuca171</td>
<td>No intervention</td>
</tr>
<tr>
<td>DeWolf Bosek172</td>
<td>No intervention</td>
</tr>
<tr>
<td>Dixon173</td>
<td>No intervention</td>
</tr>
<tr>
<td>Epstein174</td>
<td>No intervention</td>
</tr>
<tr>
<td>Fukui175</td>
<td>Not related to crisis planning</td>
</tr>
<tr>
<td>Gallagher176</td>
<td>No intervention</td>
</tr>
<tr>
<td>Geller177</td>
<td>No intervention</td>
</tr>
<tr>
<td>Geller178</td>
<td>Commentary</td>
</tr>
<tr>
<td>Halpern179</td>
<td>No intervention</td>
</tr>
<tr>
<td>Haupt180</td>
<td>Not outcome of interest</td>
</tr>
<tr>
<td>Henderson181</td>
<td>Commentary</td>
</tr>
<tr>
<td>Kisely182</td>
<td>Commentary</td>
</tr>
<tr>
<td>Knox183</td>
<td>Commentary</td>
</tr>
<tr>
<td>Leeman184</td>
<td>Commentary</td>
</tr>
<tr>
<td>Lifton185</td>
<td>Not related to crisis planning</td>
</tr>
<tr>
<td>Moran186</td>
<td>Protocol</td>
</tr>
<tr>
<td>Author</td>
<td>Nature of Study</td>
</tr>
<tr>
<td>---------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Mower</td>
<td>Not outcome of interest</td>
</tr>
<tr>
<td>Nathenson</td>
<td>No intervention</td>
</tr>
<tr>
<td>Partners in Care</td>
<td>No intervention</td>
</tr>
<tr>
<td>O'Connell</td>
<td>No intervention</td>
</tr>
<tr>
<td>O'Connell</td>
<td>No intervention</td>
</tr>
<tr>
<td>O'Donoghue</td>
<td>No intervention</td>
</tr>
<tr>
<td>O'Reilly</td>
<td>No intervention</td>
</tr>
<tr>
<td>Papageorgiou</td>
<td>Commentary</td>
</tr>
<tr>
<td>Ruchlewska</td>
<td>Protocol</td>
</tr>
<tr>
<td>Saks</td>
<td>No intervention</td>
</tr>
<tr>
<td>Salladay</td>
<td>No intervention</td>
</tr>
<tr>
<td>Savelescu</td>
<td>Commentary</td>
</tr>
<tr>
<td>Scheyett</td>
<td>No intervention</td>
</tr>
<tr>
<td>Scheyett</td>
<td>No intervention</td>
</tr>
<tr>
<td>Srebnik</td>
<td>Not outcome of interest</td>
</tr>
<tr>
<td>Srebnik</td>
<td>Not outcome of interest</td>
</tr>
<tr>
<td>Srebnik</td>
<td>Not outcome of interest</td>
</tr>
<tr>
<td>Srebnik</td>
<td>No intervention</td>
</tr>
<tr>
<td>Srebnik</td>
<td>Not outcome of interest</td>
</tr>
<tr>
<td>Szmukler</td>
<td>Commentary</td>
</tr>
<tr>
<td>Szmukler</td>
<td>No intervention</td>
</tr>
<tr>
<td>Thornicroft</td>
<td>Protocol</td>
</tr>
<tr>
<td>Van Dorn</td>
<td>Not outcome of interest</td>
</tr>
<tr>
<td>Weller</td>
<td>No intervention</td>
</tr>
<tr>
<td>Wilder</td>
<td>Not outcome of interest</td>
</tr>
<tr>
<td>Wilder</td>
<td>Not outcome of interest</td>
</tr>
<tr>
<td>Zeman</td>
<td>No intervention</td>
</tr>
</tbody>
</table>
**Included studies**

The search identified 8 relevant papers referring to 5 different studies, as follows: Sutherby-London-1999\textsuperscript{151}, Papageorgiou-London-2002\textsuperscript{152}, Swanson-North Carolina-2006\textsuperscript{153,154}, Henderson-London-2004\textsuperscript{155-157} and Henderson-New York-2009\textsuperscript{158}. These studies include the two randomised control trials that were included within the previous Cochrane review\textsuperscript{160} (Henderson-London-2004\textsuperscript{155-157} and Papageorgiou-London-2002\textsuperscript{152}) plus two studies that have been included by widening the design criteria beyond randomised control trials (Sutherby-London-1999\textsuperscript{151} and Henderson-New York-2009\textsuperscript{158}). The fifth study for inclusion (Swanson-North Carolina-2006\textsuperscript{153,154}) is a randomised control trial, although was excluded from the Cochrane review\textsuperscript{160} as the outcome of interest was whether an intervention designed to complete psychiatric advance directives had an effect on their completion (rather than being a randomised control trial into the outcomes of the planning intervention). The outcomes of the people who completed the directives are relevant to this review and therefore it is included. Quality assessments and risk of bias of the randomised control trials are provided in the Cochrane review\textsuperscript{160}. The characteristics of each study are shown in Table 10 below.

The intention for analysis has previously been documented and the findings support this intention, as the studies use different methodologies, different interventions and are concerned with different outcomes. The data is therefore not sufficient to warrant meta-analysis, and it would make more sense to present a narrative description of all included studies.
Table 10: Summary table of included studies

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of intervention</strong></td>
<td>Crisis Cards</td>
<td>Psychiatric Advance Directive (PAD)</td>
<td>Facilitated Psychiatric Advance Directive (F-PAD)</td>
<td>Joint Crisis Plan (JCP)</td>
<td>Joint Crisis Plan (JCP)</td>
</tr>
<tr>
<td><strong>Design</strong></td>
<td>Before and after design</td>
<td>Randomised Control Trial</td>
<td>Randomised Control Trial</td>
<td>Randomised Control Trial</td>
<td>After-only design</td>
</tr>
<tr>
<td><strong>Participants</strong></td>
<td>n=42</td>
<td>n=156</td>
<td>n=469</td>
<td>n=160</td>
<td>n=20</td>
</tr>
<tr>
<td></td>
<td>No information regarding age or gender</td>
<td>All with psychotic diagnosis</td>
<td>(mean of total sample) Mean age= 42 (SD= 10.7) gender= 40%male</td>
<td>All with psychotic diagnosis</td>
<td>All with psychotic diagnosis</td>
</tr>
<tr>
<td></td>
<td>All with psychotic diagnosis</td>
<td>All with psychotic diagnosis</td>
<td>Mean age= 35.5 (SD= 11.3) gender= 53% male</td>
<td>All with psychotic diagnosis</td>
<td>All with psychotic diagnosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>n=77</td>
<td>n=77</td>
<td>n=80</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean age= 36.3 (SD= 12.6) gender= 66% male</td>
<td></td>
<td>Mean age=39.5 (SD= 12.1) gender= 59% male</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean age= 35.5 (SD= 11.3) gender= 53% male</td>
<td></td>
<td>Mean age=39.5 (SD= 12.1) gender= 59% male</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean age= 35.5 (SD= 11.3) gender= 53% male</td>
<td></td>
<td>Mean age=39.5 (SD= 12.1) gender= 59% male</td>
</tr>
<tr>
<td><strong>Primary Outcome</strong></td>
<td>Hospital admissions</td>
<td>Hospital admissions</td>
<td>-Completion of F-PADs</td>
<td>-Hospital admission</td>
<td>-Service user and case managers’ experiences</td>
</tr>
<tr>
<td></td>
<td>Hospital admissions</td>
<td>Hospital admissions</td>
<td>-Working Alliance</td>
<td>-Cost</td>
<td>-Service users’ experiences</td>
</tr>
<tr>
<td><strong>Results</strong></td>
<td>Hospital admissions: In the 12 month period following the development of the crisis card there was a 30% reduction in hospital admissions.</td>
<td>Compulsory hospital admissions: Intervention group: 15 admitted (19%), 64 not admitted (81%) Control group: 16 admitted (21%); 61 not admitted (79%)</td>
<td>Completion of F-PADs Participants in the intervention arm of the trial were more likely to complete both components to the PAD: the instructional directive (56.5% versus 2.6%, p&lt;0.01) and health care attorney (47.7% versus 1.7%, p&lt;0.001).</td>
<td>Admission to hospital: A smaller proportion of the intervention group were admitted to hospital than those from the control group (30% versus 44%, risk ratio 0.69, 95% confidence interval 0.45-1.04, χ²=3.25, P=0.07). This is also true of compulsory admissions: (13% versus 27%, risk ratio 0.48, 95% confidence interval 0.24 to 0.95, χ² = 4.84, P = 0.03</td>
<td>Experiences: All 16 participants interviewed stated they would recommend the plan to others with 9 people believing that they had become more involved with their healthcare. 10 stated that they had gained a better understanding of their illness.</td>
</tr>
<tr>
<td></td>
<td>Additional findings: Use of crisis cards: For 19 of the 26 (73%) service users who had experienced a crisis, their crisis card was consulted</td>
<td>Additional findings: Use of crisis cards: For 19 of the 26 (73%) service users who had experienced a crisis, their crisis card was consulted</td>
<td>Additional findings: Use of crisis cards: For 19 of the 26 (73%) service users who had experienced a crisis, their crisis card was consulted</td>
<td>Additional findings: Use of crisis cards: For 19 of the 26 (73%) service users who had experienced a crisis, their crisis card was consulted</td>
<td>Additional findings: Use of crisis cards: For 19 of the 26 (73%) service users who had experienced a crisis, their crisis card was consulted</td>
</tr>
</tbody>
</table>
**Service User Views:** At the 12 month follow-up stage service users felt more involved in their care (57%), more positive (60%) and more in control of their mental health problem (51%).

**Additional findings:**

**Bed days:** There was no significant difference between the groups in either compulsory admissions or voluntary admissions.

**Patient’s ability to take decisions for themselves. (Self-Efficacy Scale)**

- Intervention group: 42.66
- Control group: 42.25
- P>0.05

**Coercion:** F-PAD completion was associated with lower odds of coercive interventions (adjusted OR =0.50; 95% CI= 0.26 -.096; p<0.05)

**Additional findings:**

**Working alliance at one month** (using Working Alliance Inventory)

- Participants in the facilitated session showed to have greater working alliance with their clinical team.
- R² = 0.31; F=83.53, df=2, 378, p<0.001

**Cost per patient over follow-up:** Mean difference £1095; 95% confidence interval -2814 to 5004.

**Experiences:** The best supported hypothesis was that JCP holders felt more in control of their mental health problem and empowered. Case managers positive responses at the 15 month follow-up stage ranged from 39%-85%.

The experience of completing a JCP went from positive to no change over the follow-up period.

**Additional findings:**

- The research was conducted at New York hospitals which predominantly serves low-income Latinos.
- No other information is provided.

<table>
<thead>
<tr>
<th>Attention to ethnicity issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>when socio-demographic participant characteristics were compared with those of service users who had refused, those who wanted to develop a crisis card were significantly more likely to be white (χ²=4.80, p=0.03).</td>
</tr>
</tbody>
</table>

Service users were excluded from the trial if that could not read English.

Despite the above information 46% of the participants in this trial were from ethnic minority groups (Black, Asian or Chinese).

The sample breakdown is as follows: 58% African American, 39% white and 3% from other ethnic minority backgrounds.

The study included a broad representation of participants, with the ethnic breakdown as follows: 39% white, 53% black and 8% other. However, service users were excluded from participating if they did not possess sufficient English language skills. |
Design

3 of the included studies are randomised control trials (Papageorgiou-London-2002\textsuperscript{152}, Swanson-North Carolina-2006\textsuperscript{153,154}, Henderson-London-2004\textsuperscript{155-157}), one study is a before and after design (Sutherby-London-1999\textsuperscript{151}) and the fifth is an after-only design (Henderson-New York - 2009\textsuperscript{158}).

Sample sizes

When combing the included studies, a total of 847 participants were included. The average per study was 169, with the range across studies being from 20-469 participants.

Setting

Three of the studies were conducted in London, UK, (Sutherby-London-1999\textsuperscript{151}, Papageorgiou-London-2002\textsuperscript{152} and Henderson-London-2004\textsuperscript{155-157}) whilst two studies were conducted in the USA: North-Carolina, USA (Swanson-North Carolina-2006\textsuperscript{153,154}) and New York City, USA (Henderson-London- 2009\textsuperscript{158}). All studies were related to community mental health settings, with the recruitment process commencing for inpatients in one study (Papageorgiou-London-2002\textsuperscript{152}).

Participants

All of the studies included participants who had a 100\% diagnosis of a psychotic illness. The diagnoses varied, although no specific diagnosis was of interest over another. The gender split across studies was between 40-58\% males, although no gender figures were provided in two studies (Sutherby-London-1999\textsuperscript{151} and Henderson-London- 2009\textsuperscript{158}). The average age ranged between 36-42 across studies although, once again, no documentation of age of participants was given in two studies (Sutherby-London-1999\textsuperscript{151} and Henderson-London- 2009\textsuperscript{158}).

Interventions

Table 11 below highlights the main characteristics of each intervention and clarifies which type of advance statement is made within the intervention (as previously defined in Table 8).
Table 11: Summary table of interventions designed to help service users document their treatment preferences

<table>
<thead>
<tr>
<th>Type of intervention</th>
<th>Aims of intervention</th>
<th>Type of advance statement (see Table 8)</th>
<th>Who is involved and who gets a copy of the plan?</th>
<th>Content of the plan</th>
<th>Differences between the interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crisis cards</td>
<td>*To promote self-advocacy. *To reduce coercive treatment *To reduce adverse outcomes</td>
<td>Advance statements by the service user may or may not be included</td>
<td>-The service user. The health care professional may or may not have involvement -The service user holds a copy of the crisis card</td>
<td>No set format. A crisis card may contain just basic contact information, or it may be as detailed as the JCP, if agreement cannot be made by the service user and their clinical team.</td>
<td>This is the most basic form of intervention. It is not legally binding and needs no involvement from anyone other than the service user</td>
</tr>
<tr>
<td>Psychiatric advance directive (PAD)</td>
<td>*To empower service users to take more control of their treatment *To reduce coercive treatment</td>
<td>Advance directive</td>
<td>-The service user. No involvement is necessary from the health care provider. A lawyer may also be involved. -In addition to the service user holding a copy, it is included within the medical records if the they presents their advance directive</td>
<td>There is no set format for inclusions on a PAD; it is dependent upon the service user’s preferences. They may elect to use a detailed format such as that used in the F-PADs below (although without the facilitation).</td>
<td>This intervention has more complexity than the simple crisis card, as has legal input and medico-legal enforceability</td>
</tr>
<tr>
<td>Facilitated Psychiatric Advance Directive</td>
<td>*To empower service users to take more control of their treatment</td>
<td>Advance directive</td>
<td>-The service user and a facilitator (usually a health educator).</td>
<td>-Crisis symptoms -Medications -Facility preferences -Emergency contacts</td>
<td>The F-PAD is a more advanced plan than the PAD, as it is developed with the assistance of a facilitator.</td>
</tr>
<tr>
<td>(F-PAD)</td>
<td>*To identify triggers to relapse and relapse prevention</td>
<td>-The service user holds a copy of their plan; they receive wallet cards or bracelet/necklace. This is included within medical records; US living will registry and state electronic registry for advance directives.</td>
<td>-Crisis Precipitants -Protective factors -Usual response to hospital -Preference for staff interactions -Visitation permission -ECT preferences -Other instructions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joint Crisis Plan (JCP)</td>
<td>*To empower service users to take more control of their treatment</td>
<td>Advance Agreement: The service user’s own words are used to create the document and the treatment team must be in agreement for this to be a JCP. It can be downgraded to a crisis card if this is not the case.</td>
<td>Participants’ contact details -Contact details of GP and care coordinator where participant wanted this information documenting -Details of who was involved in developing the joint crisis plan -Current care and treatment plan -Care in a crisis -Practical help in a crisis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

JCPs are perhaps the most comparable with the F-PAD, however they differ in two respects. Firstly they necessitate the direct involvement of the clinical team in helping the service user decide the content of the JCPs. The second difference is that they do not have the same degree of legal enforceability that the PAD and F-PAD have.

Table 11 is developed from an adaptation of a published typology of advance statements in mental health care. 

---

91
Crisis cards

Within the UK, ‘crisis cards’ were introduced in 1989 to initially serve as an advocacy tool to be used in mental health emergencies. Crisis cards allow patients to nominate a relevant person or provide their own instructions for future psychiatric care in the event of a crisis. Patients are asked to document the details of a friend or relative to be contacted in an emergency situation to provide support or advocacy. The completion of a crisis card also gives service users the opportunity to document their treatment preferences in the event of a future crisis, either with or without the agreement of their treatment team. The evaluation of implementing crisis cards was initially based on anecdotal evidence as they were being used with confidence across the voluntary sector; although there was no consistency in what was offered from each organisation or how the crisis cards were completed or implemented. A review of the earlier work completed with crisis cards is provided by Sutherby and Szmukler who detail their findings from a review of crisis cards being implemented at that time by organisations. There is no set template for a crisis card and investigations into the cards showed reluctance from organisations to provide much detail for fear that their documents would be reproduced.

Psychiatric advance directives

Psychiatric advance directives were developed in the USA as a legal instrument for service users to document future treatment preferences or refuse treatments. They are used by individuals who want to plan their own future health care and create a legal document. Whilst an increase in autonomy for service users completing advance directives was reported, the precise mechanisms of the tool were initially under-explored and further exploration was required after their introduction.

Facilitated advance directives

The facilitated advance directive differs from the standard advance directive because structured facilitation is offered to assist the service user in completing the advance directive; this is offered by a clinician or independent advocate. The aim of this facilitation is to overcome barriers that service users may face in completing advance directives, which may subsequently improve completion rates of these documents.
Joint crisis plans

Joint crisis plans aim to empower the service users, facilitate early detection and treatment of relapse and mental illness and decrease the use of the Mental Health Act. This approach is an advancement from the informed choice model\(^{161}\) to shared decision making in psychiatry\(^ {217} \). The move towards a more collaborative approach to advance statements has shaped the research in this area. One example of an advance agreement is the joint crisis plan. This is a document that contains service users’ preferences about treatment and the practical provisions that they would wish for in the event of a crisis, written in the words of the service user and not the clinician. The joint crisis plan differs from crisis cards and advance statements in that it is developed through the facilitation process by an independent clinician, who ensures that the service users’ views are heard whilst also confirming that the care team are in agreement; should this not be possible then the joint crisis plan would be downgraded to a crisis card.

Facilitators are trained clinicians who currently work in community mental health services and are well placed to assist the service user in formulating their plan whilst understanding the processes that must be adhered to from the clinician’s perspective. The advantage of having a trained clinician in the facilitator role over an advocate promotes the formulation of a realistic plan whilst ensuring that the service user takes control for their own treatment where possible. It is also suggested that the current advocacy service in mental health does not reflect the specific needs of ethnic minority communities, with the suggestion that such services are less accessible to black service users\(^ {218} \).

Joint crisis plans are not legally binding and more importantly they differentiate themselves from facilitated advance directives by necessitating collaborative working between the service user and their clinical team, which advance directives do not require. The process of devising a joint crisis plan offers the service user control on two levels. Firstly, they are invited to take control of their current care through an independent facilitation process; therefore being actively involved in their treatment in the present. Secondly, the joint crisis plan allows the service user to take control by having input into future support and treatment. These two advantages make the joint crisis plan unique in the mental health context.
Narrative report on included studies

In summary, from the 5 included studies, 4 interventions are tested: crisis cards (1), psychiatric advance directives (1), facilitated advance directives (1) and joint crisis plans (2). The findings of each intervention will be reported in turn to supplement the information that is provided in Table 10. The interventions will be reported on in increasing order of the empowerment of the intervention being implemented.

Crisis cards

One study reported on the findings of a crisis card intervention for service users with a diagnosis of a psychotic illness (Sutherby-London-1999\textsuperscript{151}). This study is of a before and after design as it was a feasibility study to assess the potential benefits of implementing crisis cards. It was conducted over a 12 month period within the Camberwell sector of the Maudsley hospital in south London. All participants had a diagnosis of a psychotic illness and eligibility criteria necessitated that service users had two or more admissions to hospital with at least one admission in the two years prior to the study commencing; no exclusions were reported. Crisis cards were offered to all patients within the sector with psychosis and a high risk of crisis. The cards were utilised in four different ways: provision of information; assessment of previous crises; an advocacy tool for crisis and advance plans for care in a crisis.

This study reported that for 19 of the 26 (73%) service users who had experienced a crisis, the crisis card was consulted and in the 12 month period following the development of the crisis card there was a 30% reduction in hospital admissions. At the 12 month follow-up stage service users felt more involved in their care (57%), more positive (60%) and more in control of their mental health problem (51%)

Psychiatric advance directives

One study reported on the findings of a psychiatric advance directive intervention for service users with a diagnosis of a psychotic illness (Papageorgiou-London-2002\textsuperscript{152}), with the primary outcome of compulsory hospital admissions. This study was a randomised control trial, which was conducted over a 12 month period. Allocation to the intervention arm was randomised using blocks of 12 random combinations, with sealed envelopes used; the control group was treatment as usual. Neither participants nor researchers were blinded to allocation of participants in this study. Participants
were inpatients receiving compulsory treatment in two inner-London acute wards under sections 2, 3 or 4 of the Mental Health Act and who were due for discharge between October 1997 and October 1998. Exclusions were reported as service users being on specialised sections; pending transfer; organic brain disease or not able to read English.

The advance directive was provided to the service users in the form of a booklet entitled *Preferences for Care*. It contained the contact details for the patient, the treatment team and other service providers. It also contained seven statements on future preferences for treatment. Patients who did not want to write in the booklet themselves dictated their preferences to the researcher. The document was completed by the service user with assistance given by the researcher. A caveat printed at the end of the booklet indicated that professionals were not legally bound to comply with preferences for care. Copies of the directive were given to the key worker and the GP.

The primary outcome was compulsory admissions over 12 months, collected from hospital records. Within the intervention group, 15 people were admitted (19%) and 64 not admitted (81%). Within the control group (treatment as usual) 16 were admitted (21%) and 61 not admitted (79%). \( \chi^2 = 0.08, \text{d.f}=1, p=0.8 \).

Secondary outcomes from the study which are of interest in this review are: time spent in hospital (for both compulsory and voluntary admissions) and patients’ ability to take decisions for themselves (as measured by the self-efficacy scale\(^{219}\)). For time spent in hospital there was no significant difference between the groups in either compulsory admissions or voluntary admissions. There was also no significant difference between self-efficacy between the intervention group and control group. One additional finding that is of interest is that of the 59 patients who were allocated to the advance directive group, only 8 (13.5%) stated that they found the directive useful when asked at follow-up.

*Facilitated advance directives*

One study reported on the findings of a facilitated psychiatric advance directive intervention for service users with a diagnosis of a psychotic illness (Swanson-North Carolina-2006\(^{153;154}\)) with the outcome of the main paper\(^{153}\) focusing on completion of the directives. The primary outcome of the second paper \(^{154}\) is concerned with coercive treatment. This study is a randomised control trial with a follow-up period of one month.
for completion data and 6, 12 and 24 months for measures of coercion. The study was conducted at two county-based public mental health systems in the north-central region of North Carolina, USA. Eligible participants were receiving community based treatment from one of the two county-based programmes in the north region of North Carolina. Exclusions were reported as being those service users that were unable to give informed consent.

The facilitated advance directive intervention was a semi-structured, manualised interview and guided discussion of choices involved in anticipatory mental health treatment planning. The intervention included orientation to concepts related to psychiatric advance directives, review of past treatment experiences, and documentation of future treatment preferences. The core of the intervention was a semi-structured interview and guided discussion of choices involved in planning for mental health care during periods of incapacity. If the participant wished to prepare the relevant legal psychiatric advance directive documents, the facilitator helped with the completion of the forms. The intervention was completed by 5 trained researchers and reliability and fidelity were monitored throughout. The control group were given an introduction to psychiatric advance directives, written materials describing the purpose of advance directives, copies of standard forms for psychiatric advance directives and the toll-free telephone number of the local consumer organisation that provides consultation to persons who wish to prepare psychiatric advance directives.

The primary outcome of completion of facilitated advance directives produced the following results. Participants in the intervention arm of the trial were more likely to complete both components to the psychiatric advance directive: the instructional directive (56.5% versus 2.6%, p<0.01) and health care attorney (47.7% versus 1.7%, p<0.001). Facilitated psychiatric advance directive completion was associated with lower odds of coercive interventions (adjusted OR =0.50; 95% CI= 0.26 -0.96; p<0.05).

Other outcomes of interest from the study relate to working alliance at one month, as participants in the facilitated session were shown to have a greater working alliance with their clinical team (R²= 0.31: F=83.53, df=2, 378, p<0.001). An additional finding reported that participants in the facilitated session were more likely to report that they had received the support they needed (controlling for baseline level, odds ratio= 1.57, p<0.05).
Joint crisis plans

Two studies reported on the findings of the joint crisis plan intervention for service users with a diagnosis of a psychotic illness (Henderson-London-2004\textsuperscript{155-157} and Henderson-New York- 2009\textsuperscript{158}). Both of these studies are presented in turn.

The primary outcome for the first study (Henderson-London-2004\textsuperscript{155-157}) is hospital admissions\textsuperscript{155}, with economic cost\textsuperscript{156} and service user experiences\textsuperscript{157} being the focus of secondary papers. This study is a randomised control trial where allocation was completed by minimisation, stratified by team and severity of condition. The trial was completed over 15 months and the outcome assessor was blind to allocation arm. Participants were recruited from 7 community mental health teams in south London and one in Kent, between 2000 and 2001. Eligible participants had to have at least one previous hospital admission and people were excluded if they were current inpatients or unable to give informed consent (either through incapacity or language issues).

The joint crisis plan was developed by patients together with mental health staff. Held by the patient it contained his or her choice of information and included an advance agreement for treatment preferences for any future emergency. The control group received treatment as usual plus leaflets; in accordance with standard practice in England, all patients should have received written copies of their care plan. To measure service users’ experiences a questionnaire was administered upon receipt of the joint crisis plan and again 15 months later.

The primary outcome was hospital admissions and it was found that a smaller proportion of the intervention group were admitted to hospital than those from the control group (30% versus 44%, risk ratio 0.69, 95% confidence interval 0.45-1.04, $\chi^2=3.25$, p=0.07).

No difference was found between hospital bed days for those in the intervention group compared to those in the control group (whole sample: difference 4, -18 to 26, p=0.15 Those admitted: difference -24, -72 to 24, p=0.39).

An economic evaluation of the implementation of joint crisis plans suggested that there is a greater than 78% probability that joint crisis plans are more cost effective than standardised service information in reducing the proportion of hospital admissions (mean difference £1095; 95% CI: -2814 to 5004).
The service user experience following completion of the joint crisis plan was initially positive although no change was noted after the 15 month follow-up period. At the time of their joint crisis plan completion, service user positive responses ranged from 46-96%. This widened at the 15 month follow-up to 14%-82%. The best supported hypothesis was that joint crisis plan holders felt more in control of their mental health problem. Case managers’ positive responses at the 15 month follow-up stage ranged from 39%-85%.

A secondary outcome from this study is compulsory treatment under the mental health act. This was significantly less in the intervention group than the control group (13% versus 27%, risk ratio 0.48, 0.24-0.95, \( \chi^2=4.84, p=0.03 \)).

The second study to explore the effects of the joint crisis planning intervention was a feasibility study that was conducted in the USA (Henderson-New York-2009\textsuperscript{158}). Henderson et al.\textsuperscript{158} completed a feasibility study in New York to investigate whether joint crisis plans may be effectively implemented in emergency services. This study has an after-only design as no baseline data was of interest, it focussed purely on the effects on service users following the intervention. This study was conducted in 2 publicly operated clinics and one affiliated hospital in New York City, USA. Eligible participants must have been admitted to a psychiatric inpatient service at least once in the past two years and no exclusion criteria were reported. As the intervention was a joint crisis plan being piloted in the USA, rather than a psychiatric advance directive, legal documentation was not used.

At 12 month follow-up, all 16 participants interviewed stated that they would recommend the plan to others and 9 of these people believed that they had become more involved with their healthcare. 10 stated that they had gained a better understanding of their illness. Case managers also completed questionnaires and voiced their opinions that service users had learnt more about their illness and had less anxiety about future crises. In general the intervention was welcomed although issues were raised by some service users that there had been difficulties with implementing their plan within their treatment.

**Discussion**

Initially the different studies will be discussed separately within the wider category of the intervention that is tested, prior to the discussion being expanded.
Crisis cards

The study (Sutherby-London-1999\textsuperscript{151}) demonstrates the feasibility of the introduction of crisis cards within community psychiatric services although the mechanisms of the crisis card process and the way which the findings could be generalised still needed further work. Whilst this study was primarily concerned with the feasibility of crisis cards, it was found that all the participants involved elected to develop a joint crisis plan and nobody opted for an independent crisis card. This implies that the service users valued the joint decision process and wanted their treatment to be planned for in this manner. There was no control group in this study design and so it is therefore difficult to verify the findings, particularly in relation to the hospital admission data. A limitation of before and after designs are cohort effects; it could be argued that the reduction in admissions would have naturally occurred, if admission rates were decreasing at that time. Other limitations to the study relate to there being no validated instruments used to measure service user views and participants were all recruited from London, making the generalisation across the UK unknown.

Within the study there are no reports of specific attempts to include service users from ethnic minorities. It is interesting to note that it is reported that service users who wanted to develop a crisis card were significantly more likely to be white. This may link in with the literature presented in Chapter 1, which suggested ethnic minority groups may disengage with services and may mistrust health care providers\textsuperscript{22,25-27}.

Psychiatric advance directives

The study (Papageorgiou-London-2002\textsuperscript{152}) enrolled inpatients who were due to be discharged from compulsory treatment under the Mental Health Act and found little observable results from the use of advance directives. The methodological approach to the recruitment of service users is questionable, as it may be argued that the strategy of recruiting whilst service users are currently under compulsory treatment is going against the aim of reducing coercion that such advance statements prioritise. Patients may also not be well-placed to provide informed consent if they are maintaining their treatment in involuntary conditions. Within the design of the study, researchers were unable to remain blinded to service user allocation, due to their involvement in the formulation of the plan. The study was conducted in London and so once again the results may not be generalisable to the rest of the UK. It is important to note that the
study reports that the rate for all involuntary admissions decreased, regardless of the intervention, so the trial findings may reflect a trend in the trial area.

It is pertinent to note that service users were excluded from the trial if they could not read English, therefore further reducing participation from ethnic minorities. Despite this, 46% of the participants in this trial were from ethnic minority groups (Black, Asian or Chinese) suggesting the results may be applicable across ethnic minorities. It would seem that such statistics are attributed to the location of recruitment sites rather than any attempts to actively engage service users from ethnic minority groups.

**Facilitated psychiatric advance directives**

This study (Swanson-North Carolina-2006) raises the importance of the facilitation of psychiatric advance directives away from simply providing service users with written documentation and providing suitable resources. The findings suggest that the mechanisms of this facilitation improve the effectiveness of the psychiatric advance directives and play a crucial role in their success beyond the actual document that is produced. The authors of the study raised the issue of engagement, recognising that findings may not be generalisable to people less engaged with services. This intervention did not focus on improving engagement as collaboration with the clinicians was not required to complete the process. It is therefore surprising that this study demonstrated an increased working alliance between service users and clinicians on completion of an advance directive. These findings are interesting, considering that working alliance increased despite often minimal input from the participants’ clinical team in devising their directive. Facilitated psychiatric advance directives are usually made by the participant in conjunction with a health educator or social worker rather than the service user’s own clinical team. It can therefore be assumed that the process alone of making the directive has an impact on the service users’ engagement; increased involvement of the clinical team in this process may enhance working alliance further.

The second paper from this study measured the outcome of coercion. The authors recognised the long term effects of completion of a facilitated psychiatric advance directive on coercive crisis interventions. A limitation to this finding is that due to the design of the study, people could not be randomised to receive an advance directive or not, although statistical adjustments were made in the model of analysis to take account of this.
Whilst no attempts were described to actively engage people from ethnic minorities into the research, it is of note that the sample breakdown is as follows: 58% African American, 39% white and 3% from other ethnic minority backgrounds. This implies that facilitated psychiatric advance directives may be effective for people from ethnic minority groups.

*Joint crisis plans*

The first study relating to joint crisis plans (Henderson-London-2004\textsuperscript{155-157}) showed promising findings regarding the effectiveness of the implementation of joint crisis plans. The recruitment area covered different settings across London, although these may not have been representative across the whole country. It is important to note that in this study, the rate of hospital admissions were lower than predicted from the pilot study, for the control group; this reduced the power of the trial and the confidence intervals produced were wide. A secondary paper concerned with an economic evaluation of joint crisis plans\textsuperscript{156} suggested that joint crisis plans have a financial benefit. As the results were not significant, there is a need for further work in this area to consider the cost effectiveness of the intervention. A more detailed economic evaluation with a larger sample may strengthen this finding.

The study included a follow-up of service users’ views regarding their experience of joint crisis plans\textsuperscript{157}. Whilst initial views were positive, it is of concern that the initial positive attitude of service users towards the value of joint crisis plans decreased by the 15 month follow-up stage. No explanations were provided as to why this may be, neither was consideration given to which factors over that period resulted in the change of views. It is important that the actual mechanisms of the joint crisis plans are further explored, which may give rise to providing methods of sustaining service users’ positive views towards them.

The randomised control study included a broad representation of participants, with the breakdown of ethnicity as follows: 39% white, 53% black and 8% other. Having said this, service users were excluded from participating if they did not possess sufficient English language skills, potentially excluding service users who may have benefitted from involvement in the trial. It would seem that the inclusion of service users from ethnic minorities was attributed to the geographical location of recruitment sites rather than any active involvement to encourage engagement.
The second study to explore the effects of the joint crisis plan (Henderson-New York-2009\textsuperscript{158}) is limited by its after-only design, due to it being a feasibility study of the intervention in the USA. This study had very few participants (n=20) and additional work would need to be carried out on a larger, more representative sample employing a more robust methodology for any findings to be conclusive. It is important to recognise the concerns that were raised by service users in this study about difficulties in implementing their plan within their standard treatment. It is therefore crucial that the implementation of such plans is discussed within the context of the NHS, to see how these may complement standard treatment.

The inference from the pilot studies is that joint crisis plans may reduce compulsory hospital admissions\textsuperscript{155}, may have welcomed financial implications\textsuperscript{156} and may empower their holders to obtain their preferred care and treatment in a crisis\textsuperscript{157}. Further research is needed to more clearly identify how the process of developing joint crisis plans can reduce compulsory admissions and for which groups of service users the process is the most significant for. Pilot studies evaluating the use of joint crisis plans have failed to include participants who did not speak English and therefore a large proportion of services users from ethnic minorities were excluded from the study; no detailed statistical analyses could be completed in this respect, again raising questions as to the potential generalisation of findings. It is therefore important to assess the effectiveness of joint crisis plans with a representative sample across the country, ensuring that provisions are put in place to include patients from ethnic minorities.

**General discussion**

The findings from the 5 included studies (with the exception of Papageorgiou-London-2002\textsuperscript{152}) are reasonably positive and the general consensus was that interventions designed to help service users with the planning of future treatment were welcomed by both service users and clinicians. It is argued that the crisis cards and advance directives rely more heavily on service user engagement with their treatment and the findings may not be generalisable to those not engaging with services. As engagement has recurrently been reported as a challenge with service users from ethnic minority groups\textsuperscript{22;25-27} then it is surprising that none of the studies actively tried to engage minority groups within the research. Two studies excluded service users with limited English language skills (Papageorgiou-London-2002\textsuperscript{152} and Henderson-London-
2004\textsuperscript{155-157}); despite minority groups being more likely to experience compulsory treatment\textsuperscript{9-14} and potentially being able to benefit from such interventions.

By widening the inclusion criteria for this systematic review it provides findings that supplement those by the previous Cochrane review\textsuperscript{160}, including outcomes reported in secondary papers from the randomised control trials and studies which use either a before and after design or after-only design.

\textit{On-going trials}

As reported in the search results, three other studies that are relevant to the inclusion criteria for this review were obtained. These studies are on-going and no data is available at this time; therefore they have not been included within previous discussions. One study is the CRIMSON\textsuperscript{28} trial; this will be described in detail in the methodology (Chapter 5) of this thesis. It is, however, important to note at this stage that, as previously reported in the narrative presentation of results, service users who participated in the crisis card study\textsuperscript{151} valued joint planning with their clinician over a self-made card. The same format of the plan was utilised in later research\textsuperscript{155} and is the same document that is used within the current CRIMSON trial. The plan shown in Appendix 1 is a plan used for training purposes within the CRIMSON trial, completed with a fictional case.

A brief description of the two other papers will be provided based on their published protocols. The completion of these on-going randomised control trials will add to the literature from this review \textsuperscript{28,186,195} and should also be used to update the Cochrane review\textsuperscript{160}. The first study is by Ruchlewska et al.\textsuperscript{195}; this is a randomised control trial into the effectiveness of joint crisis plans in Rotterdam, the Netherlands. It will recruit 240 participants with a psychotic diagnosis and the follow-up period will be 18 months. The primary outcome is the number of crisis contacts with the clinician or emergency (after hours) visits, involuntary admissions and the length of stay in hospital. Secondary outcomes included psychosocial functioning and treatment satisfaction.

As findings to date imply the possible effectiveness of joint crisis plans for people with psychosis, the implications for their use are considered more widespread. The final on-going trial is being conducted in London by Moran et al.\textsuperscript{186}. It is concerned with the effectiveness of joint crisis plans for people with borderline personality disorder, as to date there is no research on the intervention with this group. This is a randomised
control trial with a six month follow-up period. Whilst the diagnosis of interest is a primary diagnosis of borderline personality disorder, the findings of this trial may be relevant to this systematic review as it is likely that mixed diagnosis will include psychosis. The primary outcome from this study is any self-harm event, time to first episode of self-harm and number of self-harm events over the follow-up period.

Secondary outcomes are: length of time from contemplation to act of self-harm, help-seeking behaviour after self-harm, cost, working alliance, engagement with services and perceived coercion. Other outcome variables are quality of life, social impairment and satisfaction with treatment.

*Implementing joint crisis planning within the NHS*

This review has highlighted a number of studies with differing methodologies and testing a number of interventions. At this stage the joint crisis planning intervention has had a positive pilot study, with promising findings in community mental health settings in the UK. When crisis cards were offered to participants within the pilot it is encouraging to note that they valued the joint crisis planning process and they valued the input from their clinical team, rather than documenting their preferences alone. With positive outcomes suggested from previous work relating to hospital admission data and engagement with services, it is pertinent to consider the relevance of joint crisis planning within the current healthcare provision in community mental health services in the NHS. The rationale for the research design will be discussed within Chapter 5 of this thesis.

The Mental Capacity Act\textsuperscript{220} was enacted in October 2007 with the aim of protecting those individuals who cannot make decisions for themselves due to a learning disability or mental health condition. The framework provided is used to assess whether individuals have the capacity\textsuperscript{vii} to make decisions on their own behalf. In summary the Mental Capacity Act specifies that a person is unable to make a decision if they cannot; understand the information provided, retain the information for sufficient time to reach a decision, weigh up the information or communicate their decision.

The difficulty arises when the Mental Capacity Act and the Mental Health Act both need to be enforced. In such occasions, the Mental Health Act supersedes the Mental Capacity Act and so results in compulsory treatment being given\textsuperscript{221}. An important part

\textsuperscript{vii} Capacity is defined as the ability of a person to make decisions that may have legal consequences for themselves and/or for others affected by the decision
of the Mental Capacity Act is its documentation of ways in which individuals are able to influence what decisions are made in the future, should they not be capable of making them at the time. The Mental Capacity Act achieves this through its inclusion of advance decisions\textsuperscript{222}, an example is to refuse specified treatment or medication when in crisis. Advance decisions are, to the most extent, legally binding and therefore must be implemented by treatment teams. The exception to this, as previously mentioned, is where the individual is sectioned under the Mental Health Act. The concept of advance decisions allows the individual to take more control in their care at an early stage\textsuperscript{223}.

\textit{Existing crisis plans for patients within the NHS}

In the mental health context, service users are treated under the Care Programme Approach, which was introduced in England in 1991 as a structured framework to provide support and treatment from a multi-disciplinary team\textsuperscript{224}. The enhanced level of the Care Programme Approach includes the following components; an assessment of the health and social care needs, a written plan that is agreed by a multi-disciplinary team (including a psychiatrist) and the nomination of a care coordinator. The care plan will normally include a Crisis and Contingency Plan, although there is currently no requirement for an inclusion of shared advance decision making by the service user and their clinicians.

The available literature on the Care Programme Approach has been reviewed\textsuperscript{225}, with some interesting findings. One study\textsuperscript{226} found that two thirds of service users who had been discharged from inpatient care in London had attended a Care Programme Approach review, although only half reported to have been given a copy of their care plan. This is despite service users reporting on the value of receiving a written care plan\textsuperscript{227}. The effectiveness of the care plans has also come under scrutiny\textsuperscript{228,229} with research questioning their value in terms of their implementation. Care plans are auditable and the danger is that they may become merely a paper trail that is not effectively utilised to support and enhance the service user’s care. The idea of the Care Programme Approach being used as a performance indicator is heavily criticised\textsuperscript{230}, with the necessity to assess the content and effectiveness of the approach emphasised, beyond whether tasks have been completed. The act of writing down a care plan has no bearing on whether the plan is likely to be followed and unless something practical is done with the service user to support them in their recovery, having a plan may amount to very little.
Findings relating to how involved service users are in their care planning are mixed. Service users reportedly had little understanding of the content of their care plans\textsuperscript{231}, despite wanting to become more involved in the care planning process and be given a copy of their plan\textsuperscript{232}. A further study\textsuperscript{233} noted that half of the service users had not been involved in drawing up their plan and two thirds did not know the date of their next review. This study reported that the care planning process was the factor that was most indicative of service user satisfaction. Service users reported value in being involved in their discharge plan from hospital and wanted inclusion of factors such as housing issues and daily activities\textsuperscript{234}. Therefore, care planning is important when in the community and in hospital to ensure continuity of care. The literature suggests that service user involvement is very important in the whole process.

A thematic analysis, concerned with formulating research questions to inform mental health policy\textsuperscript{235}, identified gaps in research related to the National Service Framework\textsuperscript{224}. Standard 4 of the framework addresses care in the community for people with severe mental illness on the Care Programme Approach. Thornicroft et al.\textsuperscript{235} extracted the need for further work to address the following questions: What are the effects of crisis plans on rates of admission to hospital and on user satisfaction? What are the effects of giving service users written copies of the plans? In answer to the second question, a Cochrane review of service user held information\textsuperscript{236} had previously concluded that there were no trials that met the inclusion criteria, therefore a research need was identified. The author of this thesis has worked with the authors of that Cochrane review\textsuperscript{236} to update the paper following the completion of relevant trials. With regard to the need to explore the effects of crisis plans on hospital admissions and service user satisfaction, further work is required and the development of joint crisis plans to promote service user involvement will be explored throughout this review.

**Key themes and questions arising from this chapter**

The key themes that arise from the systematic review are those of engagement and improving control for service users. These threads run through the literature regardless of the type of intervention administered, with the trials showing reasonably promising outcomes. There is clearly work outstanding around this area to more fully understand the mechanisms of the joint crisis plans and to more comprehensively examine their benefits for people with severe mental illness. This work would also address identified gaps in research related to the National Service Framework\textsuperscript{224}, as previously
highlighted. The research included within this review takes a variable approach to the consideration of the effects of the advance statements for people from ethnic minorities. Whilst some samples included a broad range of ethnicities, this would appear to be in some part due to chance or merely the selection of the recruitment area. Service users were generally excluded on the basis that they did not have a sound command of the native language. This has a potentially big impact on ethnic minorities that may benefit from this intervention, given that the need for such an intervention to reduce hospital admissions would seem to be best directed at such groups. The disproportionate admission rates that ethnic minority groups face in comparison to their white counterparts is explored in Chapter 1 and it is the disparities in treatment provision that need to be eradicated within research trialling these new interventions. The strategies highlighted in Chapter 2 to include ethnic minorities in psychiatric research need to be incorporated into future research. These techniques will be applied in this thesis as CRIMSON provides an opportunity to assess the effectiveness in this area.

In summary the following action points and questions have arisen from this review:

- It is important that future research addresses the limitations to the methodology that have arisen from the previous research.
- Future research should move beyond excluding participants from the trial for whom the intervention would be shown to benefit. Instead a more proactive approach to incorporating strategies to aid the inclusion of ethnic minorities in research should be adopted.
- Are there particular ethnic minorities that the interventions may benefit the most, given the literature relating to hospital admission disparities?
- Would the presence of an independent facilitator allow the service users the opportunity to reflect their culture and ethnicity? This is a point that service users emphasised regarding the current advocacy system.
Chapter 4: Aims and Hypotheses

Summary of literature review

In Chapter 1 we saw that people from ethnic minorities are most likely to be admitted to hospital, probably because of difficulties in engaging with mental health services. Ethnic minorities are not only hard to engage with in mental health services, but are particularly hard to engage in mental health research, as we saw in Chapter 2. This chapter did present some strategies that are available to assist with engagement into research and break down the barriers that ethnic minority groups may face to participating in mental health research. In Chapter 3 we saw that the joint crisis planning approach is one of the few techniques available for reducing compulsory hospital admissions. Since the joint crisis plan approach works through promoting engagement, there is some evidence to suggest that it may be particularly useful for ethnic minorities. If CRIMSON is going to successfully recruit ethnic minorities into the trial it is necessary to employ some of the techniques described in the previous chapter to help overcome potential obstacles. Therefore the CRIMSON trial provides the opportunity to apply the learning from the literature review and see if it is possible to get people from ethnic minority backgrounds into psychiatric trials.

The aims of this thesis are threefold and will be presented in turn.

1. By looking at the groups of participants who have been randomised to receive the intervention, the author aims to analyse whether the findings for south Asian and black participants together show a more positive outcome in terms of: hospital admissions (formal and any admission) and working alliance as reported by the service user. The treatment effect for each will be compared to the effect for white British participants.

2. By applying the techniques highlighted in the literature, the author aims to determine if it is possible to get ethnic minorities involved in psychiatric trials.

3. Through analysis of the joint crisis plan documents completed by the service users and their clinical teams, the author aims to determine whether the intervention brings out culturally relevant statements (based on predefined categories informed by the previous literature reviews) for the service user.
Hypotheses by aim

Aim 1

Primary hypothesis

Joint crisis plans will significantly reduce the proportion of service users from south Asian and black ethnic groups treated under a section of the Mental Health Act during the 18 months follow-up period, compared with service users from south Asian and black groups in the control condition (Hypothesis 1).

Secondary hypotheses

Compared with service users from south Asian and black groups in the control condition, joint crisis plans will significantly:

1. Reduce the proportion of service users from south Asian and black ethnic groups, with a psychiatric hospital admission (formal or informal admission) at any point during the follow-up period (Hypothesis 2).

2. Improve south Asian and black service users’ perception of their therapeutic alliance with their care coordinators (Hypothesis 3).

3. In addition it is predicted that there will be a greater treatment effect size for south Asian and black service users compared to white British service users (Hypothesis 4).

Aim 2

It will be possible to get ethnic minorities involved in psychiatric trials through employing effective recruitment strategies.

Aim 3

The joint crisis planning document will bring out culturally relevant statements by the service users (to be defined within Chapter 6) that are important for the service user.
Chapter 5: Methodology CRIMSON trial

Overview

This chapter presents the methodology of CRIMSON, a multi-site randomised control trial into the effectiveness of joint crisis plans in reducing compulsory hospital admissions. This trial is funded by the Medical Research Council and has been conducted by research teams in London, Birmingham and Manchester, recruiting service users from NHS foundation trusts.

Within this chapter, consideration is given to the origins of the CRIMSON trial and the work that has informed the current methodology. This chapter provides details of CRIMSON’s methodology including the aim, setting, participants, design, outcomes, follow-up points, power calculation and statistical analysis plan.

This chapter provides the information about CRIMSON and is a precursor to Chapter 6 which will specifically provide the methodology for this thesis, which is embedded within the larger CRIMSON trial.

Rationale for CRIMSON

Chapter 1 documented the prevalence of mental illness across the UK both in general terms and then more specifically for people from ethnic minorities. Within the UK compulsory hospital admissions have risen\textsuperscript{114} which has happened concurrently with a reduction in hospital beds\textsuperscript{66,237} as documented within Chapter 1. An analysis of hospital admissions found that between 1996 and 2006, the total number of involuntary admissions per year increased by 20%; within this time, psychiatric inpatient care has changed considerably, with the case mix shifting further towards psychotic disorders\textsuperscript{114}. Formal admissions rose nationally to a high of 28,700 in 2008-2009\textsuperscript{238} showing an increase of 600 from the previous year and bringing with it an increase in cost\textsuperscript{239}.

Providing patients with control is central to many developments across healthcare provision as a whole, with a broad ethical movement to give patients more control of their care\textsuperscript{240}. This ten year framework put forward in a report by the Department of Health has reviewed the information strategy for the NHS, public health and social care. The importance of service user involvement within mental health services is growing within both the planning and evaluation of services\textsuperscript{241}. Service user outcome
data is increasingly used in community mental health services and Thornicroft and Tansella\textsuperscript{242} have proposed nine principles that mental health services in the community should be established upon. These are listed as: autonomy, continuity, effectiveness, accessibility, comprehensiveness, equity, accountability, coordination and efficiency; with service users able to make vital contributions within each of these guiding principles. Furthermore, the idea that people should be given the authority to make their own health care decisions is evolving. One aspect is allowing people who are capable of doing so to make decisions prior to loss of capacity through illness (unconsciousness or dementia are the most common reasons generally\textsuperscript{243}). However, this is perhaps more important when considered in terms of mental illness, as capacity in this context can fluctuate.

The name CRIMSON was devised from the aims of the trial, as shown: ‘CRisis plan IMpact: Subjective and Objective coercion and eNgagement’. The trial was conceived because admission rates were rising and there were particular concerns over the compulsory hospital admission rates and the level of coercion perceived by service users. CRIMSON was designed to reduce these rates by getting closer cooperation between the service user and their clinical team, to enhance engagement with services.

**Work leading up to CRIMSON**

CRIMSON grew out of work over the previous decade, which aimed to increase service user autonomy through their care planning in order to reduce hospital admissions. This work was introduced within the systematic review in Chapter 3 which focused on collaborative interventions designed to reduce hospital admissions. A feasibility study into the effectiveness of crisis cards was completed in 1999\textsuperscript{151}, utilising a before and after design, with 42 participants. Service users reported that benefits of the cards were their improved control and involvement in their care. This was in addition to a 30% reduction in hospital admissions in the follow-up period. This study found that service users valued the process of collaborative planning with their clinicians, with participants electing to complete joint crisis plans rather than independent crisis cards.

Following the preliminary work described, a larger randomised control trial followed\textsuperscript{155}, which included more participants (n=180) and randomisation of participants allowed for comparisons to be made between the control group and intervention arm. This randomised control trial explored the effectiveness of joint crisis plans in reducing
hospital admissions for people with psychosis. It was found that a smaller proportion of the intervention group were admitted to hospital than from the control group (30% versus 44%) although these findings were not statistically significant (risk ratio 0.69, 95% confidence interval 0.45-1.04, \( \chi^2=3.25, p=0.07 \)). This trial also reported that the intervention resulted in a cost reduction of £1095 per patient, although again this finding was not statistically significant. A further secondary outcome was that service users felt more in control of their health problem in addition to feeling empowered, with case managers voicing positive responses towards the intervention.

The above randomised control trial showed promising findings and more work was needed to better understand the effects of joint crisis planning, with the inclusion of more participants and more robust methodology in relation to blinding and allocation concealment of randomisation. The effects of joint crisis planning for people from ethnic minority groups were also unknown. This previous research provided the basis for CRIMSON, the definitive randomised control trial; this is comparable with the Medical Research Council (MRC) framework for the development and evaluation of randomised control trials for complex interventions to improve health. CRIMSON aims to test the effectiveness of joint crisis planning in reducing compulsory hospital admissions in addition to several secondary outcomes as documented below.

**CRIMSON hypotheses**

The primary hypothesis to be tested is whether joint crisis plans significantly reduce the proportion of service users detained or treated under a section of the Mental Health Act during the 18 month follow-up period, compared with the control group.

Secondary hypotheses will determine if compared with the control condition, joint crisis plan use will result in significant improvements in: total costs, perceived coercion, service user engagement and therapeutic alliance.

Sub-analyses will examine the effectiveness of the joint crisis plans in reducing use of the Mental Health Act for black (black Caribbean and black African) service users.
Trial design

CRIMSON is a four year individual-level single-blind randomised control trial, funded by the Medical Research Council (MRC) (Grant number G0601660). This trial has received ethical approval from King’s College Hospital Research Ethics Committee.

Recruitment sites

CRIMSON is a multi-site randomised control trial which is a collaboration between researchers from three universities: Kings College London, The University of Birmingham and The University of Manchester. The trial recruited participants from five separate NHS foundation trusts across England, which have strong research links with the universities. These trusts and the areas within each trust that were recruited from are tabulated below in Table 12. Service users were recruited from assertive outreach teams, community mental health teams and early intervention services, covering the areas documented in Table 12.

The author was the full-time researcher for the Lancashire and Manchester site and was responsible for the recruitment of participants and for liaising with professionals across the whole area to maximise the effectiveness of the trial. Each university had one full-time and one part-time researcher who recruited participants and completed baseline and follow-up assessments.

The recruitment sites were carefully selected within the NHS trusts and provided recruitment of participants from both urban and rural areas, as the East Lancashire recruitment sites were small Lancashire towns, to provide a contrast with the major UK cities. The specific recruitment areas were selected to maximise the recruitment of service users from ethnic minority groups, as each of these areas has a high proportion of non-white residents. Images are used throughout this methodology chapter to highlight the recruitment areas and provide a breakdown of the population for each site\textsuperscript{viii}. The labels on each map, which show the teams recruited from, pinpoint the location of the team base. Whilst this has limitations in that it shows where the staff are based and not necessarily the direct areas where service users live, it is the most concise way of representing location. Team boundaries are often overlapping and the assertive outreach and community mental health teams cover the same areas with

\textsuperscript{viii} Permission to reproduce these images has been granted by the copyright owners and written confirmation of this can be provided by request.
differing boundaries. Therefore a pictorial representation of this would be confusing and does not merit inclusion.

Table 12: The three recruitment sites in the trial, the NHS trusts involved and the areas covered

<table>
<thead>
<tr>
<th>Site</th>
<th>Trust</th>
<th>Service users were recruited from assertive outreach teams, community mental health teams and early intervention services, covering the following areas:</th>
</tr>
</thead>
<tbody>
<tr>
<td>London</td>
<td>South London and Maudsley Foundation Trust</td>
<td>Croydon, Lambeth, Lewisham, Northover and Southbrook</td>
</tr>
<tr>
<td>Birmingham</td>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Aston, Erdington/Stockland Green, Handsworth, Kingstanding, Ladywood, Longbridge/Northfield, Sheldon &amp; Shard End, Shenley Fields, Soho, Solihull, Sutton, Ten Acres; Warstock Lane, Washwood Heath, Yardley &amp; Acocks Green.</td>
</tr>
<tr>
<td>Manchester/Lancashire</td>
<td>Lancashire Care Foundation Trust</td>
<td>Blackburn, Burnley, Darwen, Hyndburn, Pendle, Ribble Valley and Rossendale</td>
</tr>
<tr>
<td></td>
<td>Manchester Mental Health and Social Care Foundation Trust</td>
<td>Central Manchester (East, North and South) North Manchester</td>
</tr>
<tr>
<td></td>
<td>Rotherham Doncaster and South Humber NHS Foundation Trust</td>
<td>All Manchester</td>
</tr>
</tbody>
</table>

Figure 6\textsuperscript{245} below shows the percentages of the non-white population across the UK; with the darker shaded areas depicting those areas with higher percentages of people from ethnic minorities. The recruitment areas are also shown and it is evident that these areas are the ones with the largest percentages of ethnic minorities living within them. The 2001 census\textsuperscript{246} showed that the non-white population across the UK is most concentrated in large urban areas, with around 45% of this population residing in the London area. Further figures showed that the West Midlands had 13% of the non-white population, followed closely by the North West, which had 8%.
Recruitment site 1: London

Figure 7 below is a map of London which depicts three particular areas of London which are served by the South London and Maudsley Foundation Trust. The specific mental health teams that participants were recruited from in this trial are shown alongside each area; which consists of Early Intervention Services (EIS), Community Mental Health Teams (CMHT), Assertive Outreach Teams (AOT) and Recovery and Support (R&S) Teams.
Figure 7: Map of London, showing the south London and Maudsley foundation trust teams from which participants were recruited

Key

Figure 8 below represents the non-white population by area across London. It can be seen that the highest populations of ethnic minority groups are in central parts of London, with the highest percentage of White-British people tending to reside around outer parts of London. When compared with the previous map in Figure 7 above, it is clear that Lewisham and Lambeth are in the areas with the highest percentage of ethnic minority groups with Croydon falling just outside of this, but still with a large proportion of non-white residents. This is verified by the statistics in Table 13 below which provides a breakdown of the top four ethnic groups within each of the three South London recruitment areas, showing both the number of people and the total percentage of population within each area.
Figure 8: Map of London to show non-white population

Table 13: Breakdown of top ethnic populations across the south London recruitment areas

<table>
<thead>
<tr>
<th>Area</th>
<th>Ethnicity</th>
<th>Number of people</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>White</td>
<td>166,058</td>
<td>62.4</td>
</tr>
<tr>
<td></td>
<td>Black Caribbean</td>
<td>32,139</td>
<td>12.1</td>
</tr>
<tr>
<td></td>
<td>Black African</td>
<td>30,836</td>
<td>11.6</td>
</tr>
<tr>
<td></td>
<td>Other Black</td>
<td>5,579</td>
<td>2.1</td>
</tr>
<tr>
<td>Lambeth</td>
<td>White</td>
<td>164,098</td>
<td>65.9</td>
</tr>
<tr>
<td></td>
<td>Black Caribbean</td>
<td>30,543</td>
<td>12.3</td>
</tr>
<tr>
<td></td>
<td>Black African</td>
<td>22,571</td>
<td>9.1</td>
</tr>
<tr>
<td></td>
<td>Other Black</td>
<td>5,146</td>
<td>2.1</td>
</tr>
<tr>
<td>Lewisham</td>
<td>White</td>
<td>231,945</td>
<td>70.2</td>
</tr>
<tr>
<td></td>
<td>Black Caribbean</td>
<td>26,065</td>
<td>7.9</td>
</tr>
<tr>
<td></td>
<td>Indian</td>
<td>21,246</td>
<td>6.4</td>
</tr>
<tr>
<td></td>
<td>Black African</td>
<td>14,627</td>
<td>4.4</td>
</tr>
</tbody>
</table>

(c) Guardian News & Media Ltd.
Recruitment Site 2: Birmingham

The Birmingham and Solihull Mental Health NHS Foundation trust serves a diverse population of 1.2 million people\textsuperscript{249}. Birmingham is the most ethnically diverse area within this site and so the recruitment was focussed here. Solihull has a lower proportion of ethnic minority groups residing there and so captures a different demographic with 94.6\% of residents reporting their ethnic group to be white\textsuperscript{250} and the second highest ethnic group is Indian with just 1.8\% of the population\textsuperscript{250}. Figure 9\textsuperscript{251} below, shows the areas of Birmingham by proportion of ethnic minorities and the teams from which participants were selected are highlighted by location. It is clear that the specific recruitment sites are generally focussed around those areas with the highest proportion of non-white residents. Following the map below in Figure 9, a breakdown of ethnic groups within the Birmingham area is tabulated in Table 14\textsuperscript{252}. This clearly shows the cultural diversity of the city and the range of ethnic groups that reside across the area.
Figure 9: Map of Birmingham, showing the Birmingham and Solihull mental health NHS foundation trust teams from which participants were recruited and the population of ethnic minority groups

Key

<table>
<thead>
<tr>
<th>% of Black and Minority Ethnic Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to 10%</td>
</tr>
<tr>
<td>10.1% to 20.0%</td>
</tr>
<tr>
<td>20.1% to 40.0%</td>
</tr>
<tr>
<td>40.1% to 60.0%</td>
</tr>
<tr>
<td>60.1% and above</td>
</tr>
</tbody>
</table>

(c) Birmingham City Council
Table 14: Ethnic breakdown of the population in Birmingham

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Birmingham Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>White - British</td>
<td>641,345</td>
<td>65.6%</td>
</tr>
<tr>
<td>Mixed Backgrounds</td>
<td>27,946</td>
<td>2.9%</td>
</tr>
<tr>
<td>Total Black</td>
<td>59,832</td>
<td>6.1%</td>
</tr>
<tr>
<td>Black - Caribbean</td>
<td>47,831</td>
<td>4.9%</td>
</tr>
<tr>
<td>Asian - Bangladeshi</td>
<td>20,836</td>
<td>2.1%</td>
</tr>
<tr>
<td>Asian - Indian</td>
<td>55,749</td>
<td>5.7%</td>
</tr>
<tr>
<td>Asian - Pakistani</td>
<td>104,017</td>
<td>10.6%</td>
</tr>
<tr>
<td>Total Asian</td>
<td>190,688</td>
<td>19.5%</td>
</tr>
<tr>
<td>Chinese, Other</td>
<td>11,215</td>
<td>1.1%</td>
</tr>
</tbody>
</table>

Recruitment Site 3: Lancashire/ Manchester

The third recruitment site for the trial covers the largest geographical area and this is the area that the author directly recruited participants from. They were therefore involved in building links and recruiting from teams across three separate NHS foundation trusts. The first area for discussion is Lancashire as it differs from the other recruitment sites which are all major UK cities. Figure 10 below shows the map of Lancashire, with the recruitment areas which were involved in the trial highlighted. These are all small rural towns in East Lancashire. All the teams that were involved in the trial are from East Lancashire and the reason for this is clearly evident in Figure 11 below. It can be seen that the population of non-white groups is most densely populated in the east of the county.
Figure 10: Map of Lancashire, showing the Lancashire care foundation trust teams from which participants were recruited

(c) Lancashire Care Foundation Trust

Figure 11: Map of Lancashire to Show the Non-White population

(c) Lancashire County Council
A breakdown of ethnic groups across the East Lancashire area can be seen below in Table 15\textsuperscript{254}. This expands on the graphical representation of ethnic minority groups and quantifies the numbers of each group and percentage of the population within each small area.

Table 15: Breakdown of ethnic groups in east Lancashire

<table>
<thead>
<tr>
<th></th>
<th>White</th>
<th>Mixed</th>
<th>Asian or Asian British</th>
<th>Black or Black British</th>
<th>Chinese or other ethnic group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Lancs</td>
<td>456,072</td>
<td>3,502</td>
<td>55,835</td>
<td>725</td>
<td>1,234</td>
<td>517,368</td>
</tr>
<tr>
<td>%</td>
<td>88.2</td>
<td>0.7</td>
<td>10.8</td>
<td>0.1</td>
<td>0.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Blackburn with Darwen</td>
<td>107,124</td>
<td>1,262</td>
<td>28,384</td>
<td>318</td>
<td>382</td>
<td>137,470</td>
</tr>
<tr>
<td>Burnley</td>
<td>82,171</td>
<td>630</td>
<td>6,409</td>
<td>121</td>
<td>211</td>
<td>89,542</td>
</tr>
<tr>
<td>Hyndburn</td>
<td>74,740</td>
<td>482</td>
<td>6,064</td>
<td>67</td>
<td>143</td>
<td>81,496</td>
</tr>
<tr>
<td>Pendle</td>
<td>75,799</td>
<td>606</td>
<td>12,556</td>
<td>102</td>
<td>185</td>
<td>89,248</td>
</tr>
<tr>
<td>Ribble Valley</td>
<td>53,100</td>
<td>220</td>
<td>407</td>
<td>55</td>
<td>178</td>
<td>53,960</td>
</tr>
<tr>
<td>Rossendale</td>
<td>63,138</td>
<td>302</td>
<td>2015</td>
<td>62</td>
<td>135</td>
<td>65,652</td>
</tr>
</tbody>
</table>

The second area in the North-West of England, completing the third recruitment site is Manchester. This large city contrasts with the rural towns recruited from in East Lancashire. Figure 12 below\textsuperscript{255} shows the ethnicity of the population of Manchester by specific ward. In addition the teams within Manchester Mental Health and Social Care NHS trust that have been recruited from have been highlighted. Manchester Early Intervention teams were also recruited from and these teams all fall under Rotherham, Doncaster and South Humber NHS Mental Health Foundation Trust. As explained previously, the arrow pinpoints the location of the team. The team names given were correct at the time of recruitment. These teams have since transformed and therefore the names are no longer consistent with current teams. The specific percentage breakdown of ethnic minority groups across Manchester is presented in Table 16\textsuperscript{256} below.
Figure 12: Map of Manchester, showing the Manchester mental health and social care trust teams from which participants were recruited and the population of non-white residents by area

Table 16: Breakdown of ethnic minority groups in Manchester

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>White Groups</td>
<td>76.9%</td>
</tr>
<tr>
<td>Mixed Residents</td>
<td>3.2%</td>
</tr>
<tr>
<td>Black residents</td>
<td>4.9%</td>
</tr>
<tr>
<td>Asian Residents</td>
<td>9.2%</td>
</tr>
<tr>
<td>Chinese Residents</td>
<td>2.5%</td>
</tr>
<tr>
<td>Other Ethnic Group Residents</td>
<td>3.2%</td>
</tr>
</tbody>
</table>
**Trial recruitment**

Figure 13 below shows the process of recruitment and assessment. The procedures are discussed in more detail below. Information about the baseline and follow-up assessments and the joint crisis planning process is provided in depth in later sections of this chapter.

**Figure 13: Diagram describing the process of recruitment**

1. NHS trusts from which to recruit were selected

2. Promotion of trial to managers, psychiatrists and clinical teams

3. Screening of all caseloads using strict eligibility criteria

4. Those who did not meet criteria were not to be approached

5. Those who meet criteria to be approached with assistance and consent from care coordinator

6. Service users who refuse were not to be contacted again

7. Service users who would like to participate in the trial to provide informed consent

8. Baseline Assessment to be completed (n)

9. Those in control group (n/2) to receive treatment as usual

10. Those randomly selected for intervention (n/2) to complete Joint Crisis Plan in addition to receiving treatment as usual

11. Follow-up assessment to be completed 18 months from the time of baseline assessment (n)
Promotion of the trial

Support for the trial was gained from NHS foundation trusts throughout the process of promoting the trial. The relevant permissions and letters of access were obtained in writing for each of the trusts involved. A launch event was delivered at each of the sites to which the managers, consultants and clinical teams from across the areas were invited. The author promoted the trial across all direct recruitment sites in the North-West area, which entailed meeting with the team managers, consultant psychiatrists and delivering presentations to community mental health teams, assertive outreach teams and early intervention services. Once the support was gained from clinical teams and their appreciation of the benefits of the intervention were expressed, the trial was then promoted on a much wider scale. The author met with police liaison teams, hospital ward managers, modern matrons and delivered presentations at a clinicians’ area conference. The research was also presented to GPs and academic groups to promote the aims of the trial and the possible benefits that it may have in its contribution to health care development.

Eligibility criteria

All participants in the trial were service users whose case was actively open from a range of mental health community team service providers. Each of the University sites worked closely in conjunction with the NHS trusts mentioned previously and the collaboration allowed the author to hold honorary contracts with these trusts. Electronic computer records from the NHS foundation trusts were used to categorise each service user under the caseload as being either eligible or ineligible for the trial. Eligibility criteria was assessed from the whole caseload of community teams that were invited to be involved in the study; through screening the entirety of each team’s caseload, participant selection bias was reduced. This was true for selection biases from potential participants but perhaps more importantly from biases from their clinical gatekeepers, who were generally their care coordinators. It would be likely that if asked to nominate service users from their caseload to be involved in the trial, care coordinators would not highlight those most in need of the intervention and those that are not well engaged with services. Therefore it was important that researchers invited all eligible service users to participate.
The eligibility criteria for CRIMSON are shown to the right in Box 1 and reasons for these are further explained here. Only adult patients (aged 18-65) were recruited, which corresponds with the national age range used in health services for adults. At the time of inception of CRIMSON, services differed for those aged under 18 and those aged over 65, although the NHS has since moved on and no longer uses strict age cut-offs at the upper end.

Eligible service users must have had a psychiatric hospital admission within the previous two years of date of screening. This is in line with the pilot study\textsuperscript{155} to the trial and it forms a baseline for admissions data; meaning that those service users who are most at risk of being readmitted to hospital are included within the trial. The OPCRIT\textsuperscript{257} diagnostic tool was used in order to provide a standardised framework for diagnosis, as the nature of the multi-site trial meant that many different teams and consultants had provided the diagnosis for individual participants. The tool enabled a standardised diagnosis across the country for service users and the results of this screening tool enabled an assessment of the eligibility of the teams’ caseloads.

Service users had to be allocated to the enhanced level\textsuperscript{ix} of the care programme approach (see Box 2 to the right) This was decided upon as it ensured that those with a current severe mental illness were included in the trial, as they were most likely to enter crisis or be admitted to hospital.

---

**Box 1: Eligibility criteria**

* Adult patients (aged 18-65)
* Service users were currently receiving support from the community team (community mental health team, early intervention service, assertive outreach team or support and recovery teams)
* Service users must have had a psychiatric hospital admission within the previous two years of date of screening
* Service users required a diagnosis of a psychotic illness (as defined by OPCRIT)
* Service users had to be allocated to the enhanced level of the care programme approach.

**Box 2: The Care Programme Approach**

This was introduced in England; requiring health authorities, in collaboration with Social Services Departments to make arrangements for the care and treatment of people in the community with mental illness. Care Programme Approach currently acts as the framework for best practice in mental health services. Enhanced Care Programme Approach includes the following components: An assessment of the health and social care needs (with regular reviews), a written plan that is agreed by a multidisciplinary team and the nomination of a care coordinator. The care plan will normally include a Crisis and Contingency Plan. The Care Programme Approach is clinician led and plans can be written without the presence of the patient.

\textsuperscript{ix} This level is assigned to patients with a diagnosis of a severe and persistent major mental illness, with complex mental health care needs, who require a multi-disciplinary approach.
The exclusion criteria for the CRIMSON trial are shown in Box 3 to the right. Service users were deemed ineligible to take part in the research if at that time if they were receiving support from a crisis team or home treatment team or if they were subject to a community treatment order. This was in order to avoid perceived coercion of service users to participate and, for similar reasons, inpatients were also not approached. These patients were given the label ‘status may change’ and upon a change in circumstances they may become eligible to participate later within the recruitment period. These service users were not approached at the time of screening; however their eligibility to participate in the trial was frequently revisited throughout the duration of the recruitment period. The criteria for hospital admission dates was subject to change as some service users were readmitted to hospital after the initial screening was completed. Therefore lists of hospital admissions and discharges from each area were obtained on a regular basis so that the screening could be an on-going and accurate process, so any service users that may be eligible to participate in the trial at a later date were not eliminated. Service users were not recruited to the study if they were deemed unable to give informed consent through lack of capacity. This was in order to adhere to the Mental Capacity Act. Measures were put in place by researchers to ensure that informed consent was obtained.

**Recruitment of eligible service users**

Once the eligible service users from each team had been identified, contact was made with each person’s allocated care coordinator. A care coordinator is a member of the clinical team that plans and coordinates the individual’s course of treatment, intervention and support whilst they are under the care of team. This person is likely to have a background in psychiatric nursing, social work or occupational therapy and they are responsible for maintaining contact with the service user and for ensuring that they have an up to date care plan based on an assessment of their needs for care. Engagement of the care coordinator was critical to the success of the intervention. As the care coordinators would play a crucial role in conducting the trial and indeed assessing the merit of the intervention it was important that they understood the aims of the trial, the background to it and the potential benefits for them and their clients.

**Box 3: Exclusion criteria**

*Service users receiving support from a crisis team, home treatment team, community treatment order or inpatient admission.*

*Service users unable to give informed consent, through lack of capacity*
With this in mind the researchers met with care coordinators to provide them with staff information sheets (Appendix 2) and to explain the trial in more detail, answering questions as they arose. Care coordinators were then asked to give their written consent to participate in the trial through completion of a staff consent form (Appendix 3). These collaborative discussions with care coordinators about their individual clients prompted the next course of action which was to disseminate information about the trial to the service users. Different approaches were taken at this point and if the care coordinator felt it appropriate then they would occasionally advise researchers to contact the service user directly and see if they were happy to hear more about the trial and what it would entail. On other occasions the care coordinator suggested that they ask their client first whether they were agreeable to being contacted. Alternatively, care coordinators proposed that they take written information with them to their next visit or that it be posted out to the service user. Some care coordinators offered researchers the chance to accompany them on their next meeting with the client so that they could explain the research to them together.

On meeting the service users, researchers provided them with the participant information sheet (Appendix 4) and talked through it with them, encouraging them to ask questions. Researchers consistently made an assessment of the service users' understanding of the trial by exploring areas in more detail and asking questions of them, so that it was clear they were not just agreeing to consent without fully comprehending what was being asked of them. The service users were then given time to digest the information prior to written informed consent being obtained (Appendix 5). Some service users asked to be contacted at a much later date, if personal circumstances dictated that they wanted to prioritise other issues at that time, so some people were not approached again for several months.

Some service users expressed that they did not want to be part of the trial. Numerous reasons were given for this, including: not having time; not thinking that the intervention would benefit them; their opinion that they were well now and would never be readmitted to hospital. If a service user clearly stated their preference for non-participation (rather than stating they would like time to make their decision) then it was explained to them that the research team would not make contact with them again. Contact telephone numbers and the trial patient information sheet were left with the service users in order that they could make contact, should they change their mind and want to discuss it again. They were also encouraged to discuss the trial in the future with their care coordinator if they would feel comfortable in doing so.
**Informed consent**

Participants were asked to go through the participant information sheet and consent form in detail with the researcher. They were asked to tick each of the statements on the consent form (Appendix 5). Once the participants had agreed to the consent form, they then signed and dated it and the researcher also signed and dated it underneath. This form was then filed securely in line with Good Clinical Practice Guidelines. The participants were informed that their responses would remain anonymous to the study team and they would be known by a unique identification number. They were also informed that their responses within the assessment would not be discussed with their care team and their opinions would be used for research purposes, with no impact being made on their current financial benefits. It was important that full confidentiality was not offered prior to commencing the interview with participants; should they disclose information that suggested that they were at risk of harming themselves or others, or that they had committed an offence that had not been reported to the police, then that information may have needed to be passed on.

**On-going trial promotion**

A logo, shown to the right, was developed for the trial. This logo was displayed on all materials and letters sent out to both staff and participants as well as any printed correspondence in relation to the trial.

Posters were designed and displayed in public areas at clinics and hospitals to promote the trial to patients and staff. The author contributed to an article in the ‘Insight’ magazine that is distributed across Lancashire Care Foundation Trust, explaining the trial and promoting the benefits for the trust. This was published in April 2009 and was distributed across the area to all staff and members of the trust. In addition pens, post-it notes and mugs were printed with the CRIMSON logo (Appendix 6). These were given to community teams in order to promote the trial along with printed leaflets about CRIMSON (Appendix 7) and more formal staff and information participation documents. Once the recruitment process
was underway, the author devised and distributed newsletters to service users and clinical teams to keep them up to date with the progress of the trial.

Research assessments used

The assessment tools which form the baseline and follow-up assessments of the CRIMSON trial are tabulated below in Tables 17 and 18. Table 17 describes the data collected from participants and at which stage each outcome was obtained. Table 18 provides the same information for the data collection from care coordinators. The majority of the data obtained is from self-report from the participants with the main outcome measures being gathered from NHS trust records. This data was checked with participants within interview to check validity and to enquire whether they had been admitted to hospital outside of the trust area. The participants’ psychotropic medications were also verified by electronic records, as were the community contacts with the mental health team.

Service user data collection

This data was collected from interview with the participants and, where possible, was verified by trust electronic records.

Socio-demographic information

Socio-demographic information documented in Table 17 was obtained from the participants within the face-to-face interview. The majority of this information given was verified by the electronic records. Ethnicity of participants was described using Office for National Statistics categories as they have been thoroughly tested and are known to be acceptable to the majority of the population.

Table 17: Service user outcome measures for the CRIMSON trial

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Standardised measure</th>
<th>Source</th>
<th>Baseline</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socio-demographics</td>
<td>NHS Number</td>
<td>Electronic records</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Date of Birth</td>
<td>Electronic records and interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Gender</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Clinical Diagnosis</td>
<td>Electronic records</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Date of last discharge</td>
<td>Electronic admissions records</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>------------------------</td>
<td>-------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Site</td>
<td>Electronic records</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Team</td>
<td>Electronic records and interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Marital Status</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Who they live with</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>National Identity</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Country of Birth</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Ethnic group</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>First language</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Years of contact with mental health services</td>
<td>Interview and electronic records</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Number of care coordinators since baseline</td>
<td>Interview and electronic records</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Highest level of qualification</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-demographics</td>
<td>Classification of qualification</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costs</td>
<td>Adult Service Use Schedule</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health Act use</td>
<td>Routine hospital datasets</td>
<td>Admissions electronic records and interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voluntary hospital admissions data</td>
<td>Routine hospital datasets</td>
<td>Admissions electronic records and interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recovery Style</td>
<td>The Recovery Style Questionnaire</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived coercion</td>
<td>Treatment Experience Survey</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapeutic relationship</td>
<td>Working Alliance Inventory (Client Form)</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functioning</td>
<td>Global Assessment of Functioning</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience of Joint Crisis Plans</td>
<td>Joint Crisis Plan Usage Questionnaire</td>
<td>Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience of Joint Crisis Plans</td>
<td>Focus Groups</td>
<td>Focus Groups</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

131
Table 18: Care coordinator outcome measures for the CRIMSON trial

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Standardised measure</th>
<th>Source</th>
<th>Base-line</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socio-demographics *</td>
<td>Gender</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Socio-demographics *</td>
<td>Ethnicity</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Socio-demographics *</td>
<td>Professional Qualification</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Socio-demographics *</td>
<td>Length of relationship with participant</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Socio-demographics *</td>
<td>Date of Birth</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Socio-demographics *</td>
<td>Initials</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Socio-demographics *</td>
<td>Length of practice</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Socio-demographics *</td>
<td>First language</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Socio-demographics *</td>
<td>Type of Care Coordinator</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Engagement with care</td>
<td>Engagement and Acceptance Scale</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Engagement with care</td>
<td>Service Engagement Scale</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Therapeutic relationship</td>
<td>Working Alliance Inventory</td>
<td>Interview/Questionnaire</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Experience of Joint Crisis Plans</td>
<td>Focus Groups</td>
<td>Focus Groups</td>
<td>✔</td>
<td></td>
</tr>
</tbody>
</table>

* Socio-demographic information was not collected again at follow-up stages if the care coordinator remained the same for participants.

**Adult service use schedule**

The economic evaluation of the trial used the Adult Service Use Schedule (AD-SUS)\(^{261}\). This outcome measure was designed for collecting service user information in mental health populations. It covers a wide range of services with cost implications including; health, social care, housing, community support services and criminal justice services. This incorporates the main outcome from the trial, which is hospital admissions, by measuring the cost of these admissions in addition to cost of medications, staff costs and the costs incurred through the implementation of the trial intervention (joint crisis plans).
**Hospital admissions**

Data was obtained from routine hospital datasets. Researchers verified this data with participants at interview to check for any out of area admissions. Data was collected on an admissions proforma that recorded; NHS trust, date of admission, date of discharge, date of leave, ward type and section. The proforma allowed for changes in ward type across admissions and changes in sections or voluntary status of each admission.

Figures 14-17 individually present an outcome measure used within the trial. For each measure, details are provided regarding the items, administration and validation.

**Figure 14: Recovery style questionnaire (RSQ)**

<table>
<thead>
<tr>
<th>Date scale devised</th>
<th>1998</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>This self-report tool was developed to measure recovery style in people with psychosis. Based on McGlashan, Levy &amp; Carpenter’s (1975)268 interview measure of recovery style. Four recovery styles can be classified: integration; mixed picture in which integration predominates; mixed picture in which sealing over predominates and sealing over. Higher scores represent sealing over.</td>
</tr>
<tr>
<td>Administration</td>
<td>This scale is administered to the participant for self-completion.</td>
</tr>
<tr>
<td>Number of items</td>
<td>39 questions. The participant is required to either agree or disagree with the statements.</td>
</tr>
<tr>
<td>Subscales</td>
<td>The questionnaire has 13 subscales (curiosity, education, optimism, impact, fear, liking, continuity, ownership, responsibility, help-seeking, blame, cause and satisfaction) with three related questions in each subscale. Participants’ responses are assigned either a score of 1 or 2 and a score is obtained for each subscale.</td>
</tr>
<tr>
<td>Psychometric properties</td>
<td>The RSQ correlated highly with McGlashan’s interview-based measure262,268.</td>
</tr>
<tr>
<td></td>
<td>Criterion-related validity (r=.92, p&lt;0.01)262</td>
</tr>
<tr>
<td></td>
<td>Test re-test reliability (Spearman r=.81, p&lt;0.002)262</td>
</tr>
<tr>
<td></td>
<td>Internal reliability was investigated using Cronbach’s alpha coefficient and was also found to be acceptable (α=.73)262</td>
</tr>
<tr>
<td>Trials that have used the scale</td>
<td>Tait L, Birchwood Max, Trower P. Predicting engagement with services for psychosis: insight, symptoms and recovery style. <em>The British Journal of Psychiatry</em> 2003; 182(2):123-128.269</td>
</tr>
<tr>
<td></td>
<td>Fitzgerald M. Comparison of recovery style and insight of patients with severe mental illness in secure services with those in community services. <em>Journal of Psychiatric and Mental Health Nursing</em> 2010; 17(3):229-235.271</td>
</tr>
<tr>
<td>Other scales that could have been used</td>
<td>ISOS (Integration Sealing Over Scale)272,273 which is a six point scale that guides a semi structured interview conducted by a clinician.</td>
</tr>
<tr>
<td>Rationale for selecting this scale</td>
<td>As stated, the RSQ was found to be highly correlated with the interview measure. The interview measure however was very lengthy and time consuming. It also needed to be completed by a clinician. In this trial the RSQ provided the same outcomes in less time and could be administered by the researcher.</td>
</tr>
</tbody>
</table>
Figure 15: Treatment experience survey (TES)

<table>
<thead>
<tr>
<th>Date scale devised</th>
<th>1993</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>The Treatment Experience Survey is an adapted version of the MacArthur Perceived Coercion Scale. This scale has been adapted for reference to outpatient treatment and is designed to measure participants’ experience of coercion during community treatment.</td>
</tr>
<tr>
<td>Considerations/ Administration</td>
<td>This scale is administered to the participant for self-completion.</td>
</tr>
<tr>
<td>Number of items</td>
<td>15 questions</td>
</tr>
<tr>
<td>Subscales</td>
<td>Responses to this survey generate three scales: ‘perceived coercion’, 'negative pressures' and 'process exclusion'.</td>
</tr>
<tr>
<td>Psychometric properties</td>
<td>The Admission Experience Interview and Admission Experience Survey perceived coercion scale scores, correlate r=0.79 (SD= 0.10)\textsuperscript{263}. In a later sample item-total correlations ranged from 0.60 to 0.73. Cronbach’s alpha = 0.86, indicating high internal validity. An additional study provided the following properties: r= 0.65 Cronbach’s alpha=0.90\textsuperscript{276}.</td>
</tr>
<tr>
<td>Other scales that could have been used</td>
<td>The MacArthur Admission Experience Interview and Survey\textsuperscript{263}. This includes 2 measures: One scale is derived from a structured interview: the MacArthur Admission Experience Interview (AEI). The other scale is derived from a questionnaire, which is the MacArthur Admission Experience Survey (AES).</td>
</tr>
<tr>
<td>Rationale for selecting this scale</td>
<td>The AEI was not used as this is a semi structured interview and would be a more time consuming method (30 minute interview) of measuring perceptions of coercion. The AES would have been more relevant as it was a shortened measure with the items designed to parallel the content of the AEI. It could be administered to participants for them to complete. This scale related solely to hospital admissions and not treatment in general. The adapted version of the AES was used as it has been adapted for community treatment to ascertain more general perceptions of coercive treatment away from hospital admissions.</td>
</tr>
<tr>
<td>General comments</td>
<td>This scale was verified with regards to community treatment. The sample used was 67% African American, 33% white\textsuperscript{263}.</td>
</tr>
</tbody>
</table>
Figure 16: Working alliance inventory (WAI) client version

<table>
<thead>
<tr>
<th>Date scale devised</th>
<th>1989</th>
</tr>
</thead>
</table>

Background

The Working Alliance Inventory used in this trial has been developed from the earlier version and the scale used is the short version. Participants are asked to score each item on a scale ranging from agree strongly to disagree strongly dependent upon their opinions. This inventory has shown to have good reliability and validity, although there is no specific research available to show the validity with participants from ethnic minority groups.

Administration

This scale is administered to the participant for self-completion.

Number of items

8 items are answered by the service user and 8 items are answered by their clinical gatekeeper. In this trial one additional question was asked to the participant, asking how satisfied they were with the results of the work with their care coordinator. They were given five options to select from, ranging from extremely dissatisfied to extremely satisfied.

Subscales

The items on the scale focus around; goals, tasks and the bond formed in the clinician-service user working relationship.

Psychometric properties

This table shows the internal consistency of WAI-SR subscales and total score in outpatient and inpatient samples.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Outpatients</th>
<th>Inpatients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bond</td>
<td>0.82</td>
<td>0.83</td>
</tr>
<tr>
<td>Task</td>
<td>0.85</td>
<td>0.86</td>
</tr>
<tr>
<td>Goal</td>
<td>0.81</td>
<td>0.91</td>
</tr>
<tr>
<td>Total</td>
<td>0.90</td>
<td>0.93</td>
</tr>
</tbody>
</table>

Trials that have used the scale


Hopkins M, Ramsundar N. Which factors predict case management services and how do these services relate to client outcomes? *Psychiatr Rehabil J* 2006; 29(3):219-222.

Other scales that could have been used

- Clarkin’s six-point scale to assess the therapeutic alliance
- The Barrett-Lennard Relationship Inventory
- The Therapist Patient Relationship
- The Helping Alliance scale
- Helping Alliance Questionnaire-II

Rationale for selecting this scale

WAI was selected over the other existing scales as it is the most widely used and highly regarded across mental health research. Whilst it was initially developed for psychotherapy interventions, it has shown to be valid across other areas. This scale has additional value for the trial as it was also used in the Swanson trial which was an RCT using psychiatric advance directives. This enables direct comparability between this and the CRIMSON trial.

Additional comments

A scale was developed and validated following the commencement of the CRIMSON trial. This is: Scale to assess the therapeutic relationship in community mental health (STAR). It has relevance to the current trial and would have been given consideration should it have been available sooner.

The WAI differs from the other scales used in the trial by care coordinators in that service users complete their version of the scale also. This allows for comparisons of the views of service users and professionals.

Figure 17: Global assessment of functioning (GAF)

<table>
<thead>
<tr>
<th>Date scale devised</th>
<th>1987</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>This rating scale was provided by the American psychiatric Association which was designed to measure overall psychological disturbances.</td>
</tr>
<tr>
<td>Administration</td>
<td>The GAF is administered by the researcher (or clinician) by interview and is a quick and simple measure to use.</td>
</tr>
<tr>
<td>Items</td>
<td>The GAF consists of nine behavioural descriptors eg. Absent or minimal symptoms (eg mild anxiety before an exam). Patients are rated from 0-90 with the highest score relating to least severe psychological disturbances.</td>
</tr>
<tr>
<td>Psychometric properties</td>
<td>Whilst this scale was developed in 1987 there had been little evidence to support the reliability and validity of this measure with populations experiencing severe mental illness until 1995.</td>
</tr>
<tr>
<td>Reliability coefficient single rater= 0.70</td>
<td></td>
</tr>
<tr>
<td>Reliability coefficient randomly selected raters= 0.58</td>
<td></td>
</tr>
<tr>
<td>Other scales that could have been used</td>
<td>This is the recognised scale from the DSM-III-R which is used to measure psychological disturbance and provide a score for functioning.</td>
</tr>
<tr>
<td>---------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Rationale for selecting this scale</td>
<td>As above it is the most widely used scale. It was used in the trial as it can be administered quickly within the interview with the participant. It can also be administered by a number of researchers providing that inter-rater reliability assessments have been completed prior to its administration.</td>
</tr>
<tr>
<td>Additional comments</td>
<td>Inter rater reliability assessments were completed in training prior to the GAF being administered. After completion of the GAF, the trial scientific coordinator was provided with the score and rationale for the decision for each service user. This was then verified and once the scientific coordinator was in agreement, the researchers could then become un-blinded (after the follow-up GAF) so that data could be collected from electronic records.</td>
</tr>
</tbody>
</table>

**Joint crisis plan usage questionnaire**

This questionnaire was administered to the participants in the intervention group, following the researcher becoming un-blinded to their allocation in the trial. This questionnaire was only administered to those participants who had completed a joint crisis plan. The questionnaire asked if participants still have a copy of their joint crisis plan, whether they have used it and in which ways it has impacted on their care. The final questions asked participants whether they would recommend having a joint crisis plan to others and whether they had done so.

**Focus groups**

Focus groups were held at each of the three recruitment sites and the author was involved in these alongside the scientific coordinator of the trial. Within each site one focus group was held for those people who experienced a voluntary admission in the follow-up period and one was run separately for those people who had experienced a compulsory admission within that time. These focus groups helped to gain a greater understanding about the mechanisms of the joint crisis plans, from the service users’
view of the process. It was important to examine the impact of the intervention and discuss any barriers that may have stopped it being implemented effectively in practice.

**Care Coordinator data collection**

There were a variety of methods used to collect the care coordinators’ responses at baseline and at the follow-up stage. The questionnaire was generally presented to the care coordinators in hard paper copies and they were asked to complete their socio-demographic information and tick the responses that best suited their opinions in the scales described in Figures 18 and 19, below. On occasion the questionnaires were completed immediately by the care coordinators and given back to the researcher for inputting. Due to heavy workloads care coordinators often asked to take the form and post it back to the researcher or arrange a time when it could be picked up. The data was valid for a maximum of 3 months after the service user interview, although care coordinators were encouraged to complete the form as soon as possible. On other occasions the correspondence was completed over the telephone and the researchers asked the questions and provided the options from which the care coordinator was able to select from. Some care coordinators requested that the questionnaire was emailed to them and they returned the completed form electronically to the researcher. The differences in data collections allowed for the care coordinators’ busy schedules and other commitments and showed flexibility, demonstrating responsive practice.

**Socio-demographics**

This data was also obtained through self-report from the care coordinators. The ethnicity data was gathered in the same way as it was for the service users. If the care coordinator at the recruitment stage of the trial was unchanged at the follow-up stage then the socio-demographic data was not re-collected. If the care coordinator had changed then the socio-demographic information was collected from the new clinician. Figures 18 and 19 below present information relating to the Engagement and Acceptance Scale and the Service Engagement scale.

**Figure 18: Engagement and acceptance scale (EAS)**

<table>
<thead>
<tr>
<th>Date scale devised</th>
<th>2002</th>
</tr>
</thead>
</table>
### Background

The Engagement and Acceptance scale was adapted from the Homeless engagement and acceptance scale as cited above with the omission of one question.

### Administration

This scale is administered to the care coordinators for self-completion.

### Number of items

The HEAS includes 5 questions (The question related to housing is omitted in EAS).

### Subscales

- Attitude to worker
- Engagement with worker
- Attitude to help
- Attitude to housing *Omitted in EAS
- Engagement with others

### Psychometric properties

<table>
<thead>
<tr>
<th>HEAS item</th>
<th>Inter-rater reliability</th>
<th>Clinical Value of Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1 (attitude to worker)</td>
<td>0.71</td>
<td>Good</td>
</tr>
<tr>
<td>Question 2 (engagement with worker)</td>
<td>0.46</td>
<td>Fair</td>
</tr>
<tr>
<td>Question 3 (attitude to help)</td>
<td>0.67</td>
<td>Good</td>
</tr>
<tr>
<td>Question 4 (attitude to housing)</td>
<td>0.26</td>
<td>Poor</td>
</tr>
<tr>
<td>Question 5 (engagement with others)</td>
<td>0.70</td>
<td>Good</td>
</tr>
<tr>
<td><strong>Total Score</strong></td>
<td><strong>0.77</strong></td>
<td><strong>Excellent</strong></td>
</tr>
<tr>
<td><strong>Total score omitting Question 4</strong></td>
<td><strong>0.80</strong></td>
<td><strong>Excellent</strong></td>
</tr>
</tbody>
</table>

Question 4 had poorer reliability with those who were in more secure housing or who had an intermediate housing status. This therefore suggested that this scale could be shortened with this question omitted.

The scale is able to differentiate between respondents, with high discrimination of each item being shown to obtain high correlation with the total score.

The score on the HEAS at 3 months was shown to be a significant predictor of accommodation status and adequacy of a support network at 12 months.

### Trials that have used the scale


### Other scales that could have been used

Singh O’Brien Level of Engagement Scale (SOLES). This is a new scale measuring engagement with mental health services in people with psychosis. It has been developed since the CRIMSON trial commenced and so could not have been used in this trial. It has been shown to have good psychometric properties and two version have been developed; those with and those without a key-worker.

### Rationale for selecting this scale

The scale is selected due to good psychometric properties and predictive validity. Question 4 was omitted as the participants in this trial do not generally report to be homeless, although this may apply to the minority.

### Additional Comments

This measure of engagement is only completed by the clinician. There is no companion scale that is administered to service users.

Within the validation of the scale it is important to note that consideration and input was given from service users from black and minority ethnic groups, with issues that were deemed particularly important to them being highly regarded.
**Figure 19: Service engagement scale (SES)**

<table>
<thead>
<tr>
<th>Date scale devised</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>This scale is a measure of engagement within Community Mental Health Services and the tool can be used to highlight any concerns with clients experiencing engagement difficulties. This tool has been developed following research to identify issues given credence by service users with serious mental illness.</td>
</tr>
<tr>
<td>Considerations</td>
<td>Within this research it is important to note that consideration and input was given from service users from black and minority ethnic groups, with issues that were deemed particularly important to them being highly regarded.</td>
</tr>
<tr>
<td>Number of items</td>
<td>14</td>
</tr>
<tr>
<td>Subscales</td>
<td>The scale covers sub-scales of: availability; collaboration; help-seeking and treatment adherence.</td>
</tr>
<tr>
<td>Psychometric properties</td>
<td>The psychometric properties of this scale have been tested with clinical staff in relation to their caseload and reliability and validity ranged from good to excellent as is shown below.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale and Items</th>
<th>Cronbach's alpha</th>
<th>R (inter rater reliability) *</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficult to arrange appointments</td>
<td>0.82</td>
<td>0.97</td>
</tr>
<tr>
<td>When visit arranged client is available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client avoids making appointments</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Collaboration</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client resists advice</td>
<td>0.76</td>
<td>0.80</td>
</tr>
<tr>
<td>Actively participates in planning treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client participates in managing illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Help-Seeking</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client seeks help when needed</td>
<td>0.90</td>
<td>0.92</td>
</tr>
<tr>
<td>Difficulty in asking for help</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client seeks help to prevent crisis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client does not seek help</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Treatment Adherence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client adheres to treatment</td>
<td>0.82</td>
<td>0.88</td>
</tr>
<tr>
<td>Client understands need for medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client refuses treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client has difficulties with medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Full Scale</strong></td>
<td></td>
<td>0.90</td>
</tr>
</tbody>
</table>

* For each p value p<0.000

| Trials that have used the scale | Tait L, Birchwood M, Trower P. Adapting to the challenge of psychosis: personal resilience and the use of sealing-over (avoidant) coping strategies. *British Journal of Psychiatry* 2004; 185:410-415. |
Other scales that could have been used

Singh O’Brien Level of Engagement Scale (SOLES). This is a new scale measuring engagement with mental health services in people with psychosis. It has been developed since the CRIMSON trial commenced and so could not have been used in this trial. It has been shown to have good psychometric properties and two version have been developed; those with and those without a key-worker.

Rationale for selecting this scale

This scale was administered to participants and to clinical teams in the trial alongside the Engagement and Acceptance Scale. Rationale for using both is that the SES is a larger instrument and so would be more sensitive to change. It will support the data obtained from clinicians’ responses on the EAS to add to the wealth of data.

Additional comments

This measure of engagement (as with the Engagement and Acceptance Scale) is only completed by the clinician. There is no companion scale that is administered to service users.

It is very difficult to categorise the concept of engagement. May authors use differing criteria to measure it. In the past it has been closely linked with working alliance- although it can be said that service users may form a relationship with the service as a whole rather than with one professional.

Recognition is needed that this scale only acknowledges engagement from the clinician’s view. WAI uses both service user and clinician.

---

**Working alliance inventory (WAI) clinician version**

This tool has been previously described in detail, regarding the client version, in Figure 16 above. The questions asked to the care coordinators correspond to the equivalent questions posed to the participants.

**Focus groups**

Focus groups were completed with care coordinators who had been involved in the trial and who had gone through the process of making a joint crisis plan with their service user(s). These groups were held across all three sites after the completion of follow-up data being obtained. The purpose of these focus groups was to gain more knowledge and a greater understanding of the joint crisis planning process from the perspective of front line clinicians. It was possible to get a better picture of organisational issues, current mechanisms in place and factors that may support, or prove to be an obstacle to joint crisis plans being devised and implemented appropriately.
Once all of the follow-up data was obtained from participants, the researchers completed a form to report of any blinding issues. They were asked to state whether they had remained blind to the participant’s allocated arm of the trial. If they had not remained blind then they were asked to provide brief explanations as to how they had become un-blinded.

Randomisation of participants

As stated earlier in this chapter the CRIMSON trial selected randomisation of participants at an individual level with the design. This was decided upon because the trialists wanted direct comparability between CRIMSON and the pilot study; changes to the study design may have affected the effect of the intervention and it would be difficult to confidently determine if findings were affected by changes to the study design or other factors (for example site effects, closer approximation to routine care). The benefits of randomising at an individual level are that participant characteristics can be closely matched across trial arms, actively reducing confounding participant variables.

At this stage it is beneficial to document that another design option would have been to randomise at a cluster level. Cluster trials are becoming increasingly common in health services research when testing effects of interventions designed to change service user or clinician behaviour. This randomisation strategy is recommended if there are concerns regarding contamination of the intervention; in this case it may be argued that care coordinators who are involved in planning the joint crisis plan with a service user in the intervention group may use the same techniques (either consciously or not) with a service user in the control group. Whilst cluster trials are becoming increasingly popular, the true efficiency in their reduction of contamination is questionable. Cluster trials are also considered to be more difficult to manage and are thus costlier to run, requiring a larger sample size than necessary within individual level randomisation. Furthermore they have been criticised for their association with problems of recruitment bias.

Following the data collection at baseline, the data was entered into the study database and each participant was randomly allocated to either the intervention group or the control group (treatment as usual). Allocation was done by randomised permuted
blocks of randomly varying block size, with equal allocation to the two arms, stratified by centre. Randomisation was completed off site to avoid biases and was managed by an independent system that provided random allocation to all sites when provided with subject identification numbers. This ensured the concealment of allocation of service user status in the two arms of the trial. Confirmation of eligibility and consent, and minimal baseline data was obtained prior to randomisation.

**Blinding and concealment of allocation**

As a research worker who collected outcome data at both stages of data collection, it was important that the author remained blinded to the allocation of participants. Various strategies were used to ensure this. Firstly, standardised assessment tools were used to eliminate bias. Office space was sought away from the intervention facilitator’s base and discussions about individual participants were avoided between the author and the facilitator. Letters that were regularly sent to participants and to clinicians always contained a reminder that researchers were unaware of the allocation of participants in the trial. At the beginning of any telephone or face to face contact that the author had with participants, they would clearly explain that they did not know whether they had made a joint crisis plan or not. The trial administrator’s telephone contacts were given to care coordinators and participants so that if they had any queries they could contact this person first and if appropriate, messages could be passed on, without the author becoming un-blinded.

**Training and supervision process**

The author’s professional background is within the discipline of Psychology, having worked within the prison service in this area for over five years. They therefore came into the research trial equipped with a wealth of clinical experience in working with vulnerable adults and engaging clients, in addition to strong research skills from consultancy work within the prison service. Prior to the commencement of the recruitment period, the author attended a two day initial training programme at the Institute of Psychiatry in London. This training provided more information about the trial and the main procedures that should be followed. As researchers were working in different geographical areas of England, standardisation of the process across trial sites was imperative. The training allowed opportunities for researchers to complete inter-rater reliability exercises for the Global Assessment of Functioning (GAF).
assessment tool. The author completed formal external training around the area of randomised control trials prior to commencing recruitment of participants.

Throughout the duration of the trial the author received regular supervision from the scientific coordinator, both in person through on-site visits and by telephone or virtual access grid meetings. The scientific coordinator assisted with recruitment issues, data collection issues and checking the data that had been inputted for any discrepancies, as well as verifying the rationale and score given for the global assessment of functioning. Supervision was provided at a local level by the Principal Investigator who assisted with recruitment queries and any issues with the involvement of clinical teams within the trial.

The facilitators across each of the three recruitment sites were all community psychiatric nurses who were seconded from their employment within their clinical teams to work on the trial. The facilitators attended specific training on the research process and the development of joint crisis plans, which was delivered by the scientific coordinator and the facilitator clinical supervisor. Facilitators were required to role-play the joint crisis plan development process and write up the documentation to a specified standard with an assessment of their competence being made. Facilitators then had weekly access grid meetings with their clinical supervisor and the scientific coordinator at which they discussed their progress and any commonalities in problems across the recruitment sites. Every joint crisis plan document was supervised by the clinical lead and feedback was provided to ensure they were all completed to the same high standard.
The joint crisis plan intervention

For those allocated to the control group, the care and treatment provided followed the Care Programme Approach (as previously described in Box 2). Those participants allocated to the intervention group were invited to receive a joint crisis plan in addition to the Care Programme Approach. The process of making a joint crisis plan is presented in Box 4 to the right, which documents the different planning meetings required and who was involved at each stage. The content of the joint crisis plan document is shown in Box 5 below. Once the document had been drawn up and the collaborative meeting had concluded, the joint crisis plan was typed up by the facilitator and sent to the participant for a final check regarding its contents. Once approved, the joint crisis plan was held by the participant and anyone they nominated to carry a copy, for example a family member, friend, their care team or GP. The author worked together with Lancashire Care Foundation Trust’s IT services to ensure that an application could be made on the patient electronic record system so the joint crisis plan documents could be uploaded to the relevant records. This had a significant impact as it meant that the joint crisis plan could be accessed by all relevant clinicians. In addition, from a research perspective, an audit could be completed at the end of the trial to assess on how many occasions the documents were accessed, at what times and by whom.

The author had no direct input into the process of conducting the intervention as

**Box 4: Joint crisis plan process**

In the intervention group, facilitators arranged an initial meeting with the service user and their care coordinator. This initial meeting was to introduce the joint crisis plan to the service user and to show them the menu (Appendix 8) from which they would be choosing the topics to be included in their plan. This meeting also gave the service user time to familiarise themselves with the type of discussion that would occur in the second meeting. The facilitator in each site was a trained psychiatric nurse who had experience of working within Community Mental Health community services. They were therefore well placed to take a lead in the intervention with the participant and could develop good professional rapport with clinical teams and Consultant Psychiatrists.

The second meeting was held with the facilitator, the participant, their nominee, the care coordinator and psychiatrist. Participants’ nominees were often a family member or a close friend. In some instances it was a religious leader or another professional from the community. In this meeting the facilitator directed the discussion of items on the menu impartially and decisions were noted down onto the joint crisis plan document. The discussion took a collaborative approach and whilst the facilitator led discussions, the content of the plan was ultimately service user driven.

**Box 5: Content of the joint crisis plan**

*Participants’ contact details
*Contact details of GP and care coordinator where participant wanted this information documenting.
*Details of who was involved in developing the joint crisis plan
*Current care and treatment plan
*Care in a crisis
they remained blinded to the allocation of each participant. Where participants’ consent was given, the multi-disciplinary meetings were recorded using a dictaphone and the coordinating centre in London scrutinised the implementation of the intervention across sites. This was done to ensure the fidelity and comparability of the intervention was preserved, using a rating scale for this purpose along with analysis of taped interviews.

**Maintaining contact with participants throughout the trial**

It was important to ensure that contact was maintained with all participants throughout the trial. This was arguably even more important for those participants who were allocated to the control arm of the study. These participants would have contact with researchers at the initial stages of the trial and then they would not be visited again for 18 months. As it was important that participants remembered the trial and felt a valuable part of it, the author ensured that they were kept informed of the progress at various stages within the 18 month period. The author devised newsletters and distributed these to service users’ home addresses to tell them about the recruitment and include any informal feedback that had been given on the trial to date. Participants were sent a form which asked them to inform the research team (through the administrator, so as not to become un-blinded) of any change of circumstances, including name, address, phone number and email address.

On receiving informed consent from participants the author completed a contact details sheet (Appendix 9) with them. All contact details across as many mediums as possible were obtained and details of a person that could be contacted in the event that the service user could not be reached were also collected. This information was stored on an electronic contacts database and was regularly updated. Each contact that was made with a participant, or with a care coordinator in relation to a participant, was recorded on this contacts database and so an accurate record was upheld. The contacts database was updated at the change of any details and this enabled the research team to send out birthday cards and festive cards to participants to keep in contact with them.

**Summary of how CRIMSON has addressed the limitations of previous research**

Chapter 3 highlighted a review of previous literature around interventions designed to reduce hospital admissions through helping service users plan their future treatment. This chapter concluded that there were several limitations to this work, with an
outstanding need to complete further work in this area. This methodology chapter has addressed the limitations previously cited and, in summary, the following actions have been taken to address previous shortcomings:

- Researchers are blind to allocation of participants into intervention group
- Interpreters are used to aid the recruitment process and intervention
- Participants are recruited from CMHTs, EIS and AOTs
- The geographical spread of sites allows findings to be better generalised across the UK.
- The trial is powered to detect the effects of intervention

In addition to the above, there is one other way that the limitations in existing literature have been addressed that is key to the methodology of this thesis (to be explored further within Chapter 6). The research materials were translated into Urdu and Gujarati. No other translations were made throughout the study despite this being given consideration from the trialists from the outset, as the key subgroup of interest was black (black African and black Caribbean) service users. The trial had a budget for translations into any languages for eligible participants, which was decided on a needs basis and throughout the recruitment stage, this was only necessary for south Asian participants. The vast majority of the black participants were recruited from London and did not require translated materials, due to sufficient English language skills. More information on the translation process is offered within Chapter 6.

**Power calculation**

The power calculation was completed prior to the authors’ involvement in the CRIMSON trial, hence the information in this section is collected from discussions with the trial statistician, the published protocol and CRIMSON clinical outcomes findings. The pilot study for the CRIMSON trial, along with Mental Health Act figures, implied that in total over an 18 month period, 30% of service users would be admitted to hospital under a Mental Health Act section. The sample size of 540 was calculated, with 270 participants in each trial arm. These numbers would have the ability for a reduction by half in the primary outcome (the overall proportion of participants involuntarily admitted to hospital) to be detected with 90% power (from 30% to 15%). This is true after allowing for 15% loss to follow up and using a 0.05 level of significance.

As stated earlier within this chapter, pre-defined sub analyses will examine the effectiveness of the intervention of black (black Caribbean and black African) service
users. Hence the CRIMSON trialists calculated that based on the proportions of black service users at the three recruitment sites, it is likely that from a sample of 270 per arm, 91 people would be from a black ethnic group (black African/black Caribbean)²⁸. This sample size would also allow detection of a proportionate reduction for this pre-specified subgroup of black patients, with 80% power (from 40% to 20%, alpha=0.05).

**Analysis Plan for CRIMSON**

The author had no involvement in the analysis plan for CRIMSON. Details are provided from the published protocol of the trial²⁸.

- The principal analysis of effectiveness will compare the primary and secondary outcome measures at 18 months, combined over centres. The proportions admitted to hospital under a section at follow-up will be compared between randomisation groups using logistic regression controlling for centre.

- Other (continuous) outcomes such as therapeutic alliance and engagement with mental health services will be analysed using analysis of covariance controlling for baseline (pre-intervention) measures and centre.

- Number of admissions will be analysed using Poisson regression.

- Time to first admission will be analysed using survival analysis.

- Bed-days and other very skewed data will be analysed using bootstrapping to obtain confidence intervals and p-values.

- Short scales will be analysed using ordered logistic regression.

- An intention-to-treat analysis will be applied in the first instance (i.e. analysing all available data from service users as randomised).

- Time trends in measures available at baseline and two time points will be analysed using methods for longitudinal data such as random effects regression.

- Sensitivity analyses will be performed to assess the influence of loss to follow-up and refusals, including imputation of missing baseline values from the within-centre means; multiple imputation of follow-up values (where feasible from other variables).

- Health economic analysis will also be completed.
Chapter 6: Methodology for this thesis within CRIMSON

Overview

Chapter 5 documented the methodology of the CRIMSON trial and this thesis takes the opportunity presented by the trial to meet the current objectives. As documented in Chapters 1 and 3, it is particularly important that the intervention (joint crisis plan) is effective with ethnic minority groups, as they have such high admission rates. This thesis therefore focuses on ethnic minority groups involved in the trial; from their recruitment into the trial, the joint crisis plan documents produced and their effectiveness in reducing hospital admissions and improving working alliance with their clinicians. This chapter describes how the thesis is situated within CRIMSON and how the methodology is distinct from that of the main trial.

Rationale for this thesis

The rationale for this thesis has been presented over the first three chapters; in summary, ethnic minority groups have higher rates of mental illness than white British people in the UK and psychosis is a particular problem for these groups. This results in higher rates of hospital admissions for ethnic minorities, particularly under the Mental Health Act. Whilst many explanations are offered for such disparities in admission rates, the common theme emerging is that of engagement, with ethnic minorities reporting less satisfaction with services. Whilst ethnic minorities are over-represented in terms of hospital admissions they are under-represented in their participation in psychiatric research, with numerous barriers being reported which may contribute to this pattern. The systematic review of barriers to participation in research from ethnic minorities is presented in Chapter 2, providing a compilation of those barriers that can be overcome.

Beyond the evidence presented thus far within the thesis, there has been success in ethnic-specific strategies to increase ethnic minority involvement in research and engagement with services away from mental health settings; these strategies can provide broader lessons for mental health research and can therefore add to this thesis. For example, a number of studies have looked at effective recruitment of south Asian participants into health research. Experiences of frontline staff were explored during the recruitment of south Asians into a cancer trial. The involvement of male senior doctors...
was deemed valuable by south Asian service users and helped successful recruitment of these ethnic minority participants. In a trial concerned with the prevention of diabetes and obesity in south Asians, authors showed that a personal approach to recruitment was helpful within the trial setting, which enhanced participant engagement. Within a cardiac rehabilitation trial, authors placed emphasis on the importance of enhancing eligibility of south Asian minority groups through the use of interpreted research materials. The findings of this research can be useful in community based trials involving south Asians so, despite not being in a mental health setting, such learning can be transferred into the current studies.

CRIMSON provides an ideal opportunity to apply the learning from the literature reviews presented within this thesis so far as this randomised trial into the effectiveness of joint crisis plans aims to reduce compulsory hospital admissions. It is particularly important that ethnic minorities are recruited into this trial, as these groups are more likely to be admitted and have shown to be more likely to disengage with services. Literature from outside of mental health settings can be used to transfer the learning into this current research.

**Defining ethnicity**

Chapter 1 presented a discussion around the key terms of culture, race and ethnicity, exploring commonalities within definitions and the usefulness of such terms. With any categorisation system of ethnicity that is adopted, some flaws and inaccuracies will be noted. Common arguments, as previously discussed, relate to the limitations of grouping more discrete subgroups; which may result in any key differences between these being counteracted and becoming null. The term ethnic minority will continue to be used throughout this thesis to refer to anyone that is not white British. It is important to consider the specific ethnic minorities that will be included within the methodology and results of this thesis, with explanations given about the rationale behind these inclusions. It is important that terminology reflects the hypothesis that is being tested and that within their research authors describe the logic behind their ethnic groupings. This thesis therefore places value on the recommendations made by Clarke et al. for future researchers to ensure clarity throughout their research decisions involving ethnic minorities. Such guidelines ensure that researchers provide a rationale as to why ethnicity is important to their outcome, provide a clear definition of ethnicity, relating it to the research questions and provide clarity in decisions made regarding ethnic categories utilised within their studies.
The recommendations from Clarke et al\textsuperscript{301} have been adhered to throughout this thesis; a clear definition of ethnicity was provided and explored within chapter one, which also presented exploration around the fluidity of the concept and various factors which interplay within this broader term. Chapter 1 also investigated why ethnicity is important to the outcome of the trial (psychiatric hospital admissions) and related it to the research question of the CRIMSON trial. At this stage in the thesis it is imperative to build on earlier discussions and ensure transparency in the reasons that specific minorities were chosen for inclusion in the current studies, considering the categorisation system used.

Throughout the methodology and results presented within this thesis, the author has followed guidance from the Official for National Statistics in defining ethnic groups\textsuperscript{57}. The strengths and limitations of this categorisation system have previously been presented within Chapter 1, and whilst there is recognition of the limitations to this, the advantages of this standard classification system allow for comparability of findings across time and across health care interventions. ONS also has Government backing and is used for recording hospital admission data and service user information across services. In addition, national ethnicity minority data (EMPIRIC)\textsuperscript{4} was carried out using the ONS classification system.

**Ethnic minorities in this thesis**

The thesis will focus on south Asian and black service users. Figure 20 below illustrates the countries that make up south Asia and Figure 21 shows a map of the world with Africa and the Caribbean highlighted in the darker shaded areas.
Black service users are inclusive of the following ethnic groups:

- Black/Black British (Caribbean)
- Black/Black British (African)
- Black/Black British (Other)
The wider categories outlined above contain the groups that are widely reported across mental health literature which are African American and African Caribbean. These groups simply refer to American/Caribbean people of African descent. Whilst some literature refers to the recommendation that the word black be phased out of ethnic group descriptions\textsuperscript{302}, the guidelines from the Office for National Statistics have been followed throughout this thesis\textsuperscript{303}. In terms of the ethnic minority terms used within this thesis, it is important to note that such terms may be limited and potential inter-group differences cannot be accounted for\textsuperscript{14}. These categories are used as they are the most frequently used in research in this area.

Within the data collection, all participants were asked to document their ethnicity and they were given a list of categories from the ONS categorisation system. In addition to the set categories, there was a free text option box for those participants who wished to respond ‘other’ beyond the given options, following best practice recommendations\textsuperscript{53}. Participants were presented with the following categories which are relevant to this thesis: Asian/Asian British (Indian), Asian/Asian British (Pakistani), Asian/Asian British (Bangladeshi), Asian/Asian British (Other), Black/Black British (Caribbean), Black/Black British (African), Black/Black British (Other). These categories were then collapsed into the two broad categories of south Asian and Black ethnic groups.

**Summary of reasons for inclusion of south Asian and black service users only**

The main hypotheses of the CRIMSON trial are concerned with the effectiveness of joint crisis plans for all participants. Subgroup analysis will be completed on black (black African and black Caribbean) participants as this group specifically has been shown to have higher rates of compulsory hospital admissions.

This thesis will focus on south Asian and black participants and there are several justifications for this decision to include both broad groups, when CRIMSON only focuses on black participants.

1) Chapter 5 provided information regarding the ethnic breakdown of residents of the three recruitment sites; the majority of the populations of these areas, after white-British, are black and Asian. This is true of the breakdown of ethnicity across the UK, with the next largest ethnic minority group being Chinese, with a considerably lower representation.
2) The Manchester/East Lancashire area where the author worked on the trial has a high representation of south Asian participants, which provides the opportunity to explore the recruitment and engagement of this group.

3) The literature covered within this thesis has documented similar barriers and issues for both of these broad categories of ethnic groups in terms of admissions and engagement with services.

4) Giving consideration to the above evidence, it was decided that this thesis should include those participants with a self-reported ethnic group of black or south Asian together. It would seem there are more similarities and common issues with these two broad groups and hence more merit in combining them than treating them separately.

5) In summary there is no good reason a priori to think that south Asian and black minorities will respond differently to the intervention, therefore including south Asians gives increased power and may indeed reveal differences.

It would be remiss to exclude all other non-white ethnic groups from consideration in this thesis. By including south Asian and black participants only, hence excluding other ethnic minorities, the assertion is not that the joint crisis planning intervention will have no effect on these other groups, more that the effects are somewhat unknown, given the dearth of literature for smaller minority groups. Other ethnic minority groups will be included within additional sensitivity analysis, which will be described in greater detail later within this chapter.

Studies within this thesis

The methods used within this thesis are split into three studies and each will be described in turn, as each relates to an aim of this thesis as documented in Chapter 4.

1. The effectiveness of joint crisis plans

Aim

This study addresses the first aim of this thesis: By looking at the groups of participants who have been randomised to receive the intervention, the author aims to analyse whether the findings for south Asian and black participants together show a more
positive outcome in terms of: hospital admissions (compulsory and then any admission) and working alliance as reported by the service user.

*Research instruments used*

This thesis does not utilise all of the data collected from the CRIMSON trial as reported in Chapter 5. The socio-demographic data self-reported by the participants is crucial in this study regarding which participants from the CRIMSON trial are included in the data analysis. Hospital admissions data for both voluntary and compulsory admissions was collected from official trust records and verified with the participants at the time of baseline and follow-up assessment, to check for out-of-area admissions. Service users’ reported working alliance with their care coordinator was measured using the Working Alliance Inventory (Client Form)\textsuperscript{264}

*Statistical analysis*

The statistical analysis was conducted using PASW Statistics\textsuperscript{304}. The main analysis of effectiveness compared the primary and secondary outcomes at 18 months, combined across centres. No mid-trial analyses were completed and all analyses included adjustment for site. Baseline characteristics were analysed with a view to exploring which variables may be associated with missing data. Further adjustments were made, if necessary, within the analysis for those variables found to be significantly associated with such missing data. No further adjustments were made if no associated variables were found.

- Differences between compulsory hospital admissions and mixed hospital admissions (including both formal and informal admissions) have been calculated through chi-square analysis.
- The proportions admitted to hospital were compared between groups, separately for both compulsory admissions and mixed admissions (including both formal and informal admissions) using logistic regression.
- Service users’ perceptions of working alliance with their care coordinators were analysed through linear regression.
The results from this study will be presented in tables to 3 decimal places. For conciseness within the written text, these figures will be summarised to 2 decimal places.

Definitions for comparison of admission status by randomisation arm

Formal admission status during follow-up is calculated from the date of randomisation as follows:

Section status for each admission in coded:
* Informal if sections are recorded as 0 or section 17 (leave of absence from hospital)
* Formal if no sections during the time of admissions are 0
* Mixed, if there are both formal and informal sections during the admission.

Sum across all admissions since randomisation:
* 0 = All informal if all admissions are only informal as coded above
* 1 = Mixed or formal if there is at least one formal section
* 3 = No admissions

Comparison of proportion of participants with a formal admission in the follow-up period since randomisation versus no formal admission is therefore defined as mixed/formal versus informal admissions/no admissions (1 vs. 0 and 3 above). Comparison of proportion of participants with at least one admission (formal or informal section) in the follow-up period since randomisation versus no admissions is 0 and 1 vs. 3 above.

Sensitivity analysis

The above analysis was completed for those participants from south Asian and black ethnic groups (combined) as specified in the aims of this thesis. Following this analysis, sensitivity analysis is presented in the results chapter to include other ethnic minority groups that are not previously included. In terms of the literature, mixed race service users are somewhat unknown about in relation to the barriers they may face with engagement. In addition there are other ethnic minorities that are non-white which are very small in terms of their representation. Therefore the analysis is presented for black service users, and then the following groups were added to the analysis cumulatively: south Asians, other non-white minorities, mixed race and then white ethnic minorities.
The analysis was completed for white British participants as a separate group, in order that the treatment effect for this group could be compared to the treatment effect of the south Asian and black combined group. Separate analysis on the south Asian subgroup only and black group only was also conducted for each hypothesis.
2. The recruitment of ethnic minorities in Manchester/Lancashire

Aim

This study addresses the second aim of the thesis; by applying the techniques highlighted in the literature, the author aims to determine if it is possible to get south Asians involved in psychiatric trials.

Addressing barriers to recruitment of ethnic minorities into CRIMSON

Chapter 2 presented a compilation of barriers to ethnic minorities’ participation in psychiatric research. This study accounts for those barriers, documenting how each has been addressed in the methodology; this is summarised in Table 19 below.

Table 19: How barriers were addressed within the trial

<table>
<thead>
<tr>
<th>Barrier</th>
<th>How barrier has been addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant Related Barriers</strong></td>
<td></td>
</tr>
<tr>
<td>Explanatory models of illness</td>
<td>Researchers promoted the intervention in a way that was the most appropriate to each individual, dependent upon their circumstances.</td>
</tr>
<tr>
<td>Help-seeking/ negative attitude to psychotherapy</td>
<td>All eligible service users were invited to participate, regardless of their engagement with their healthcare services.</td>
</tr>
<tr>
<td>Language</td>
<td>Translated materials and interpreters were used</td>
</tr>
<tr>
<td>Religious beliefs</td>
<td>Timing of assessments was considered around religious festivals and worship time.</td>
</tr>
<tr>
<td>Trust</td>
<td>Several visits were arranged where necessary with a collaborative approach involving care coordinators and family members.</td>
</tr>
<tr>
<td>Stigma</td>
<td>Participants were already receiving treatment from community teams, researchers worked collaboratively with them. The location of assessment was important and anonymity was assured.</td>
</tr>
<tr>
<td>Gender</td>
<td>Male/female staff visited dependent upon which was more appropriate.</td>
</tr>
<tr>
<td>* Psychopathology/Substance misuse</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Fear of being reported to immigration</td>
<td>Confidentiality and anonymity were offered within limits previously documented. Participants were already registered with the community teams.</td>
</tr>
<tr>
<td><strong>Practical Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Lack of childcare</td>
<td>Assessments completed at their homes</td>
</tr>
<tr>
<td>Transport provision</td>
<td>Assessments completed at their homes</td>
</tr>
<tr>
<td>Financial constraints</td>
<td>No cost for participant, incentive offered</td>
</tr>
<tr>
<td>Culturally inappropriate incentive</td>
<td>Monetary incentive offered</td>
</tr>
<tr>
<td>* Medical insurance</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Lack of time</td>
<td>Assessments and intervention were not time consuming</td>
</tr>
<tr>
<td>Location of interview</td>
<td>Assessments completed at their homes</td>
</tr>
<tr>
<td>Employment status</td>
<td>Assessments completed at flexible time, weekend and evenings where requested</td>
</tr>
<tr>
<td><strong>Family/Community Related Barriers</strong></td>
<td></td>
</tr>
<tr>
<td>Husbands’ influence</td>
<td>Husband was contacted to discuss research prior to visiting</td>
</tr>
<tr>
<td>Family perspectives</td>
<td>Families were included throughout the recruitment period</td>
</tr>
<tr>
<td>Stigma for family</td>
<td>Assessments completed at their homes</td>
</tr>
<tr>
<td><strong>Health Service Related</strong></td>
<td></td>
</tr>
<tr>
<td>* Underutilisation of mental health services</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Language of professional/intervention</td>
<td>Interpreters were used in assessments and intervention</td>
</tr>
<tr>
<td>Lack of communication and cultural awareness between staff and participants</td>
<td>Interpreters assisted with communication. The principal investigator (consultant psychiatrist) contacted some participants in their own language</td>
</tr>
<tr>
<td>Staff personal attributes</td>
<td>Researchers completed training around the assessment process and engaging service users</td>
</tr>
<tr>
<td><strong>Research Process</strong></td>
<td></td>
</tr>
<tr>
<td>Limited willingness and enthusiasm of researchers</td>
<td>Researchers were willing and enthusiastic about recruiting participants from ethnic minorities</td>
</tr>
<tr>
<td>Understanding the need for ethnic participation</td>
<td>Researchers completed training on the rationale of the trial including disproportionate admissions for ethnic minorities and the aim of completing sub analyses on black participants.</td>
</tr>
<tr>
<td>Paucity of resources available</td>
<td>Financial resources were allocated to training, interpreters and translators at the planning stage of the trial.</td>
</tr>
<tr>
<td>Appropriateness of assessment tools</td>
<td>Assessment tools were translated using back to back translation.</td>
</tr>
<tr>
<td>Non-availability of translated materials</td>
<td>Translated materials were available</td>
</tr>
<tr>
<td>Lack of culturally competent staff</td>
<td>Research staff were culturally competent</td>
</tr>
<tr>
<td>Lack of culturally matched staff</td>
<td>Research staff were not culturally matched, as literature indicates cultural competence is more effective.</td>
</tr>
<tr>
<td>Under-representation of ethnic minorities at recruitment sites</td>
<td>This was addressed by selection of recruitment sites as documented in Chapter 5</td>
</tr>
<tr>
<td>Understanding of consent process</td>
<td>Researchers completed training in this area</td>
</tr>
</tbody>
</table>

The following information aims to complement the descriptions provided above in Table 19 and expand on the detail provided in the CRIMSON methodology presented in Chapter 5. As discussed in Chapter 2, these barriers are not exclusive to ethnic minority groups although the way in which they manifest themselves may be different and therefore all are barriers presented are given consideration. This study focuses on south Asians as they are the most represented ethnic minority group in the Manchester/Lancashire site, where the author was involved in recruitment.
One participant related barrier was addressed in this trial by the use of translated trial materials and interpreters (Urdu and Gujarati). An external company was employed to assist with the translation process and the method used was ‘back to back’ or ‘back-translation’\(^\text{305}\). Through this method, the English text was translated into Urdu and Gujarati then the Urdu/Gujarati was translated back into English. An expert then looked at the quality of the translations and the documents were finalised. Letters that were sent to participants were tailored to their individual circumstances and the information that had been obtained through their care team. These letters were drafted by the principal investigator of the trial on a case by case basis. Interpreters with experience of mental health work were involved throughout the research process. They contacted service users and their family members by phone and attended all face to face contact meetings with the research team to ensure they could interpret all of the questions and discussions. Urdu and Gujarati translations were made as they are the most widely spoken languages after English throughout the recruitment sites.

Practical barriers to the recruitment of ethnic minorities include the location and timing of the assessment. Interviews with participants were completed at their homes where possible to ensure that they were not inconvenienced by having to travel to a site. This meant that service users did not incur additional time or cost expenses and that child care was not a barrier. On occasion, service users requested meeting at the clinic site as they felt more comfortable meeting in a familiar place without the intrusion of having a stranger in their home. This may also have had a secondary purpose of reducing stigma for them. Assessments at clinic sites were also adopted for those service users who had highlighted risk issues with home visits, as clinic sites were the most practical and safe interview location. Each of the three recruitment sites had a local protocol which covered safety checking for researchers conducting home visits. Participants in the trial were offered £20 as an incentive, as compensation for their time and efforts. The barrier to recruitment highlighted previously requires that the incentive should be culturally appropriate and not in danger of causing offence. The way in which the incentive was explained and offered was important and if any discomfort with accepting the financial payment was evident then alternative options were offered. For example, the money could be donated to a charity of their choosing.

The communication between the services and participants was a health service related barrier. Within the trial this was addressed in numerous ways. Male senior research staff and consultant psychiatrists aided communication when it was proving difficult. Male representation from the trial was important when speaking with some participants’
husband or father and the presence of a doctor added value to the trial promotion. The interpreters used had clinical and research expertise and could so assist with the discussions beyond their role as a direct interpreter.

The research process endeavoured to overcome barriers through providing training to research staff and allocating resources from the outset so that barriers could be overcome. These resources include time, as additional efforts meant additional time allocated to the recruitment period, as well as the financial resources allocated to translators and interpreters.

Recruitment diaries of researchers

The strategies highlighted above were implemented within the trial and, to illustrate how they were applied, researchers working in the Manchester/Lancashire recruitment site kept recruitment diaries of their experiences. Greater Manchester and East Lancashire have significant south Asian populations, mainly from India and Pakistan (Greater Manchester 3.8%, Burnley 7.15%, Blackburn 20.6%)\(^{306}\). Challenges and culturally sensitive strategies used to recruit south Asian participants are explored by the researchers in these diaries and in addition, contact made with those people who refused to participate is documented, along with the reasons for refusal.

Based on previous experience in community based data collection alongside the systematic review of barriers to recruitment in Chapter 2, some barriers to recruitment of south Asians were anticipated. Researchers decided to keep diaries detailing accounts of the recruitment process for all south Asians approached (excluding those with very fluent English, e.g. as first/only language). The diaries were maintained by field researchers (the author and one part time researcher) and interpreters (One Urdu and one Gujarati interpreter). In addition the principal investigator was able to offer support to the field researchers and converse with participants, both over the telephone and in person, to assist the recruitment process. This study was completed with an aim to use findings for furthering knowledge in this area and assisting future researchers.

Analysis

The methodology employed to address the barriers have been described and the effectiveness of such strategies will be tested in two different ways. Firstly the success
is measured numerically by reporting on how many south Asian service users were recruited into CRIMSON.

The second analysis relates to the diary entries that have been generated by research staff. The purpose of the diary entries was to provide qualitative data for subsequent thematic analysis. In the analysis of the diaries, a thematic analysis method was used to analyse the transcribed data following a systematic, iterative process whereby codes were applied to the transcripts, and further refined and organised into categories that represent the main themes arising from the data. Initially themes contained in the diaries were identified, grouped and refined for analysis, in order to identify the ‘story’ behind each theme and how it fits into the broader ‘overall’ story – i.e., how researchers overcame the barriers to recruitment of south Asians into the CRIMSON trial. Subsequently new codes were added where the initial categorisation proved inadequate to reflect participants’ experiences. Findings were discussed periodically within the research team to refine, challenge and clarify the emerging conceptual understanding of the participants’ recruitment experiences.
3. **Joint crisis plans culturally relevant statement analysis**

**Aim**

This study addresses the third aim of this thesis: through analysis of the joint crisis plan documents completed by the service users and their clinical teams, the author aims to determine whether the intervention brings out culturally relevant statements for service users from south Asian and black ethnic groups.

**Joint crisis plan analysis**

The joint crisis planning documents were produced as described in Chapter 5. The word documents from those service users from south Asian and black groups were uploaded into NVivo version 8. The author set pre-defined criteria as to which content on the joint crisis plans warranted inclusion as a culturally relevant statement. The criteria were defined following work presented in this thesis from the literature reviews. The themes which were pre-selected a priori to the analysis were those arising from the systematic review and were: language, religion, reference to another country and family involvement. The author added an additional theme to this list which did not arise from the systematic review, which was that of diet. This theme was selected based on the author’s experiences during the duration of the trial of recruiting participants and listening to their experiences of past crises and treatment. Diet was also listed as an important element of culture as documented within Chapter 1 of this thesis, with food contributing to tradition and social group behaviours. The set criteria for inclusion were not concrete and so themes were allowed to evolve during analysis of the plans which would allow for new considerations which had not been pre-empted.

Within the NVivo programme, each section of the joint crisis plan document was entered as a tree node and themes were given under each section which were those expected to be the most relevant. A sample of 10 joint crisis plans were piloted using the coding frame and the child nodes were adjusted accordingly as new themes emerged. Following the thematic analysis of the plans each section was revisited and those transcripts which were deemed by the author to include culturally relevant statements were selected.
Chapter 7: Results

Overview

This chapter begins with a summary of the findings from the CRIMSON trial. In the main these findings are negative, including the findings of the pre-specified subgroup analysis of black service users. The findings of each of the sub-studies conducted by the author of this thesis then follow. These are:

(1) Additional sub-analysis looking at the effectiveness of joint crisis plans for south Asian and black participants with regards to hospital admissions and their working alliance with their clinician. Sensitivity analysis follows the main findings to include all other ethnic minorities recruited to the CRIMSON trial.

(2) A thematic analysis of the diary entries from researchers, documenting the recruitment of participants from ethnic minorities in the Manchester/Lancashire recruitment site. Challenges that were faced during recruitment are documented with consideration given to attempts to overcome them.

(3) Content analysis of joint crisis plans completed by south Asian and black participants, focusing on culturally relevant statements made by the service users. This analysis is completed for south Asian and black participants and differences between the type and number of culturally relevant statements made is reported. A culturally relevant statement is defined as any statement made within the joint crisis plan which the author deems relevant to the culture of that individual when reviewed against pre-defined criteria (as described within Chapter 6).
Findings of the CRIMSON trial

Table 20 below, shows the baseline demographics by randomisation arm for all participants recruited to the CRIMSON trial.

Table 20: Baseline demographics by randomisation arm for the CRIMSON trial

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category Value</th>
<th>Total N=569, n (%)</th>
<th>Control N=284, n (%)</th>
<th>JCP N=285, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site</td>
<td>Birmingham</td>
<td>192 (34%)</td>
<td>96 (34%)</td>
<td>96 (34%)</td>
</tr>
<tr>
<td></td>
<td>London</td>
<td>192 (34%)</td>
<td>96 (34%)</td>
<td>96 (34%)</td>
</tr>
<tr>
<td></td>
<td>Manchester/Lancashire</td>
<td>185 (33%)</td>
<td>92 (33%)</td>
<td>93 (33%)</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>285 (50%)</td>
<td>146 (51%)</td>
<td>139 (49%)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>284 (50%)</td>
<td>138 (49%)</td>
<td>146 (51%)</td>
</tr>
<tr>
<td>Age</td>
<td>mean (sd)</td>
<td>39.8 (11.9)</td>
<td>39.6 (12.1)</td>
<td>40.0 (11.8)</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married / cohabiting</td>
<td>113 (20%)</td>
<td>62 (22%)</td>
<td>51 (18%)</td>
</tr>
<tr>
<td></td>
<td>Widowed/separated/divorced</td>
<td>107 (19%)</td>
<td>46 (16%)</td>
<td>61 (21%)</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>346 (61%)</td>
<td>176 (62%)</td>
<td>170 (60%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>3 (1%)</td>
<td>0</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Living status</td>
<td>Alone</td>
<td>251 (44%)</td>
<td>122 (43%)</td>
<td>129 (45%)</td>
</tr>
<tr>
<td></td>
<td>Not alone</td>
<td>318 (56%)</td>
<td>162 (57%)</td>
<td>156 (55%)</td>
</tr>
<tr>
<td>Nationality</td>
<td>English</td>
<td>206 (36%)</td>
<td>104 (37%)</td>
<td>102 (36%)</td>
</tr>
<tr>
<td></td>
<td>Scottish</td>
<td>4 (1%)</td>
<td>2 (1%)</td>
<td>2 (1%)</td>
</tr>
<tr>
<td></td>
<td>Welsh</td>
<td>2 (0%)</td>
<td>1 (0%)</td>
<td>1 (0%)</td>
</tr>
<tr>
<td></td>
<td>Irish</td>
<td>16 (3%)</td>
<td>7 (2%)</td>
<td>9 (3%)</td>
</tr>
<tr>
<td></td>
<td>British</td>
<td>256 (45%)</td>
<td>129 (45%)</td>
<td>127 (45%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>84 (15%)</td>
<td>40 (14%)</td>
<td>44 (15%)</td>
</tr>
<tr>
<td></td>
<td>Participant unwilling to answer</td>
<td>1 (0%)</td>
<td>1 (0%)</td>
<td>0</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Asian / Asian British (Indian)</td>
<td>20 (4%)</td>
<td>7 (3%)</td>
<td>13 (5%)</td>
</tr>
<tr>
<td></td>
<td>Asian / Asian British (Pakistani)</td>
<td>29 (5%)</td>
<td>14 (5%)</td>
<td>15 (5%)</td>
</tr>
<tr>
<td></td>
<td>Asian / Asian British (Bangladeshi)</td>
<td>3 (1%)</td>
<td>1 (0%)</td>
<td>2 (1%)</td>
</tr>
<tr>
<td></td>
<td>Asian / Asian British (Other)</td>
<td>4 (1%)</td>
<td>1 (0%)</td>
<td>3 (1%)</td>
</tr>
<tr>
<td></td>
<td>Black / Black British (Caribbean)</td>
<td>73 (13%)</td>
<td>40 (14%)</td>
<td>33 (12%)</td>
</tr>
<tr>
<td></td>
<td>Black / Black British (African)</td>
<td>39 (7%)</td>
<td>21 (7%)</td>
<td>18 (6%)</td>
</tr>
<tr>
<td></td>
<td>Black / Black British (Other)</td>
<td>14 (3%)</td>
<td>4 (1%)</td>
<td>10 (4%)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>N=561</td>
<td>Mean (sd)</td>
<td>158 (56%)</td>
<td>318 (56%)</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>-------</td>
<td>-------------</td>
<td>-----------</td>
<td>-----------</td>
</tr>
<tr>
<td>Mixed (White and Black Caribbean)</td>
<td>15</td>
<td>15.91(6.4)</td>
<td>15.72 (6.3)</td>
<td>16.15 (6.6)</td>
</tr>
<tr>
<td>Mixed (White and Black African)</td>
<td>7</td>
<td>15.91(6.4)</td>
<td>15.72 (6.3)</td>
<td>16.15 (6.6)</td>
</tr>
<tr>
<td>Mixed (Other)</td>
<td>5</td>
<td>15.91(6.4)</td>
<td>15.72 (6.3)</td>
<td>16.15 (6.6)</td>
</tr>
<tr>
<td>White (British)</td>
<td>182</td>
<td>15.91(6.4)</td>
<td>15.72 (6.3)</td>
<td>16.15 (6.6)</td>
</tr>
<tr>
<td>White (Irish)</td>
<td>3</td>
<td>15.91(6.4)</td>
<td>15.72 (6.3)</td>
<td>16.15 (6.6)</td>
</tr>
<tr>
<td>White (Other)</td>
<td>5</td>
<td>15.91(6.4)</td>
<td>15.72 (6.3)</td>
<td>16.15 (6.6)</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>15.91(6.4)</td>
<td>15.72 (6.3)</td>
<td>16.15 (6.6)</td>
</tr>
<tr>
<td>Participant unwilling to answer</td>
<td>1</td>
<td>15.91(6.4)</td>
<td>15.72 (6.3)</td>
<td>16.15 (6.6)</td>
</tr>
</tbody>
</table>

**Primary outcomes analysis**

The primary outcomes in the CRIMSON trial were hospital admissions. The primary hypothesis tested was whether joint crisis plans significantly reduced the proportion of service users detained or treated under a section of the Mental Health Act during the 18 month follow-up period, compared with the control group. This hypothesis was also
tested for any hospital admission; meaning that the participants may have experienced a compulsory or voluntary hospital admission within the follow-up period.

569 participants were recruited to the trial and randomised to receive a joint crisis plan (n=285) or not (n=284). Baseline characteristics indicated that therapeutic alliance, as rated by the self-rated working alliance inventory (WAIC), was associated with missing admissions data. Adjustments were therefore made within the analysis based on baseline data, these adjustments were not made through probability weighting. The unadjusted proportions of participants admitted to hospital are shown in Table 21 and the adjusted figures (with adjustments made for WAIC, which was associated with missing data as determined through baseline data) are shown in Table 22.

Table 21: Proportions admitted by trial arm

<table>
<thead>
<tr>
<th></th>
<th>Control</th>
<th>JCP</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No formal admissions</td>
<td>224 (80%)</td>
<td>218 (82%)</td>
<td>442 (81%)</td>
</tr>
<tr>
<td>At least one period of formal admission</td>
<td>56 (20%)</td>
<td>49 (18%)</td>
<td>105 (19%)</td>
</tr>
<tr>
<td>No admissions</td>
<td>199 (71%)</td>
<td>190 (71%)</td>
<td>389 (71%)</td>
</tr>
<tr>
<td>At least one admission (formal or informal)</td>
<td>81 (29%)</td>
<td>77 (29%)</td>
<td>158 (29%)</td>
</tr>
<tr>
<td>Total</td>
<td>280</td>
<td>267</td>
<td>547</td>
</tr>
</tbody>
</table>

Table 22 below shows no significant differences in formal admissions between the control group and intervention group. There was also no significant difference when any admission was taken into account (this included both formal and informal admissions) or when figures were adjusted for site and ethnic group, as well as site, ethnic group and WAIC scores.
Table 22: Logistic regression, joint crisis plan vs. control group

<table>
<thead>
<tr>
<th>Outcome</th>
<th>N</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one formal admission</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusted for site and ethnic group</td>
<td>546</td>
<td>0.89</td>
<td>0.57 - 1.37</td>
<td>0.583</td>
</tr>
<tr>
<td>Adjusted for site, ethnic group, WAIC</td>
<td>543</td>
<td>0.87</td>
<td>0.56 - 1.34</td>
<td>0.520</td>
</tr>
<tr>
<td>Any admission formal or informal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusted for site and ethnic group</td>
<td>546</td>
<td>1.00</td>
<td>0.69 - 1.45</td>
<td>0.988</td>
</tr>
<tr>
<td>Adjusted for site, ethnic group, WAIC</td>
<td>543</td>
<td>1.00</td>
<td>0.69 - 1.46</td>
<td>0.996</td>
</tr>
</tbody>
</table>

Table 23 below shows the unadjusted figures for the number of days admitted to hospital for the control and intervention group; no significant differences are reported. Adjusted figures are shown below in Table 24, including the confidence intervals. Adjustments have been made for site and ethnic group, in addition to site, ethnic group and WAIC scores. Once again, the findings are not significant.

Table 23: Summary of number of days admitted (including formal and informal sections) by trial arm

<table>
<thead>
<tr>
<th></th>
<th>Control (n=280)</th>
<th>JCP (n=267)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of days admitted: mean (sd)</td>
<td>26 (76)</td>
<td>29 (76)</td>
<td>0.640</td>
</tr>
<tr>
<td>Number of days admitted: median (range)</td>
<td>0 (0-600)</td>
<td>0 (0-507)</td>
<td>0.922</td>
</tr>
</tbody>
</table>

Table 24: Linear regression of number of days admitted, robust standard errors, joint crisis plan vs. control group

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Coefficient</th>
<th>95% Confidence Interval (Robust)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of days admitted</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusted for site and ethnic group</td>
<td>546</td>
<td>3.19</td>
<td>-9.44 - 15.82</td>
<td>0.620</td>
</tr>
<tr>
<td>Adjusted for site, ethnic group, WAIC</td>
<td>543</td>
<td>3.04</td>
<td>-9.56 - 15.65</td>
<td>0.636</td>
</tr>
</tbody>
</table>

Table 25 below reports on the number of admissions during the 18 month follow-up period for those in the control group and intervention group. These unadjusted figures

---

The joint crisis planning (intervention) arm of the trial is favoured by an odds ratio < 1.
show no significant findings between trial arms. This is also true when adjustments were made for site and ethnic group through Poisson regression (p=0.65, 95% CI=0.78-1.50) and then for site, ethnic group and WAIC (p=0.67, 95% CI=0.77-1.50). It must be noted that the variable of number of admissions is confounded by the fact that some participants had very long admissions.

Table 25: Summary of number of admissions during follow-up period by trial arm

<table>
<thead>
<tr>
<th></th>
<th>Control (n=280)</th>
<th>JCP (n=267)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of admissions: mean (sd)</td>
<td>0.48 (0.92)</td>
<td>0.51 (1.01)</td>
<td>0.718</td>
</tr>
<tr>
<td>Number of admissions: median (range)</td>
<td>0 (0-6)</td>
<td>0 (0-7)</td>
<td>0.962</td>
</tr>
<tr>
<td>Categorised admissions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 admissions</td>
<td>199 (71%)</td>
<td>190 (71%)</td>
<td></td>
</tr>
<tr>
<td>1 admissions</td>
<td>49 (18%)</td>
<td>46 (17%)</td>
<td></td>
</tr>
<tr>
<td>2+ admissions</td>
<td>32 (11%)</td>
<td>31 (12%)</td>
<td>0.995</td>
</tr>
</tbody>
</table>

Subgroup analysis

The CRIMSON trial always intended to carry out a pre-specified sub-analysis because previous work had suggested that the intervention may be particularly effective in this group. The subgroup was defined as Black / Black British (Caribbean) and Black / Black British (African),

Tables 26 and 27 below show the unadjusted and adjusted admissions data, for the black subgroup. Both reveal that no significant differences are found between the joint crisis plan group and the control group.

Table 26: Comparison of admission by randomisation arm for black subgroup

<table>
<thead>
<tr>
<th></th>
<th>Control</th>
<th>JCP</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No formal admissions</td>
<td>49 (68%)</td>
<td>53 (80%)</td>
<td>102 (74%)</td>
</tr>
<tr>
<td>At least one period of formal admission</td>
<td>23 (32%)</td>
<td>13 (20%)</td>
<td>36 (26%)</td>
</tr>
<tr>
<td>No admissions</td>
<td>45 (63%)</td>
<td>48 (73%)</td>
<td>93 (67%)</td>
</tr>
<tr>
<td>At least one admission (formal or informal)</td>
<td>27 (38%)</td>
<td>18 (27%)</td>
<td>45 (33%)</td>
</tr>
<tr>
<td>Total</td>
<td>72</td>
<td>66</td>
<td>138</td>
</tr>
</tbody>
</table>
Table 27: Logistic regression, joint crisis plan vs. control group for black subgroup

<table>
<thead>
<tr>
<th>Outcome</th>
<th>N</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one formal admission</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusted for site *</td>
<td>127</td>
<td>0.553</td>
<td>0.249 1.226</td>
<td>0.144</td>
</tr>
<tr>
<td>Adjusted for site *, WAIC</td>
<td>126</td>
<td>0.556</td>
<td>0.247 1.255</td>
<td>0.158</td>
</tr>
<tr>
<td>Any admission formal or informal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusted for site and ethnic group</td>
<td>138</td>
<td>0.644</td>
<td>0.311 1.334</td>
<td>0.236</td>
</tr>
<tr>
<td>Adjusted for site, WAIC</td>
<td>137</td>
<td>0.668</td>
<td>0.320 1.391</td>
<td>0.281</td>
</tr>
</tbody>
</table>

Table 28 below reports the data for the number of days admitted to hospital, by randomisation arm, with no significant differences between trial arms. Linear regression of number of days admitted during the follow-up period, with robust standard errors allowed adjustment to be made by site (p=0.39, 95% CI= -53.44-20.89) and site and WAIC (p=0.47, 95% CI=-50.95-23.32). Adjustments produced non-significant findings.

Table 28: Summary of number of days admitted (under formal or informal section) by randomisation arm for black subgroup

<table>
<thead>
<tr>
<th></th>
<th>Control (n=72)</th>
<th>JCP (n=66)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of days admitted: mean (sd)</td>
<td>55 (121)</td>
<td>36 (98)</td>
<td>0.332</td>
</tr>
<tr>
<td>Number of days admitted: median (range)</td>
<td>0 (0-600)</td>
<td>0 (0-507)</td>
<td>0.168</td>
</tr>
<tr>
<td>Days admitted: Grouped</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quantile 1</td>
<td>45 (63%)</td>
<td>48 (73%)</td>
<td></td>
</tr>
<tr>
<td>Quantile 2</td>
<td>8 (11%)</td>
<td>11 (17%)</td>
<td></td>
</tr>
<tr>
<td>Quantile 3</td>
<td>19 (26%)</td>
<td>7 (11%)</td>
<td>0.053</td>
</tr>
</tbody>
</table>

Table 29 below shows no significant differences between the number of admissions in the follow-up period between the joint crisis plan group and control group. Adjustments were made through Poisson regression for site and ethnic group (p=0.79, 95% CI=0.47-1.77) and then for site, ethnic group and WAIC (p=0.86, 95% CI=0.49-1.80).
Table 29: Summary of number of admissions in follow-up period by randomisation arm for black subgroup

<table>
<thead>
<tr>
<th></th>
<th>Control (n=72)</th>
<th>JCP (n=66)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of admissions: mean (sd)</td>
<td>0.64 (1.15)</td>
<td>0.58 (1.24)</td>
<td>0.757</td>
</tr>
<tr>
<td>Number of admissions: median (range)</td>
<td>0 (0-6)</td>
<td>0 (0-7)</td>
<td>0.309</td>
</tr>
<tr>
<td>Categorised admissions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 admissions</td>
<td>45 (63%)</td>
<td>48 (73%)</td>
<td></td>
</tr>
<tr>
<td>1 admissions</td>
<td>19 (26%)</td>
<td>9 (14%)</td>
<td></td>
</tr>
<tr>
<td>2+ admissions</td>
<td>8 (11%)</td>
<td>9 (14%)</td>
<td>0.176</td>
</tr>
</tbody>
</table>

**Secondary outcomes analysis**

Secondary hypotheses of the CRIMSON trial determined if compared with the control condition, joint crisis plan use resulted in significant improvements in: recovery style, perceived coercion, service user engagement and therapeutic alliance.

Table 30 below shows the unadjusted secondary outcome data by intervention arm; no findings were statistically significant.

Table 30: Summary of secondary outcomes and t-test by randomisation arm

<table>
<thead>
<tr>
<th>Scale</th>
<th>Scale</th>
<th>Control group</th>
<th>JCP group</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Recover Style (RSQ: percent integrated)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>181</td>
<td>158</td>
<td>0.362</td>
</tr>
<tr>
<td></td>
<td>mean (sd)</td>
<td>62.8 (16.8)</td>
<td>64.4 (16.2)</td>
<td></td>
</tr>
<tr>
<td>Perceived Coercion</td>
<td>Total</td>
<td>260</td>
<td>238</td>
<td>0.909</td>
</tr>
<tr>
<td></td>
<td>mean (sd)</td>
<td>3.13 (2.33)</td>
<td>3.16 (2.62)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pro-rated</td>
<td>262</td>
<td>239</td>
<td>0.878</td>
</tr>
<tr>
<td></td>
<td>mean (sd)</td>
<td>3.15 (2.34)</td>
<td>3.18 (2.64)</td>
<td></td>
</tr>
<tr>
<td>Engagement with Care (SES)</td>
<td>Total</td>
<td>228</td>
<td>202</td>
<td>0.653</td>
</tr>
<tr>
<td></td>
<td>mean (sd)</td>
<td>9.74 (7.26)</td>
<td>10.05 (7.15)</td>
<td></td>
</tr>
<tr>
<td>Therapeutic Alliance self-report (WAIC)</td>
<td>Total</td>
<td>238</td>
<td>202</td>
<td>0.057</td>
</tr>
<tr>
<td></td>
<td>mean (sd)</td>
<td>17.3 (7.7)</td>
<td>16.0 (7.1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pro-rated</td>
<td>240</td>
<td>206</td>
<td>0.066</td>
</tr>
<tr>
<td></td>
<td>mean (sd)</td>
<td>17.3 (7.6)</td>
<td>16.0 (7.1)</td>
<td></td>
</tr>
<tr>
<td>Therapeutic Alliance staff-rated (WAIT)</td>
<td>Total</td>
<td>236</td>
<td>197</td>
<td>0.292</td>
</tr>
<tr>
<td></td>
<td>mean (sd)</td>
<td>17.5 (5.1)</td>
<td>17.0 (5.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pro-rated</td>
<td>238</td>
<td>208</td>
<td>0.374</td>
</tr>
<tr>
<td></td>
<td>mean (sd)</td>
<td>17.5 (5.1)</td>
<td>17.1 (5.2)</td>
<td></td>
</tr>
</tbody>
</table>
An adjusted analysis is presented in Table 31 below. Two adjustments were made; the first was for outcome, site and ethnicity. The second accounted for factors associated with missing follow-up for each outcome. The data presented in Table 31 shows some evidence to suggest that the intervention may have resulted in an improvement in self-reported therapeutic relationship (WAIC) in the intervention arm when controlling for baseline, associated factors, site and ethnicity (-1.28, 95% CI= -2.56 to -0.01, p=0.049). The value presented is for the WAIC total score although, with the application of multiple testing and no Bonferroni correction made, this statistically significant finding may still likely have occurred by chance. There is recognition that Bonferroni correction could have been made although the trialists did not complete this analysis. There is very little agreement on how to do multiple testing and it is thought to be overly conservative and it increases the chances of erroneously accepting the null hypothesis309.

Table 31: Individual linear regression models of outcomes by randomisation arm

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Model</th>
<th>N</th>
<th>Coefficient</th>
<th>95% Confidence Interval</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>RSQ: percent integrated</td>
<td>Basic adjustment</td>
<td>268</td>
<td>1.887</td>
<td>-1.635</td>
<td>5.409</td>
</tr>
<tr>
<td></td>
<td>Full adjustment</td>
<td>223</td>
<td>1.385</td>
<td>-2.522</td>
<td>5.292</td>
</tr>
<tr>
<td>Perceived Coercion Total</td>
<td>Basic adjustment</td>
<td>371</td>
<td>0.106</td>
<td>-0.367</td>
<td>0.580</td>
</tr>
<tr>
<td></td>
<td>Full adjustment</td>
<td>312</td>
<td>0.272</td>
<td>-0.258</td>
<td>0.802</td>
</tr>
<tr>
<td>Perceived Coercion - pro-rated</td>
<td>Basic adjustment</td>
<td>458</td>
<td>0.083</td>
<td>-0.349</td>
<td>0.514</td>
</tr>
<tr>
<td></td>
<td>Full adjustment</td>
<td>380</td>
<td>0.239</td>
<td>-0.242</td>
<td>0.719</td>
</tr>
<tr>
<td>SES</td>
<td>Basic adjustment</td>
<td>362</td>
<td>0.648</td>
<td>-0.666</td>
<td>1.962</td>
</tr>
<tr>
<td></td>
<td>Full adjustment</td>
<td>362</td>
<td>0.473</td>
<td>-0.841</td>
<td>1.988</td>
</tr>
<tr>
<td>WAIC - Total</td>
<td>Basic adjustment</td>
<td>443</td>
<td>-1.332</td>
<td>-2.590</td>
<td>-0.071</td>
</tr>
<tr>
<td></td>
<td>Full adjustment</td>
<td>443</td>
<td>-1.280</td>
<td>-2.561</td>
<td>0.012</td>
</tr>
<tr>
<td>WAIC - pro-rated</td>
<td>Basic adjustment</td>
<td>442</td>
<td>-1.339</td>
<td>-2.605</td>
<td>-0.072</td>
</tr>
<tr>
<td></td>
<td>Full adjustment</td>
<td>369</td>
<td>-1.187</td>
<td>-2.601</td>
<td>0.227</td>
</tr>
<tr>
<td>WAIT - Total</td>
<td>Basic adjustment</td>
<td>393</td>
<td>-0.513</td>
<td>-1.448</td>
<td>0.421</td>
</tr>
<tr>
<td></td>
<td>Full adjustment</td>
<td>354</td>
<td>-0.628</td>
<td>-1.618</td>
<td>0.363</td>
</tr>
<tr>
<td>WAIT - pro-rated</td>
<td>Basic adjustment</td>
<td>418</td>
<td>-0.332</td>
<td>-1.245</td>
<td>0.581</td>
</tr>
<tr>
<td></td>
<td>Full adjustment</td>
<td>374</td>
<td>-0.380</td>
<td>-1.352</td>
<td>0.591</td>
</tr>
</tbody>
</table>

* Significant finding
Study 1: The effectiveness of joint crisis plans

Purpose of this study

This study is embedded within the larger CRIMSON trial. By looking at the groups of participants who have been randomised to receive the joint crisis plan intervention, the author aims to analyse whether the findings for south Asian and black participants together show a more positive outcome in terms of hospital admissions (formal and any admission) and working alliance, as reported by the service user. The treatment effect for each will be compared to the effect for white British participants.

Study trial diagram

Figure 22 below is specific to the author’s sub-analysis within this thesis, which includes only south Asian and black participants, and shows the consort diagram from the study. The division made by the dotted line requires explanation as the figures for total participants recruited and randomised above this line are taken from the full CRIMSON trial. This is because initially ethical approval was not acquired for the recording of personal data for those people that did not consent to participate in the trial. Therefore the ethnicity of participants screened and then later approached was not recorded unless they were part of the trial. This meant that ethnicity data for those screened could not be included within Figure 22 below. The data below the dotted line is that taken from the study within this thesis, i.e. it includes only data from south Asian and black participants. The 182 participants from south Asian and black ethnic groups (grouped together) were allocated as follows:

- 94 people were randomised to the intervention group (to receive a joint crisis plan)
- 88 people were randomised to the control group (treatment as usual)

Figure 22 below shows the breakdown of participants for those who were recruited, randomised, followed up and whose data was analysed. This shows that despite not all participants being followed up, analysis is initially presented from the data of all participants in the trial, with regards to baseline characteristics and missing data analysis. Within the analysis for specific hypotheses, missing outcome data prohibits all participants from being included in the analysis. In each case the number of included participants (n) is provided when reporting on each hypothesis.
From the 94 participants who were randomised to the intervention group and were invited to formulate a joint crisis plan with their care teams, 71 (76%) completed this process and 23 (24%) did not. This is tabulated below in Table 32. The comparative
figures are also presented for the white British participants, of which 80% of those who were allocated to formulate a joint crisis plan actually completed one.

Table 32: Number of completed joint crisis plans for south Asian and black and white British participants

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number allocated to intervention</th>
<th>Number completing intervention</th>
<th>Number of non-completers</th>
<th>% completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>south Asian and black</td>
<td>94</td>
<td>71</td>
<td>23</td>
<td>76</td>
</tr>
<tr>
<td>White British</td>
<td>151</td>
<td>121</td>
<td>130</td>
<td>80</td>
</tr>
</tbody>
</table>

Reasons for non-completion of joint crisis plans by site

The reasons for participants from south Asian and black ethnic groups not completing the joint crisis planning process are reported below in Table 33. This adds to the understanding of research issues which are discussed further within this thesis.

Table 33: Summary of reasons for non-completion by ethnic group

<table>
<thead>
<tr>
<th>Reason for non-completion</th>
<th>Black/Black British (n)</th>
<th>Asian/Asian British (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too unwell</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Non-engagement with intervention</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Withdrawal from trial</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Discharged to GP</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Primary outcomes analysis

182 south Asian and black participants were randomised to receive a joint crisis plan or not. The characteristics of these participants by the trial arm allocation are shown in Table 34 below. There were no significant differences between any of the characteristics across trial arms. The baseline demographic information presented in Table 34 shows the demographic information of participants across trial arms, including data relating directly to the hypotheses in this thesis. Therefore the number of admissions and duration of admissions in the two years prior to baseline assessment are documented, with no significant difference between trial arms being detected. The measure of therapeutic relationship (working alliance inventory) was also accounted for and once again there was no significant difference between participants across trial arms at baseline.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Category Value</th>
<th>Total N=182, n (%)</th>
<th>Control N=88, n (%)</th>
<th>JCP N=94, n (%)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site</td>
<td>Birmingham</td>
<td>56 (31%)</td>
<td>27 (31%)</td>
<td>29 (31%)</td>
<td>0.708</td>
</tr>
<tr>
<td></td>
<td>London</td>
<td>95 (52%)</td>
<td>48 (54%)</td>
<td>47 (50%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Manchester/Lancashire</td>
<td>31 (17%)</td>
<td>13 (15%)</td>
<td>18 (19%)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>96 (53%)</td>
<td>46 (52%)</td>
<td>50 (53%)</td>
<td>0.901</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>86 (47%)</td>
<td>42 (48%)</td>
<td>44 (47%)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>mean (sd)</td>
<td>36.7 (10.9)</td>
<td>35.9 (11.0)</td>
<td>37.5 (10.9)</td>
<td>0.337</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married / cohabiting</td>
<td>35 (19%)</td>
<td>15 (17%)</td>
<td>20 (21%)</td>
<td>0.527</td>
</tr>
<tr>
<td></td>
<td>Widowed/separated/divorced</td>
<td>28 (15%)</td>
<td>12 (14%)</td>
<td>16 (17%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>118 (65%)</td>
<td>61 (69%)</td>
<td>57 (61%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>1 (1%)</td>
<td>0</td>
<td>1 (1%)</td>
<td></td>
</tr>
<tr>
<td>Living status</td>
<td>Alone</td>
<td>83 (46%)</td>
<td>40 (45%)</td>
<td>43 (46%)</td>
<td>0.969</td>
</tr>
<tr>
<td></td>
<td>Not alone</td>
<td>99 (54%)</td>
<td>48 (55%)</td>
<td>51 (54%)</td>
<td></td>
</tr>
<tr>
<td>Nationality</td>
<td>English</td>
<td>12 (7%)</td>
<td>4 (5%)</td>
<td>8 (9%)</td>
<td>0.528</td>
</tr>
<tr>
<td></td>
<td>Welsh</td>
<td>1 (1%)</td>
<td>1 (1%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>British</td>
<td>109 (60%)</td>
<td>53 (60%)</td>
<td>56 (60%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>60 (33%)</td>
<td>30 (34%)</td>
<td>30 (32%)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Asian/Asian British (Indian)</td>
<td>20 (11%)</td>
<td>7 (8%)</td>
<td>13 (14%)</td>
<td>0.375</td>
</tr>
<tr>
<td></td>
<td>Asian/Asian British (Pakistani)</td>
<td>29 (16%)</td>
<td>14 (16%)</td>
<td>15 (16%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Asian/Asian British (Bangladeshi)</td>
<td>3 (2%)</td>
<td>1 (1%)</td>
<td>2 (2%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Asian/Asian British (Other)</td>
<td>4 (2%)</td>
<td>1 (1%)</td>
<td>3 (3%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Black/Black British (Caribbean)</td>
<td>73 (40%)</td>
<td>40 (45%)</td>
<td>33 (35%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Black/Black British (African)</td>
<td>39 (21%)</td>
<td>21 (24%)</td>
<td>18 (19%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Black/Black British (Other)</td>
<td>14 (8%)</td>
<td>4 (5%)</td>
<td>10 (11%)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>None</td>
<td>42 (23%)</td>
<td>20 (23%)</td>
<td>22 (23%)</td>
<td>0.840</td>
</tr>
<tr>
<td></td>
<td>School</td>
<td>99 (54%)</td>
<td>49 (56%)</td>
<td>50 (53%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Vocational</td>
<td>18 (10%)</td>
<td>7 (8%)</td>
<td>11 (12%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Higher</td>
<td>23 (13%)</td>
<td>12 (14%)</td>
<td>11 (12%)</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Schizophrenia</td>
<td>92 (51%)</td>
<td>43 (49%)</td>
<td>49 (52%)</td>
<td></td>
</tr>
<tr>
<td>OPCRIT</td>
<td>Schizopreniform Disorder</td>
<td>2 (1%)</td>
<td>0</td>
<td>2 (2%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Schizoaffective Depressive</td>
<td>6 (3%)</td>
<td>2 (2%)</td>
<td>4 (6%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Schizoaffective Bipolar</td>
<td>9 (5%)</td>
<td>6 (7%)</td>
<td>3 (3%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Delusional Disorder</td>
<td>6 (3%)</td>
<td>3 (3%)</td>
<td>3 (3%)</td>
<td></td>
</tr>
</tbody>
</table>
6 of the 182 participants (3%) did not have data available on the primary outcome admission to hospital. A further 14 had admission records but no follow-up interview giving 20 (11%) with no follow-up self-report measures.

An analysis of missing data is presented in Table 35 below for admissions during the follow-up period and for those who could not be contacted for the follow-up interview. There was additional missing data on some questions within the interviews. Differences in patient characteristics between those with and without outcomes data were assessed using t-tests and chi-square tests or the non-parametric Wilcoxon rank-sum test, where appropriate, determined by baseline data, hence no probability weighting was carried out. The results, as shown in Table 35, indicate that there were no variables that were associated with missing admissions data, beyond OPCRIT diagnosis. In this case the spread of diagnoses and the small number within each category make adjusting for these differences unprofitable. As stated within the methodology, the reason for identifying baseline characteristics, associated with missing data, was to select those variables that were significant in order that they could be adjusted for within future analysis. The analysis therefore ensures that all findings
were adjusted for by site, due to the multi-site nature of the trial, although no further adjustments were made.

Table 35: Baseline characteristics associated with missing outcome data

<table>
<thead>
<tr>
<th>Variable</th>
<th>Missing follow-up interview</th>
<th>Missing Admission Data</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No (n=162)</td>
<td>Yes (n=20)</td>
</tr>
<tr>
<td>Site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birmingham</td>
<td>51 (31%)</td>
<td>5 (25%)</td>
</tr>
<tr>
<td>London</td>
<td>84 (52%)</td>
<td>11 (55%)</td>
</tr>
<tr>
<td>Manchester/Lancashire</td>
<td>27 (17%)</td>
<td>4 (0.2%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>85 (52%)</td>
<td>11 (55%)</td>
</tr>
<tr>
<td>Female</td>
<td>77 (48%)</td>
<td>9 (45%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean (sd)</td>
<td>36.65 (11.1)</td>
<td>37.45 (9.1)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/cohabiting</td>
<td>33 (20%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Widowed/separated/divorced</td>
<td>23 (14%)</td>
<td>5 (25%)</td>
</tr>
<tr>
<td>Single</td>
<td>105 (65%)</td>
<td>13 (65%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td>Living status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>69 (43%)</td>
<td>14 (70%)</td>
</tr>
<tr>
<td>Not alone</td>
<td>93 (57%)</td>
<td>6 (30%)</td>
</tr>
<tr>
<td>Ethnicity (grouped)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black/Black British - all</td>
<td>112 (69%)</td>
<td>14 (70%)</td>
</tr>
<tr>
<td>Other</td>
<td>50 (31%)</td>
<td>6 (30%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>37 (23%)</td>
<td>5 (25%)</td>
</tr>
<tr>
<td>School</td>
<td>90 (56%)</td>
<td>9 (45%)</td>
</tr>
<tr>
<td>Vocational</td>
<td>15 (9%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Higher</td>
<td>20 (12%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>OPCRIT Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>82 (51%)</td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Schizophreniform Disorder</td>
<td>1 (1%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Schizoaffective Depressive</td>
<td>6 (4%)</td>
<td>0</td>
</tr>
<tr>
<td>Schizoaffective Bipolar</td>
<td>8 (5%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Delusional Disorder</td>
<td>4 (2%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Psychosis</td>
<td>36 (22%)</td>
<td>3 (15%)</td>
</tr>
</tbody>
</table>

P<0.001
<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Bipolar I</th>
<th>Bipolar II</th>
<th>Major Depressive Disorder with psychosis</th>
<th>NOS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4 (2%)</td>
<td>3 (15%)</td>
<td>7 (4%)</td>
<td>0</td>
</tr>
<tr>
<td>Bipolar II</td>
<td>17 (10%)</td>
<td>0</td>
<td>17 (10%)</td>
<td>0</td>
</tr>
<tr>
<td>Major Depressive Disorder with psychosis</td>
<td>4 (2%)</td>
<td>0</td>
<td>0.028</td>
<td>4 (2%)</td>
</tr>
</tbody>
</table>

**Grouped OPCRIT Diagnosis**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Schizophrenia Spectrum disorder</th>
<th>Affective disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>137 (85%)</td>
<td>25 (15%)</td>
</tr>
<tr>
<td></td>
<td>17 (85%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td></td>
<td>148 (84%)</td>
<td>0.960</td>
</tr>
<tr>
<td></td>
<td>6 (100%)</td>
<td>28 (16%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.288</td>
</tr>
</tbody>
</table>

**Baseline measures**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Number of previous admissions (2 years prior)</th>
<th>1.52</th>
<th>2.00</th>
<th>0.204</th>
<th>1.51</th>
<th>1.80 (15)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>0.99</td>
<td>0.63</td>
<td>0.89</td>
<td>0.99</td>
<td>0.82 (1.5)</td>
</tr>
</tbody>
</table>

**Grouped admissions**

<table>
<thead>
<tr>
<th>Number of admissions</th>
<th>1 admission</th>
<th>2 admissions</th>
<th>3+ admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>108 (67%)</td>
<td>36 (22%)</td>
<td>18 (11%)</td>
</tr>
<tr>
<td></td>
<td>11 (55%)</td>
<td>7 (35%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td></td>
<td>118 (67%)</td>
<td>39 (22%)</td>
<td>0.102</td>
</tr>
<tr>
<td></td>
<td>1 (17%)</td>
<td>4 (67%)</td>
<td>19 (11%)</td>
</tr>
</tbody>
</table>

**Total duration of admissions- days (2 years prior)**

<table>
<thead>
<tr>
<th></th>
<th>102.3</th>
<th>90.2</th>
<th>0.333</th>
<th>91.8</th>
<th>82.3</th>
<th>0.665</th>
</tr>
</thead>
</table>

**Therapeutic relationship**

| Work Alliance Inventory total self-rated (pro-rated) | 15.80 (6.4) | 16.75 (5.1) | 0.452 | 15.8 (6.3) | 19.7 (2.7) | 0.148 |

*non-parametric test

**Intention to treat analysis**

The analysis that follows is based on intention to treat, which means that all data from randomised participants is used, despite the fact that 23 of 94 participants allocated to receive a joint crisis plan did not complete one. This means that the findings from the analysis will show the effects of prescribing the intervention to service users rather than the effects of service users receiving the intervention.

The breakdown of ethnic groups within the full sample of the CRIMSON trial is presented in Table 36 below, by trial arm. The number of participants with missing admissions data and missing working alliance data is also provided. The ethnic groups are broken down into those, which are later used for sensitivity analysis.
Table 36: Ethnic breakdown of full sample by trial arm including missing data

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>Ethnic subgroup</th>
<th>N</th>
<th>Control (n)</th>
<th>JCP (n)</th>
<th>Missing admissions data (n)</th>
<th>Missing WAIC data</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British (n=318)</td>
<td>-</td>
<td>318</td>
<td>166</td>
<td>152</td>
<td>11</td>
<td>69</td>
</tr>
<tr>
<td>Black (n=126)</td>
<td>Black/ Black British (Caribbean)</td>
<td>73</td>
<td>40</td>
<td>33</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Black / Black British (African)</td>
<td>39</td>
<td>21</td>
<td>18</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Black / Black British (Other)</td>
<td>14</td>
<td>4</td>
<td>10</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>South Asian (n=56)</td>
<td>Asian / Asian British (Indian)</td>
<td>20</td>
<td>7</td>
<td>13</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Asian / Asian British (Pakistani)</td>
<td>29</td>
<td>14</td>
<td>15</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Asian / Asian British (Bangladeshi)</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Asian / Asian British (Other)</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other non-white (n=5)</td>
<td>-</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Mixed race (n=28)</td>
<td>Mixed (White and Black Caribbean)</td>
<td>15</td>
<td>7</td>
<td>8</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Mixed (White and Black African)*</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Mixed (Other)</td>
<td>7</td>
<td>3</td>
<td>4</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>White ethnic minorities (n=31)</td>
<td>White (Irish)</td>
<td>17</td>
<td>8</td>
<td>9</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>White (Other)</td>
<td>18</td>
<td>5</td>
<td>13</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>568</td>
<td>283</td>
<td>285</td>
<td>22</td>
<td>129</td>
</tr>
</tbody>
</table>

Results by hypotheses

Analysis is completed for each hypothesis for the south Asian and black participants. Sensitivity analysis to include other ethnic minorities follows and finally, analysis for white British participants is completed; in order that any treatment effects can be compared between the combined south Asian and black group and the white British group. As previously stated, adjustments were made for missing data based on baseline data and no probability weighting was completed. For reasons previously outlined, additional adjustments, for example the Bonferroni correction for multiple hypothesis testing, were not made. No post hoc analysis beyond the a priori subgroups of south Asian and black were completed. Such further analysis, for example splitting up black African and African Caribbean participants to produce data on more defined ethnic groups would have reduced numbers within each analysis and the problem of additional multiple testing would have increased the chance of a type 1 error.
**Primary hypothesis**

Joint crisis plans will significantly reduce the proportion of service users from south Asian and black ethnic groups, treated under a section of the Mental Health Act during the follow-up period, compared with service users from south Asian and black groups in the control condition (*Hypothesis 1*).

The proportions of participants formally admitted by intervention group are shown in Table 37 below and significance is determined using the chi-square test.

**Table 37: Number of south Asian and black participants admitted by trial arm**

<table>
<thead>
<tr>
<th></th>
<th>Control</th>
<th>JCP</th>
<th>Total</th>
<th>Unadjusted odds ratio</th>
<th>Significance*</th>
</tr>
</thead>
<tbody>
<tr>
<td>No formal admissions</td>
<td>64 (74%)</td>
<td>70 (78%)</td>
<td>134 (76%)</td>
<td>0.724</td>
<td>0.601</td>
</tr>
<tr>
<td>At least one period of formal admission</td>
<td>22 (26%)</td>
<td>20 (22%)</td>
<td>42 (24%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>90</td>
<td>176</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Chi-square test for differences has produced significance

Logistic regression was used to complete the data analysis for the primary hypothesis, which aimed to answer whether those people who are allocated to receive the joint crisis plan intervention were less likely to have a compulsory hospital admission in the follow-up period than those in the control group. As ethnicity was a characteristic that was accounted for within the randomisation process and this sample only includes south Asian and black participants, it was not necessary to adjust by ethnicity further. The statistical analysis included an adjustment for recruitment site. The adjusted findings are shown in Table 38 below. This shows that the chance of having an admission was 0.87 lower for the intervention arm than the control arm. Those in the intervention arm were 12.6% less likely to have an admission than those in the control group, although this finding is not significant (*p*=0.71, 95% CI= 0.43-1.77).

Those participants in Birmingham were 1.8 times more likely to have a formal admission than those from Manchester/Lancashire recruitment sites, although this finding is not significant (*p*=0.15, 95% CI= 0.81-4.00).
Those from London were less likely to have a formal admission than those from Manchester/Lancashire but this difference is not statistically significant (p=0.23, 95%CI= 0.11-1.69).

**Table 38: Logistic regression, intervention group versus the control group for formal admissions adjusted by site (n=176)**

<table>
<thead>
<tr>
<th></th>
<th>Odds ratio</th>
<th>Confidence Intervals</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment effect</td>
<td>.874</td>
<td>0.431-1.774</td>
<td>.710</td>
</tr>
<tr>
<td>Reference: Manchester</td>
<td></td>
<td></td>
<td>.052</td>
</tr>
<tr>
<td>Site: Birmingham</td>
<td>1.802</td>
<td>0.812-4.002</td>
<td>.148</td>
</tr>
<tr>
<td>Site: London</td>
<td>.433</td>
<td>0.111-1.690</td>
<td>.228</td>
</tr>
</tbody>
</table>

*The comparison site code is Manchester/Lancashire

Sensitivity analysis is reported in Table 39 below, which includes additional ethnic groups. The results are firstly presented for black participants and then other non-white groups were added to the previously presented findings for south Asian and black groups. Mixed race participants were then added into the analysis and finally white ethnic minority groups were included; hence all participants other than white British (n=307) were included in the final analysis. All of the analyses were adjusted for by site and the results show that the addition of other ethnic minority groups to the analysis does not substantially alter the findings. The significance as denoted by the p-value is the lowest for the black subgroup, although wide confidence intervals and non-significant findings make it difficult to make any inferences from this.

**Table 39: Sensitivity analysis: Logistic regression, intervention group versus the control group for formal admissions adjusted by site**

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>N</th>
<th>Odds ratio</th>
<th>Confidence Intervals</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Asian</td>
<td>55</td>
<td>6.97</td>
<td>0.801-60.872</td>
<td>0.081</td>
</tr>
<tr>
<td>Black</td>
<td>121</td>
<td>0.563</td>
<td>0.243-1.300</td>
<td>0.178</td>
</tr>
<tr>
<td>Black + south Asian</td>
<td>176</td>
<td>0.874</td>
<td>0.431-1.774</td>
<td>0.710</td>
</tr>
<tr>
<td>Black + south Asian+ other non-white groups</td>
<td>180</td>
<td>0.904</td>
<td>0.451-1.812</td>
<td>0.776</td>
</tr>
<tr>
<td>Black + south Asian+ other non-white groups + mixed race groups</td>
<td>204</td>
<td>0.819</td>
<td>0.426-1.575</td>
<td>0.550</td>
</tr>
<tr>
<td>Black + south Asian+ other non-white groups + mixed race groups + white ethnic minority groups</td>
<td>239</td>
<td>0.689</td>
<td>0.373-1.270</td>
<td>0.232</td>
</tr>
</tbody>
</table>
The final analysis to be presented within this primary hypothesis is the analysis for the remaining white British participants (n=307), which is shown in Table 40 below, alongside the treatment effect for south Asian and black participants.

**Table 40: Logistic regression, intervention group versus the control group for formal admissions for white British participants (n=307) and south Asian and black participants (176), adjusted by site**

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Odds ratio</th>
<th>Confidence Intervals</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>307</td>
<td>1.139</td>
<td>0.614-2.114</td>
<td>0.680</td>
</tr>
<tr>
<td>south Asian and black</td>
<td>176</td>
<td>0.874</td>
<td>0.431-1.774</td>
<td>0.710</td>
</tr>
</tbody>
</table>

Table 40 allows for comparisons to be made between the treatment effect for white British and south Asian and black groups, neither of which produced significant findings; although findings are in opposing directions.

*Secondary hypotheses*

Compared with service users from south Asian and black groups in the control condition, joint crisis plans will significantly:

1. Reduce the proportion of service users from south Asian and black ethnic groups, with a psychiatric hospital admission (formal or informal admission) at any point during the follow-up period (*Hypothesis 2*).

2. Improve south Asian and black service users’ perception of their therapeutic alliance with their care coordinators (*Hypothesis 3*)

3. In addition it is predicted that there will be a greater treatment effect size for south Asian and black service users compared to white British service users (*Hypothesis 4*). This will be addressed throughout the analyses of the previous 3 hypotheses.
**Hypothesis 2**

‘Compared with service users from south Asian and black groups in the control condition, joint crisis plans will significantly reduce the proportion of service users from south Asian and black ethnic groups, with a psychiatric hospital admission (formal or informal admission) at any point during the follow-up period’

The analysis for this hypothesis is very similar to that completed for the primary hypothesis which focussed on formal admissions. As stated previously this is a comparison of proportion of participants with at least one admission (formal or informal) in the follow-up period since randomisation versus no admissions. Table 41 below shows the unadjusted figures for proportions of south Asian and black participants experiencing any type of hospital admission.

**Table 41: Table to show proportions admitted by trial arm**

<table>
<thead>
<tr>
<th></th>
<th>Control</th>
<th>JCP</th>
<th>Total</th>
<th>Unadjusted odds ratio</th>
<th>Significance*</th>
</tr>
</thead>
<tbody>
<tr>
<td>No admissions</td>
<td>60 (70%)</td>
<td>60 (67%)</td>
<td>120 (68%)</td>
<td>0.747</td>
<td>0.659</td>
</tr>
<tr>
<td>At least one admission (formal or informal)</td>
<td>26 (30%)</td>
<td>30 (33%)</td>
<td>56 (32%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>90</td>
<td>176</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Chi-square test for differences has produced significance

Table 42 below presents the results adjusted by site, through logistic regression. This table shows that the chance of having an admission is 1.18 higher for the intervention arm than the control arm. Those in the intervention arm are 18% more likely to have an admission (mixed, including formal and informal) than those in the control group, although this finding is not significant (p=0.62, 95%CI= 0.62-2.24).

Those participants in Birmingham are 1.97 times more likely to have an admission than those from Manchester/Lancashire recruitment sites, although this finding is not significant (p= 0.08, 95%CI= 0.93-4.19).

Those from London are 0.3 times more likely to have an admission than those from Manchester/Lancashire or more appropriately, 70% less likely to have an admission than those from Manchester/Lancashire. Once again this findings is not significant (p=0.60, 95%CI= 0.48-3.54).
Table 42: Logistic regression, intervention groups versus the control group for mixed admissions, adjusted for by site (n=176)

<table>
<thead>
<tr>
<th>Treatment effect</th>
<th>Odds ratio</th>
<th>Confidence Intervals</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reference:</td>
<td>1.179</td>
<td>0.620-2.244</td>
<td>0.616</td>
</tr>
<tr>
<td>Manchester</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site: Birmingham</td>
<td>1.970</td>
<td>0.926-4.191</td>
<td>0.078</td>
</tr>
<tr>
<td>Site: London</td>
<td>1.307</td>
<td>0.483-3.537</td>
<td>0.599</td>
</tr>
</tbody>
</table>

*The comparison site code is Manchester/Lancashire

As previously described, sensitivity analysis was completed by adding additional ethnic groups into the analysis. Once again no findings were significant, as shown in Table 43 below.

Table 43: Sensitivity analysis: Logistic regression, intervention group versus the control group for any admissions adjusted by site

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>N</th>
<th>Odds ratio</th>
<th>Confidence Intervals</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Asian</td>
<td>55</td>
<td>4.63</td>
<td>1.109-19.214</td>
<td>0.043</td>
</tr>
<tr>
<td>Black</td>
<td>121</td>
<td>0.720</td>
<td>0.331-1.568</td>
<td>0.409</td>
</tr>
<tr>
<td>Black + south Asian</td>
<td>176</td>
<td>1.179</td>
<td>0.620-2.244</td>
<td>0.616</td>
</tr>
<tr>
<td>Black + south Asian+ other non- white groups</td>
<td>180</td>
<td>1.220</td>
<td>0.647-2.301</td>
<td>0.540</td>
</tr>
<tr>
<td>Black + south Asian+ other non- white groups + mixed race groups</td>
<td>204</td>
<td>1.048</td>
<td>0.580-1.893</td>
<td>0.877</td>
</tr>
<tr>
<td>Black + south Asian+ other non- white groups + mixed race groups + white ethnic minority groups</td>
<td>239</td>
<td>0.830</td>
<td>0.477-1.445</td>
<td>0.510</td>
</tr>
</tbody>
</table>

Table 44 below presents the treatment effect for white British participants alongside the previously reported effects of the intervention for south Asian and black groups. Neither treatment effect is significant and the wide confidence intervals suggest no evidence of effect for the joint crisis plans on proportion of hospital admissions.

Table 44: Logistic regression, intervention group versus the control group for any admissions for white British participants (n=307) and south Asian and black participants (176), adjusted by site

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>N</th>
<th>Odds ratio</th>
<th>Confidence Intervals</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>307</td>
<td>1.190</td>
<td>0.716-1.979</td>
<td>0.502</td>
</tr>
<tr>
<td>south Asian and black</td>
<td>182</td>
<td>1.179</td>
<td>0.620-2.244</td>
<td>.616</td>
</tr>
</tbody>
</table>
Hypothesis 3

‘Compared with service users from south Asian and black groups in the control condition, joint crisis plans will significantly improve south Asian and black service users’ perception of their therapeutic alliance with their care coordinators’.

This analysis used service user self-report responses on the working alliance inventory (client form). The total score from the scale was calculated and higher scores were associated with a less positive rating of working alliance with their clinician by the service user. The mean scores are shown in Table 45 below along with the unadjusted significance as determined through the use of t-tests. From the summary presented in Table 45, those that were randomised to receive a joint crisis plan reported on average a more positive working alliance that those in the control group. This finding was not statistically significant (p=0.49).

Table 45: Summary of unadjusted working alliance scores and t-test by randomisation arm (n=139)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Control</th>
<th>JCP</th>
<th>Mean difference</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic Alliance self-report (WAIC)</td>
<td>N=74</td>
<td>N=65</td>
<td>0.799 (95% CI=-3.023 to 1.466)</td>
<td>0.494</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale</th>
<th>Control</th>
<th>JCP</th>
<th>Mean difference</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic Alliance self-report (WAIC)</td>
<td>N=74</td>
<td>N=65</td>
<td>0.799 (95% CI=-3.023 to 1.466)</td>
<td>0.494</td>
</tr>
</tbody>
</table>

Linear regression was used to complete data analysis of service users’ working alliance inventory scores. Adjustments were made to account for their scores on this measure at the baseline assessment. Within the analysis recruitment site was also adjusted for. The results for this are shown in Table 46 below. When adjusted for baseline scores, the treatment effect of the joint crisis on service users’ self-report of their working alliance with their clinician, was not significant. The treatment coefficient shows the scores at follow up are more positive for the people who were allocated to receive joint crisis plans, compared with the participants in the control group, although these findings are not significant (B= 2.69, p=0.35, 95%CI= -2.95-8.32).
Table 46: Linear regression model of working alliance inventory scores adjusted by site and baseline working alliance scores (n=139)

<table>
<thead>
<tr>
<th>Measure</th>
<th>B</th>
<th>Std. Error</th>
<th>t</th>
<th>Sig.</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working alliance inventory total score</td>
<td>2.686</td>
<td>2.847</td>
<td>.943</td>
<td>.347</td>
<td>-2.947 to 8.319</td>
</tr>
</tbody>
</table>

This sensitivity analysis, as shown in Table 47, mirrors the sensitivity analyses for the previous two hypotheses, whereby the addition of other ethnic minority groups into the analysis reports non-significant findings.

Table 47: Sensitivity analysis: Linear regression model of working alliance inventory scores adjusted by site and baseline working alliance scores

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>N</th>
<th>B</th>
<th>Std. Error</th>
<th>t</th>
<th>Sig.</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Asian</td>
<td>39</td>
<td>1.572</td>
<td>3.882</td>
<td>0.405</td>
<td>0.683</td>
<td>-6.33-9.48</td>
</tr>
<tr>
<td>Black</td>
<td>100</td>
<td>0.18</td>
<td>1.336</td>
<td>0.13</td>
<td>0.989</td>
<td>-2.636-2.672</td>
</tr>
<tr>
<td>Black + south Asian</td>
<td>139</td>
<td>2.686</td>
<td>2.847</td>
<td>.943</td>
<td>0.347</td>
<td>-2.947-8.319</td>
</tr>
<tr>
<td>Black + south Asian+ other non- white groups</td>
<td>142</td>
<td>2.165</td>
<td>2.854</td>
<td>0.759</td>
<td>0.449</td>
<td>-3.479-7.809</td>
</tr>
<tr>
<td>Black + south Asian+ other non- white groups + mixed race groups</td>
<td>164</td>
<td>2.374</td>
<td>2.938</td>
<td>0.808</td>
<td>0.420</td>
<td>-3.430-8.177</td>
</tr>
<tr>
<td>Black + south Asian+ other non- white groups + mixed race groups + white ethnic minority groups</td>
<td>190</td>
<td>1.631</td>
<td>2.640</td>
<td>0.618</td>
<td>0.538</td>
<td>-3.579-6.841</td>
</tr>
</tbody>
</table>

Table 48 below enables a comparison between the treatment effect for joint crisis plans on working alliance between white British and south Asian and black participants. The findings are non-significant for both and the wide confidence intervals indicate no evidence of effect of the intervention on working alliance.

Table 48: Linear regression model of working alliance inventory scores adjusted by site and baseline working alliance scores for white British (n=249) and south Asian and black (n=139) participants

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>N</th>
<th>B</th>
<th>Std. Error</th>
<th>t</th>
<th>Sig.</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>249</td>
<td>1.992</td>
<td>1.373</td>
<td>1.451</td>
<td>0.148</td>
<td>-0.712-4.696</td>
</tr>
<tr>
<td>Black + south Asian</td>
<td>139</td>
<td>2.686</td>
<td>2.847</td>
<td>.943</td>
<td>0.347</td>
<td>-2.947-8.319</td>
</tr>
</tbody>
</table>
Hypothesis 4

‘There will be a greater treatment effect size of joint crisis plans for south Asian and black service users compared to white British service users’

This secondary hypothesis has been incorporated into the previous results, within each previous hypothesis. It is concluded that no results are significant for either the combined south Asian and black group or the white British group. No conclusions about differences in treatment effect size can be supported from these findings as no evidence of effect was observed across both groups.
Study 2: Recruiting ethnic minorities into the CRIMSON trial

Purpose of this study

By applying the techniques highlighted in the literature, the author aims to determine if it is possible to get ethnic minorities involved in psychiatric trials. This study focuses on the recruitment from the Manchester/Lancashire site, where the author led the recruitment.

Number of south Asian participants recruited

The following figures relate to recruitment into the CRIMSON trial of south Asian service users from the Manchester/Lancashire recruitment site. In total, 46 south Asian service users were screened to be eligible and 50% (n=23) of these were successfully recruited (as illustrated below in Figure 23). In comparison, 276 white British service users were screened to be eligible, with 51% (n=142) being successfully recruited into the study. Of the white British service users, 99 refused to participate; either directly with the researchers or through their care coordinator and 35 were not approached, due to their mental health at the time.

It is not possible to report on the total number of south Asian participants who were screened; ethical approval was not granted to include demographic information on those who did not provide consent, as previously discussed. This was not a particular problem for this study which is situated within the wider CRIMSON trial, as for the overall trial the focus of recruitment was not on south Asian service users specifically. CRIMSON was concerned with the whole population within recruitment sites, hence the recruitment strategy was to approach all eligible service users within the clinical teams. Likewise the ratio of those south Asian participants was not of interest in terms of either the geographical population or the health service rates.

Results from diary entries

Diary entries were made for those service users where there was a need to consider cultural issues in the recruitment process. In this case, cultural issues are defined as issues that require researchers to go above and beyond the standard recruitment procedures for the trial. Ethnic minority participants who did not have any language barriers to recruitment or need any additional strategies to be employed to assist their
recruitment were classified as having 'no cultural issues'. Figure 23 below, shows the number of south Asian participants who were recruited from the Manchester/Lancashire site and the number that were included in the diary accounts by the research team. The term 'delayed refusal' introduced in the diagram refers to those participants who initially stated that they would like to be involved within the trial and then who later failed to engage and withdrew their interest. This process is described in more detail within the diary entries that are presented within this study.

**Figure 23: Flowchart to show the recruitment of south Asian participants from the Manchester/Lancashire site**

A breakdown of the ethnicity of the participants is tabulated below in Table 49, showing a comparison between those that presented cultural issues for consideration against those that did not.
Table 49: Socio-demographics of south Asian participants

<table>
<thead>
<tr>
<th></th>
<th>Cultural Issues (n=10)</th>
<th>No Cultural Issues (n=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Mean Age (years)</td>
<td>39.2</td>
<td>32.7</td>
</tr>
</tbody>
</table>

Cultural Issues

<table>
<thead>
<tr>
<th></th>
<th>No Cultural Issues (n=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>UK born</td>
<td>2</td>
</tr>
<tr>
<td>Non UK born</td>
<td>4</td>
</tr>
<tr>
<td>Indian</td>
<td></td>
</tr>
<tr>
<td>UK born</td>
<td>2</td>
</tr>
<tr>
<td>Non UK born</td>
<td>1</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>UK born</td>
<td>-</td>
</tr>
<tr>
<td>Non UK born</td>
<td>1</td>
</tr>
</tbody>
</table>

The 13 south Asian participants that did not require additional cultural considerations during the process were recruited without any issues and so diary entries were not made for these people. The remaining 10 participants that were recruited, along with the 9 people that were approached but refused, are referred to in the following diary extracts, taken from field researchers’ experiences of the recruitment process. The recruitment of south Asian participants into the CRIMSON trial often required numerous visits; one participant (NA, 31 years old, UK-born Pakistani female) was visited three times and it took six separate visits to recruit another participant (NM, 29 years old, Pakistani-born male). The range of visits to successfully recruit the 23 south Asian participants into the study was 1-6 with the mean being 1.74. The recruitment of white British participants took less visits with the number of visits needed not exceeding 2. The range for the recruitment of this group was 1-2, with the mean being 1.10.

The analysis from the diary entries produced 12 themes, which are explored in turn below. The quotes provided are taken directly from the field researchers’ diary entries and refer to their experiences with the recruitment of participants. The details of the participant that the diary entry relates to are provided.

Theme one: Care coordinator involvement

Due to the structure of mental health services and the way the trial was designed, care coordinator involvement was crucial for recruitment as the coordinators acted as gatekeepers to the researchers by opening communication with the service users. The service user could not be approached directly by the researchers without prior consent being obtained by the care coordinator. Their role served several functions, from conducting a joint visit or providing their support in discussing and encouraging
recruitment. On occasions the care coordinator was instrumental in actually arranging the appointment where the trial would be discussed.

“It was agreed that the participant would discuss this in the near future with their care coordinator who would consequently contact me with the information” (MI, 55 years old, Pakistani-born male).

The role of the care coordinator varied depending on whether they could speak the potential participant’s first language. In some cases an English-only-speaking care coordinator would be limited to providing an introduction to the researchers. On other occasions, multi-lingual care coordinators were able to actively promote the research in the participant’s first language.

“My first contact with her was a joint visit with her English-only-speaking care coordinator” (GB, 36 years old, Bangladeshi-born female).

“At my first visit to this woman I was accompanied by the Urdu-speaking care coordinator” (RK, 29 years old, Pakistani-born female).

“I visited the service user with their care coordinator and an interpreter who could assist with asking the questions in Gujarati” (AB, 42 years old, UK-born Indian female).

Theme two: Availability of bilingual information

The research team ensured that all study materials were translated into Urdu and Gujarati so as to avoid exclusion on the basis of limited English language skills. This included information sheets, consent forms, baseline assessments and intervention materials. Such information sheets were offered to all potential participants for whom Urdu or Gujarati was their first language. Depending on the individual concerned and advice from their care coordinator, information sheets were either posted out first or delivered in person and information sheets were also sent out to their families or key workers where appropriate.

“As SU’s first language is Gujarati, an information sheet was posted out to her in Gujarati with an accompanying note saying that someone would be in contact soon” (AW, 53 years old, African-born Indian female).
“The participant information sheet was left in both the English and the Urdu version” (MI, 55 years old, Pakistani-born male).

**Theme three: Need for multilingual staff/interpreters**

Five participants that were recruited required the presence of an interpreter so that consent and baseline information could be obtained in Urdu. Occasionally the allocated care coordinator was involved in assisting the consent process by interpreting the study information and facilitating a meeting with the participant and researchers.

“This participant’s first language is Urdu so on the first visit I went along with their care coordinator who was able to translate the study information for them to help them make a decision about whether they would like to hear more about it” (MI, 55 years old, Pakistani-born male).

In one instance the care coordinator always planned their regular visits alongside an interpreter and they were instrumental in setting up an appointment with the researcher.

“The care coordinator arranged her appointments by visiting with an interpreter and setting a date for the next visit before leaving the house. We arranged to offer the service user a provisional date for myself and our interpreter to visit in the same way, which was successful” (AB, 51 years old, Pakistani-born female).

The recruitment process highlighted the necessity of researchers to check the language skills of participants. One participant’s first language was Bengali, and whilst it was originally thought that a Bengali interpreter would be necessary, initial contact with an Urdu speaking senior researcher showed that the participant’s Urdu skills were adequate to complete the assessment. This particular assessment required flexibility from the researcher as they explain:

“The discussion included her husband, who did not have Urdu fluency, was in all three languages, with the service-user interpreting her husband’s Bengali into Urdu for the interpreter to convey to me” (GB, 36 years old, Bangladeshi-born female).

On occasion family members assisted the translation process:
“His wife knew how to speak English. All the same it was important that he understood what was going on so I translated for him in Urdu. My problem with this interview was that mostly his wife answered for him and on some questions she would answer even before I had a chance to translate it for him, however I am confident that we got accurate answers” (NM, 29 years old, Pakistani-born male).

Two participants required a Gujarati interpreter throughout the recruitment process. One of these was a member of the Community Mental Health Team, who was not directly involved in the service user’s care. The second was a clinical studies officer who worked as part of the Mental Health Research Network (MHRN) a government funded network to support and coordinate research. The input from these professionals was invaluable in recruiting these participants.

“During the consenting visit it was really useful to have the CSO [Clinical Studies Officer] there as their care coordinator reports that they don't usually take an interpreter on their standard visits which can lead to limited communication” (AW, 53 years old, African-born Indian female).

The presence of an interpreter, when this has previously been lacking in the service user’s treatment, was found to have a beneficial effect on the participant’s clinical care as recounted in the observations below. In this instance the care coordinator had previously told the researcher that they did not know which language the service user spoke.

“The participant also said that they really felt listened to by having someone converse with them in their first language; so much so that they shed tears as they felt someone understood them. The CSO called the service user in a few days’ time and they said that they would like to take part, so the baseline assessment date was set up. The service user once again commented on how good it was to speak openly with the CSO as they felt understood and that someone was really listening to them” (AW, 53 years old, African-born Indian female).

The interpreter reports their experiences of the aforementioned visit highlighting the value of them being present from their perspective:

“The husband sat in majority of the visit, conversing at times about his wife’s illness. They were both very respectful and seemed very pleased to have someone that spoke their language. She was very happy to speak to someone that was listening to what
she had to say and at one point she did start to cry and reassurance was given. She seemed very confused and unclear about her treatment and in general about her mental illness. The impression I got from the two visits with this person was that she lacked knowledge about the mental health service, what they provided her and whom she should contact. For example, one of the questions she repeatedly asked me was ‘why do they keep giving me the injection? It makes me very ill and I want to stop it’. Hence it appeared she had no understanding/education around the depot injection.

Also she kept referring me to as ‘bhati’ which means daughter in English, rather than my name, in Gujarati this is used in the community for the elderly to name the younger females. In addition to this she kept saying in Gujarati, directing at me that ‘us Indians know what it is like in the ethnic community and being around a big nuclear family, having a busy household’.” (AW, 53 years old, African-born Indian female).

On one occasion an interpreter assisted the researcher in explaining the trial to the potential participant over the phone prior to the visit. The presence of an interpreter and a conversation with a male Urdu-speaking doctor did not affect the service user’s decision to refuse participation. They were clear that they did not want to attend meetings with people that were not already involved in their care. The researcher’s account describes the recruitment attempts.

“This man’s care coordinator told me that his first language is Pashtu, but that he also has some Urdu and English. In order to test whether the Urdu was sufficient for assessment, an Urdu-speaking male doctor arranged an appointment by telephone in Urdu for myself and the interpreter to visit to explain the study further. At the house, we met him and his married sister whose family he lives with. We spoke in English throughout as both were fluent and explained the study. Neither the service user nor his sister wanted to become involved in research” (HK, 31 years old, Pakistani-born male).

**Theme four: Timing of appointments**

The timing of appointments affected the likelihood of getting consent. It was important to select the most convenient time for the participant. It was also important that researchers were flexible to attend service user’s pre-arranged appointments with their care coordinators, where appropriate.
“Unfortunately this was at a rather stressful time for the family (school holidays) and care coordinator (the appointment had been delayed over an hour due to a crisis with another service user). The care coordinator had not informed the service user of the delay, but was nonetheless welcomed” (NM, 29 years old, Pakistani-born male).

“At this appointment the service user was visibly very tired indeed and it was clearly an inappropriate time to seek informed consent for research. His wife said that they had relatives visiting and had all been up very late the night before. She told me that this happens quite a lot, and I had the impression that they found it overbearing, but had to go along with it for fear of offending family. School holidays were again due, so we agreed to leave it for the present” (NM, 29 years old, Pakistani-born male).

An interpreter describes how the timing of the appointment needed to be changed during their initial visit.

“When she eventually came for the interview she could not get on with the interview as there was a lot of interference from her father in law. She was asked to leave the interview and make breakfast for him. Additionally she seemed ill at ease and a bit flustered hence we decided to re-arrange the interview for another day” (RK, 29 years old, Pakistani-born female).

Throughout the recruitment process, it was not unusual for appointments to be cancelled at short notice or for participants not to be at home at the arranged time. This required persistence and flexibility from the researchers.

“I was able to make an appointment to visit them on my own. However, they weren’t in and his wife later telephoned to apologise and re-set the appointment. As she has good English, she had had to accompany a non-English-speaking relative to a hospital appointment, which she has to do for a number of people” (NM, 29 years old, Pakistani-born male).

“The interpreter’s child was ill, so she had to cancel the appointment. I explained this to the service user’s wife and arranged another date” (NM, 29 years old, Pakistani-born male).
**Theme five: Awareness of religious obligations and festivities**

The timing of appointments, as explored above needs to be considered not only in terms of timings of the day or fitting around other appointments, but in terms of religious obligations. This cultural sensitivity was shown in the recruitment of one participant as explained below.

“Upon arriving at the participant’s house the care coordinator noticed that the participant looked extremely tired and his behaviour indicated limited concentration. The participant explained that he was currently fasting for Ramadan and had been up very late the previous night worshipping. I made a joint decision with the care coordinator that I would provide a very brief amount of information about the research and then if they were interested in hearing more about it then I would arrange to come and visit again after Eid. The participant was able to concentrate enough to take in the research summary information and was very eager for me to visit again and so suggested a date the following week” (EP, 36 years old, UK-born Indian male).

**Theme six: Family involvement**

The most frequent issue that arose from recruitment of south Asian participants was the necessity to include family members in visits and in the decision as to whether participation was right for them. Family involvement often resulted in participants requiring numerous visits, as highlighted later in the diary extracts, and the flexibility of researchers in providing sufficient time to allow that decision to be made.

“On the first visit the participant was very interested in the study and asked if I could also talk through the information with their sister, stating that they would like to discuss it as a family after I had gone. I arranged to contact the participant again by phone and another appointment was arranged, where this time I met their father and brother” (NA, 31 years old, UK-born Pakistani female).

In addition to general requirement of family involvement in recruiting participants, it was observed that with female participants it was also necessary to involve male family members; usually their husband, father, father-in-law, or uncle. This involvement helped to develop trust between the family and the researcher and was often crucial in the participants obtaining permission from this person to take part.
“On the first visit the female was in the house alone and was concerned that their husband was not in, so after a discussion it was decided that it may be helpful if she called her sister that lived across the street from her. On the second visit the participant had previously discussed the study with their family and they ensured that their husband was in the house. I was formally introduced to their husband and the participant said they felt it important for me to sit with him and get to know him before we began the interview. For this participant an important factor in her decision to participate was whether her husband trusted me and agreed to her participating or not. Therefore additional time was needed to build up this relationship prior to commencing the baseline interview” (NA, 30 years old, UK-born Pakistani female).

“Service user’s husband and son advised them to take part and whilst they fully understood the study and gave informed consent, without the approval from their family, it would have been far more difficult to engage her” (AB, 42 years old, UK-born Indian female).

“She said that she would need to ask her uncle for permission” (RK, 29 years old, Pakistani-born female).

Family involvement in recruitment was also shown to be useful in terms of the family having insight into the service user’s illness. This was helpful in relation to the research as they could highlight the specific benefits that involvement in the research could have for the individual.

“The service user was rather preoccupied with other problems and was not really interested in the study, but his wife was extremely interested because she saw the potential value of the intervention in helping her manage her husband’s crises. We agreed that I would contact them again in several months’ time” (NM, 29 years old, Pakistani-born male).

Theme seven: Rapport with participants

The rapport that both the researchers and interpreters built up with the participants over the initial meetings with them was a key factor in whether they were successfully recruited into the study or not.

“The interpreter asked the majority of the questions and this really helped engage the service user, as they also spoke a lot about more general things that appeared to build up trust from them” (AB, 42 years old, UK-born Indian female).
“It was clear that the service user’s wife and the interpreter had immediate rapport on the topic of concern over young children’s health, which made the atmosphere very pleasant” (NM, 29 years old, Pakistani-born male).

Theme eight: Clear and unambiguous explanations of the study

The explanation of the study and the researchers’ ability to describe processes in culturally sensitive terms was important in obtaining informed consent from the participants.

“A long time was spent with the family exploring what the potential benefits of being involved in the trial may be and I frequently reiterated the importance of anonymity and confidentiality within the study” (AB, 42 years old, UK-born Indian female).

It was found to not only be general study terms that require clarity in their explanations, but an awareness of specific word meanings and how they could be misinterpreted was necessary, as explained below.

“The service user remembered my visit with her previous care coordinator and said that she had misunderstood what was involved for her. She thought that because the project was described as a study, that she would have to go to college, which she didn’t want to do” (RK, 29 years old, Pakistani-born female).

The clinical and research terminologies used by researchers and their explanations of confidentiality addressed most participants concerns. However at times, particularly in case of accessing medical case notes, participants’ suspicions could not be overcome.

“I spoke with the service user on the phone. They wouldn’t allow their medical documents to be accessed under any circumstances and did not want any involvement in 18 months’ time for the follow-up period” (DB, 44 years old, UK-born Pakistani male).

Theme nine: Service users did not think that the research could benefit them

Following communication between the researchers and service users with regards to the trial, five south Asian service users refused their participation in the trial on the grounds that they did not feel that it could benefit them.

“I spoke with the service user several times on the phone and posted out information. They recognised it sounded interesting but said ‘it’s not for me’. They said they want to
look forward and forget the past; they do not want to talk about their illness and wants to move on with their life” (IA, 31 years old, UK-born Pakistani male).

Other reasons for service users not valuing the potential benefits that the research might offer related to their level of insight into their illness or to the service user putting greater priority on addressing their current treatment.

“She doesn’t want to take part because she states that she doesn’t have mental health problems anymore” (HP, 37 years old, UK-born Indian female).

“I visited the service user, who refused and didn’t see the benefits. He is more concerned with changing his medication” (HA, 34 years old, UK-born Pakistani male).

An interpreter described one of their experiences where family were involved in relaying the potential participant’s views:

“We never really had the chance to interview him because when we sat down for the interview his sister who could speak fluent English came and said that he doesn’t want to be involved in any interviews as he already has a lot to do and does not want to take on anymore involvement in any kind of interviews” (HK, 31 years old, Pakistani-born male).

Theme ten: Participant did not attend appointments because they felt if they did they would be unable to refuse consent

On two separate occasions, after initial telephone contact, two service users appeared to be very interested in hearing more about the trial and becoming involved. Yet, despite this apparent interest, the service users both withdrew their expressions of interest. It would appear that they had not felt that they could express their true views when conversing with the researcher, as they were keen to please and not disappoint.

“I arranged an appointment with the service user who sounded keen. I arrived at their house and they were not there. I rang the service user and they said they had forgotten and so I arranged another appointment. I rang them prior to the new appointment to check that they were still available; they said they are not interested and do not want to meet up despite having arranged meeting previously” (MS, 40 years old, UK-born Pakistani male).

“I spoke to the service user on the phone, they sounded eager to set up an appointment, so a provisional date was set. Prior to the appointment date, the service
user texted me to cancel the appointment and said they would text back in a day or two to set a new appointment. I had not heard back from them so I texted them a week later to see if wanted to rearrange, to which they replied ‘no but thanks!’ In this case they obviously didn’t feel that they could say no to the researcher when speaking over the phone”. (FD, 25 years old, UK-born Indian female).

**Theme eleven: Needing time to decide**

Providing sufficient time to reflect on the written study information was crucial to recruiting south Asian participants. This extra time provided an opportunity for potential participants to have discussion with their family, which helped them to make a decision.

“The participant expressed initial interest in participating and requested that they have some time to think about it and discuss it with their son” (MI, 53 years old, Pakistani-born male).

“It was decided that the participant should be given time to digest the information about the study and so information sheets were left with her and her husband” (AW, 53 years old, African-born Indian female).

**Theme twelve: Opportunity to communicate with senior research staff**

During the recruitment process the researchers received assistance from an Urdu speaking male psychiatrist (WW) who was a senior member of the research team. On two separate occasions he was able to telephone the participant (or participant’s family) and make the initial contact. Making this initial contact in Urdu helped build rapport and made it easier to assess the willingness of the participant to become further involved in the recruitment process.

“I never received an answer from the uncle, but the new care coordinator had no objection to him being approached directly in Urdu. A male Urdu-speaking doctor telephoned him and he quickly gave his permission for the service user to participate, and passed the phone to her and an appointment was made for myself and the interpreter to visit the following week, which we did, successfully” (RK, 29 years old, Pakistani-born female).

There was one occasion where the doctor accompanied a researcher on the consent visit. The participant appreciated the presence of a doctor who was able to explain the study in Urdu.
“I asked if I might visit with an Urdu-speaking doctor (male). This visit was extremely successful. The conversation was mostly, but not wholly in Urdu and the tone very cordial. The outcome was that the service user agreed to be assessed for the study and we arranged an appointment with the interpreter” (NM, 29 years old, Pakistani-born male).
Study 3: Joint crisis plan culturally relevant statement analysis

**Purpose of this study**

Through analysis of the joint crisis plan documents completed by the service users and their clinical teams, the author aims to determine whether the intervention brings out cultural issues for the service user. This section of the results will report on the joint crisis plan content from the south Asian and black participants across all three recruitment sites (n=71). Following the thematic analysis of the plans (as described in Chapter 6) each section of the plan was revisited and those transcripts which were deemed by the author to have a cultural reference, whether that be related to ethnicity, language, family, geographical area or religion were selected.

**Numbers of south Asian and black participants who made a culturally relevant statement within their joint crisis plan**

Table 50 below shows the number of people from two combined ethnic groups (south Asian and black, which includes African and Caribbean) who made joint crisis plans and the percentage of those who made culturally relevant statements within their plan. In total 20 service users (9 from London, 7 from Manchester/Lancashire and 4 from Birmingham) made a culturally relevant statement, related to their treatment preference, refusal or general issues surrounding their mental illness.

**Table 50: Number of people who made cultural references**

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number of people who made JCPs</th>
<th>Number of people who made cultural references</th>
<th>% who included cultural references</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Asian</td>
<td>25</td>
<td>11</td>
<td>44%</td>
</tr>
<tr>
<td>Black</td>
<td>46</td>
<td>9</td>
<td>20%</td>
</tr>
<tr>
<td>Total</td>
<td>71</td>
<td>20</td>
<td>28%</td>
</tr>
</tbody>
</table>

The ethnic breakdown of these participants is highlighted in Table 51 below, which also documents the particular section of the joint crisis plan in which they made the reference to a cultural issue.
Table 51: Number of participants included within content analysis, their ethnicity and sections of the joint crisis plan they made cultural references within

<table>
<thead>
<tr>
<th>Trial number</th>
<th>Ethnicity</th>
<th>Circumstances leading to illness</th>
<th>Other information</th>
<th>Specific refusal</th>
<th>Helpful during crisis</th>
<th>Not helpful during crisis</th>
<th>What happens when first unwell</th>
<th>Preference for when first unwell</th>
</tr>
</thead>
<tbody>
<tr>
<td>P01109</td>
<td>Asian/Asian British (Pakistani)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P01151</td>
<td>Black/Black British (Caribbean)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P01189</td>
<td>Asian/Asian British (Pakistani)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P01191</td>
<td>Asian/Asian British (Pakistani)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>P02047</td>
<td>Black/Black British (African)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P02087</td>
<td>Asian/Asian British (Bangladeshi)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P02103</td>
<td>Asian/Asian British (Indian)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P02105</td>
<td>Black/Black British (African)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>P02121</td>
<td>Black/Black British</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>P02126</td>
<td>Black/Black British (African)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P02172</td>
<td>Black/Black British (Caribbean)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P02174</td>
<td>Black/Black British (Caribbean)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>P02186</td>
<td>Asian/Asian British other (Sri Lankan)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>P03038</td>
<td>Asian/Asian British (Indian)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>P03040</td>
<td>Asian/Asian British (Pakistani)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P03058</td>
<td>Asian/Asian British (Pakistani)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P03059</td>
<td>Asian/Asian British (Pakistani)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P03064</td>
<td>Black/Black British (African)</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>P03081</td>
<td>Black/Black British (African)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P03142</td>
<td>Asian/Asian British (Indian)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
Content analysis of joint crisis plans

The content analysis from the joint crisis plan was completed and the transcript of cultural references is documented below, categorised by sections of the plan, which have been labelled with letters for the purpose of this analysis. The headings within each joint crisis plan were not mutually exclusive and a service user may have made a comment within one section that could be applied to another. For the purpose of this analysis they have been kept within the context of the section they appeared on their joint crisis plan. As previously stated, the author of this thesis had no involvement with the formulation of the joint crisis plans. The category within which service users’ statements were recorded within was therefore ultimately the decision of the facilitator. The menu of options given to service users contained a range of considerations which may be relevant and there were no specific rules in regard of what was acceptable under each category; it was very much left to the autonomy of the service user with guidance and support from their nominee, clinical team and intervention facilitator. Hence within any one category a mixture of factors were considered and some statements include independent life events, cultural attributions or delusional thinking. No differentiation was made between these inclusions, as the content remained under the heading where it had been initially recorded.

Section A: Circumstances that may lead to me becoming unwell or have done in the past

12 service users reported that the circumstances leading to them becoming unwell included a cultural issue. These issues ranged from religion, travelling, concerns relating to their home country and to gaining asylum. The number accompanying each culturally relevant statements is the participant’s unique trial identification number.

- P01189: “Too many big stressors happening all at once e.g. moving house, Eid and the anniversary of my brother’s death. I find any special occasion (Eid, Christmas) difficult to deal with due to the increased stress”.
- P01191: “Travelling abroad- I became unwell whilst travelling in Pakistan and delving too deep into religion”.
- P02047: “Staying on my own -my wife is in the Congo”.
- P02103: “I went to a Scientology group, these are bullies”.
- P02126: “Stress, like waiting to hear about leave to remain in the country and worried about my future. (I now have leave to remain in the country)”.
- P02172: “Sometimes too much medication and prayer”.
- P03038: “Jinns attacking me (beating me)”.
- P03058: “Seeing police on the T.V, and anything associated with bad things to do with Pakistan- I worry about my mother & home”.
- P03059: “I worry all the time about how I will get to live in Pakistan”.
- P03064: “The Jinn attacks me all the time, the spirit is female and she wishes to control me, when she attacks me this is when I become unwell”.
- P03081: “Difficulties with gaining asylum in this country”.
- P03142: “Missing my children - if they are at school or have gone away on holiday to India, being alone for a long period”.

**Section B: Other information I would like to be known or taken into account**

The eight people who mentioned cultural information within this section all referred to the importance of their diets, with one person adding that they did not want to be seen by male doctors and two people emphasising the importance of their faith.

- P01109: “Special diets”.
- P01151: “No Pork or drinks with orange to be offered to me”.
- P01191: “Halal food to be offered to me”
- P02087: “No male doctors. I do not eat pork or beef”.
- P03038: “Halal food or vegetarian”.
- P03040: “Low fat diet & Halal diet”.
- P03064: “I would like to have a Halal food and time to pray”.
- P03142: “I would like a halal diet and I would like my faith to be considered when looking at treatment options”.

**Section C: Specific refusals regarding treatment during a crisis or relapse**

One service user made a refusal based on her religious beliefs.

- P03142: “Does not want male staff nursing her due to her religion, although this is ok if no female staff are available as long as her husband is present”.

206
Section D: Treatments or other things that have been helpful during crises or relapses in the past

Two people documented things that were helpful during past crises to be related to praying and seeking support from a religious leader.

- P03038: “Having time to pray”
- P03064: “I have to block out the Jinn and ignore what she is saying to me. My medication helps a little with the Jinn, I can cope a little better with the medication. Also having time to talk to care coordinator and seeing my Imam helps me”.

Section E: Treatments or other things that have not been helpful during crises or relapses in the past

Two people included comments about unhelpful things during crisis to be their feelings of discomfort with people talking in languages they don’t understand and hospital to relieve distress.

- P03064: “I did not find hospital helped me at all, the noise and the other patients made me feel worse. But some of the nurses did help by talking to me and the Jinn became less distressing”.
- P02174: “Staff around me talking in foreign languages- makes me paranoid that they are talking about me”.

Section F: What happens when I first start to become unwell?

All seven people who made cultural references to the onset of their illness included comments relating to their religion.

- P01151: “My church beliefs got affected”.
- P01191: “I read the Quran a lot more. I changed my sect from one way of understanding Islam to another”.
- P02121: “I think about religion more than usual”.
- P02126: “Hearing voices in different African languages, they sometimes tell me to harm other people and harm myself. I have tried to cut my arm with a knife. I have crazy thoughts about a powerful German/Sudanese who has lots of
money and lots of women and will destroy America and I think I can be like him. In my head there was a conflict between this powerful German and the Prophet Mohammed and I hated my religion and the Koran. In my head I was becoming like a powerful Prophet”.

- P02186: “Sometimes I am thinking I am like a God and can help people, like blocking traffic so people can cross. Once I went to the temple and started to fix things and they called the police”.
- P03038: “I believe the jinn will attack me and has done in the past”.
- P03064: “The Jinn will begin to shout at me, at this point my sleep is disturbed and my diet goes. I will listen to the Quran (Koran) and begin to write things down out of the Quran. This makes the Jinn worse and she attacks me”.

Section G: What I would like to be done when I first start to become unwell

One person referred to church support to be useful when they first become unwell.

- P02105: “Use outside support for distraction such as my church”.

Summary of results

Table 50 shows that in total 28% of people from south Asian and Black ethnic groups made a culturally relevant statement within their joint crisis plan. Furthermore whilst only 20% of black service users from the small sample did (9/46), the figure for south Asian service users was much higher at 44% (11/25). The chi-square statistical test was administered which found this difference between ethnic groups to be significant (p=0.03).

The transcripts show that cultural references were made throughout the joint crisis planning documents with service users citing cultural influences on them becoming unwell and in their treatment preferences.
Chapter 8: Discussion – Differential effect of joint crisis plans, yet positive implications for ethnic minority trial recruitment

Overview

This discussion will begin by summarising the main findings of the three studies that make up this thesis, considering reasons for divergent findings where appropriate. The limitations and strengths of each component study will be examined in turn, before considering the broader implications for future research on joint crisis plans and the inclusion of ethnic minorities in research.

Study 1 found no significant treatment effects for south Asian and black participants combined. Further sub-analysis found that south Asian service users may well respond differently to black service users (and more like white-British participants), with hospital admissions increasing, rather than decreasing. The testing of hypothesis 3 suggested that these paradoxical treatment effects cannot be explained by therapeutic working alliance. It is possible that different ethnic minorities respond very differently to joint crisis plans and this may therefore in effect be a culture bound intervention.

Study 2 found that through addressing the barriers to recruitment highlighted in previous literature, recruitment of ethnic minorities could be improved and strategies included to eliminate barriers, with the diary entries adding to existing knowledge. Analysis of joint crisis plans in study 3 provided less culturally relevant statements than anticipated within the sample, although such statements were more frequent with south Asians compared to black service users.

The three studies have added to existing knowledge about joint crisis plans by focussing on ethnic minorities, the findings suggesting a difference in effect for different ethnic subgroups. Future research with joint crisis plans would require development of the intervention to promote cultural considerations. Future qualitative work is suggested to explore what lies behind these apparent differential effects for ethnic minorities. Training to develop cultural awareness in clinicians and researchers has been suggested following the diary entries, which could inform ethnic minority recruitment across mental health research.
Study 1: Strengths, limitations and implications

Summary of findings

Whilst it was expected that there would be an effect in CRIMSON overall on the three hypotheses, and that this effect would be even greater with ethnic minorities, this was not found to be the case. CRIMSON showed no evidence of effect for the intervention (with the exception of some evidence to support an improvement in working alliance). In study 1, three hypotheses were tested, which predicted that joint crisis plans would result in a significant reduction in compulsory hospital admissions and ‘any’ hospital admissions and an improvement in working alliance. This analysis includes a sample of south Asian and black (black African/black Caribbean) participants. These hypotheses all fall under study 1 of this thesis. Hypothesis 4 predicted a greater treatment effect for the ethnic minority group compared with the white British group. These findings will be discussed within the context of the previous three hypotheses.

Hypothesis 1: Joint crisis plans will significantly reduce the proportion of service users from south Asian and black ethnic groups, treated under a section of the Mental Health Act at any point during the follow-up period, compared with service users from south Asian and black groups in the control condition.

Hypothesis 1 was not supported. South Asian and black participants in the intervention arm were 12.6% less likely to have an admission than those in the control group, although this finding was not significant (p=0.71, 95% CI= 0.43-1.77). This is in line with the CRIMSON trial (OR = 0.89, p=0.58, 95% CI= 0.57-1.37). Analysis on the black group only (n=121) found the odds ratio was 0.56 (p=0.18, 95% CI= 0.24-1.30) whilst for south Asians (n=55) the odds ratio was 6.97 (p=0.08, 95% CI= 0.80- 60.87). These findings for the black group were in the direction predicted, although were not significant. The findings for south Asian participants were in the opposite direction to that predicted and imply that the intervention increases the odds of a compulsory hospital admission, although these findings were not significant. Analysis on the white British participants (n=307) also showed non-significant findings (OR= 1.14, p=0.68, 95%CI= 0.61-2.11), although this was in the opposite direction predicted (in line with the south Asian subgroup).
Hypothesis 2: Joint crisis plans will significantly reduce the proportion of service users from south Asian and black ethnic groups, with a psychiatric hospital admission (formal or informal admission) at any point during the follow-up period.

Hypothesis 2 was not supported. South Asian and black participants in the intervention arm were 18% more likely to have an admission than those in the control group, although this finding was not significant (p=0.62, 95%CI= 0.62-2.24). This finding is similar to the analysis on white British participants (n=307, OR=1.19, p=0.50, 95%CI= 0.72-1.98). Whilst not significant, this does raise concerns as it implies that joint crisis plans work in the opposite way than predicted, in that they cause rather than prevent hospital admissions; this is an area that will be explored throughout this chapter. That said, as the finding is non-significant and the confidence intervals are wide, no evidence of effect is observed. Analysis completed on the black group only (n=121) found that the odds ratio was 0.72 (p=0.41, 95% CI= 0.33-1.57) with findings in the direction predicted, although these were not significant. The confidence intervals are wide, so a clinically significant effect cannot be excluded, suggesting that the study is underpowered for this sub-analysis. Findings for the south Asians (n=55) were significant in the opposite direction to that predicted with those in the intervention group more likely to be admitted to hospital (OR= 4.63, p=0.04, 95% CI= 1.11-19.21), whilst there was no effect observed in the overall CRIMSON trial (OR= 1.00, p=0.99, 95% CI= 0.69-1.45).

In summary, when ethnicity is considered there is a tendency for black participants to have fewer admission and white British and south Asians to have more; in the case of south Asians this finding is actually significant. The significant finding for south Asians in this analysis is not surprising as compulsory and all admissions are correlated (as compulsory admissions also count in all admissions). Thus evidence is mounting that not all ethnic groups react to joint crisis plans in the same way; the black group has possibly seen a reduction in admissions whilst south Asian and white British groups have actually gone up.

Hypothesis 3: Joint crisis plans will significantly improve service users’ perception of their therapeutic alliance with their care coordinators.

Hypothesis 3 was not supported in this study. Whilst the results show an improved self-reported therapeutic relationship (WAIC) in the intervention arm for south Asian and black participants combined, neither the unadjusted difference (mean 0.80, 95% CI= -
3.02-1.47, p=0.49) nor the adjusted treatment coefficient (B=2.69, 95% CI= -2.95 -8.32, p=0.35) were statistically significant. This finding was consistent when analysis was completed on south Asian participants only (B=1.57, p=0.69, 95%CI= -6.33-9.48 and black participants (B= 0.18, p= 0.99, 95%CI= -2.64-2.67). The findings for the overall CRIMSON trial did support a significant improvement in working alliance for participants in the intervention arm (B=1.28, p=0.049, 95%CI= 0.01-2.56), hence a critical factor is whether the size of the effect was similar in the ethnic minority group to that found in the white group. When the analysis was completed for white British participants only (n=249), the finding indicated a more positive working alliance although this was also not significant (B=1.99, p=0.15, 95%CI= -0.71-4.70). The implication from this finding is that working alliance does not account for the paradoxical effects of joint crisis plans on hospital admissions; as whilst non-significant, the consistent tendency is for working alliance to improve after the joint crisis plan in all ethnic groups, with a significant finding observed within the overall CRIMSON trial.

In summary, all 3 hypotheses were not supported in this study for the combined south Asian and black group. This is surprising on two levels; firstly as it was predicted that they would be supported for the CRIMSON trial and, secondly, that the treatment effect would be anticipated to be greater within the ethnic minority sub-analysis within this particular study. The findings suggested that the joint crisis plan worked differently for south Asian participants compared with the subgroup analysis of black participants only; with south Asians responding in a similar way to white British participants. Previous findings have predominantly shown an effect for joint crisis plans on the whole sample, as previously reported, although CRIMSON is the first trial to explore the effects on ethnic minorities as a pre-specified subgroup; therefore there are no directly comparable findings in terms of the south Asian and black group analysed within this study. The strengths and limitations of this study will be discussed prior to exploration of the external and internal validity of the above findings.

**Strengths and limitations**

The key strengths of this study are the reliability of the joint crisis planning intervention, in that CRIMSON has followed pilot work around crisis cards and joint crisis planning with the same format of intervention being adopted in this current study. The methodology of the study was robust; participants were randomised to either the intervention or control arm of the trial and rigorous strategies were implemented to ensure the researchers remained blinded to the allocation of participants. The overall CRIMSON trial was
relatively large and it can be assumed, from the numbers involved and the multiple recruitment sites that the overall sample is likely to be a representative group. That said, the sample size for study 1 is just 128, which could be argued to be a limitation. Whilst it could be said that the numbers in study 1 are actually too small to show a clinically significant treatment effect, this is unlikely as the overall CRIMSON trial was powered to show a difference on black participants alone, so there should be adequate numbers for the combined ethnic groups. This consideration may be more important in respect of the analysis completed on the smaller number of south Asian participants only.

It is also important to highlight that it was decided not to make adjustments for multiple comparisons. This was to avoid presenting an overly conservative finding, which may incorrectly accept the null hypothesis. This needs to be considered alongside the decision not to complete exploratory post hoc analysis on more defined ethnic subgroups; as the limitations of grouping a number of distinct ethnic groups under the overall broader category of south Asians has previously been discussed. One option to overcome such differences would have been to complete analysis on specific south Asian ethnic groups to detect any differences in these groups; this could have similarly been done to detect any differences within the studies between black African and African Caribbean service users. The decision to omit such exploratory analysis from the studies is related to the methodological considerations of meaningfulness of the data; given such small numbers within subgroups and the effects of multiple testing affecting the findings. The analysis would also have reduced the transferability of the findings to wider research and clinical practice.

The inclusion of translated materials within the study was designed to increase the recruitment of ethnic minorities into the research, in line with recommendations previously made within this thesis. It also aimed to account for limitations to previous research and this is considered to be both strength and a weakness. Whilst these translations enabled the study to recruit south Asian participants with the first languages of Gujarati and Urdu, no translations into additional languages were made. Whilst the decision to withhold additional translations was due to there being less need, there is a clear limitation in that the original approach to participants was not always in their first language. The majority of black participants spoke English as their first language and translations into additional languages could have increased the representation of black participants who did not speak English well. However, additional full translations would have incurred greater costs despite only being for a small number of individuals. It is therefore accepted that a representative sample of
black participants may not have been achieved, although it must be noted that the recruitment figure for black (black African and black Caribbean) participants was only marginally under the target recruitment figure.

A weakness of this study would be the argument that ethnic groups are heterogeneous in their effects, so adding the south Asian and black participants together does not make much sense. It would seem from the summary of results that this is the case as the findings often showed a paradoxical effect of joint crisis plans for south Asians compared with black participants. Despite training for the facilitators regarding delivery of the intervention and close supervision to ensure standardisation and quality of the joint crisis plans, it is not clear that there was sufficient cultural sensitivity in the way in which it was delivered. This is explored in detail within study 3 of this thesis. The unplanned sub-analysis on the south Asian participants may indicate a study weakness, as the findings may be due to chance. However it is notable that few studies are large enough to look at ethnic minorities as a separate group, so it would be unwise to entirely dismiss the possibility that the findings are correct.

*Divergence of findings for south Asian and black participants*

It is important to consider why the hospital admission findings may be divergent for south Asian compared to black participants. It is proposed that the issue of language has relevance here as, to make a generalisation, it was observed that most black participants spoke English as their first language. There were a higher proportion of south Asian participants for whom English was not their first language and required the use of an interpreter within the trial, whereas interpreters were not needed for any of the black participants. A plausible explanation is that south Asians are somehow being inappropriately excluded from using inpatient care because of language and cultural barriers; the effect of CRIMSON was therefore to help the care coordinators cement links that had previously been weak. Conversely, with black service users, there was overuse of inpatient care, indicating a build-up of trust that could potentially have led to earlier responses to developing crises. Given the limited data this cannot be said to be a definitive reason, but is a plausible explanation for such differences.

*Validity of findings*

The discussion now progresses to consider whether the current findings are valid, exploring whether they may be attributable to chance through multiple testing, or whether other arguments are more plausible. Reference will be made to previous
studies and the findings of this study will be placed within the context of the wider CRIMSON trial findings.

A summary of previous findings is presented with the caveat that none have completed sub-analysis on ethnic minorities, hence findings are not directly comparable to this study. Papageorgiou\textsuperscript{152} reported that there was little observable impact on compulsory admissions ($\chi^2 = 0.08$, d.f.=1, p=0.8) for those that completed advance directives; a finding which is consistent with the current findings. The findings of Papageorgiou\textsuperscript{152} were based on a slightly smaller sample (n=156) than the current study (n=176) and the lower than predicted admission rates as a whole may have reflected trends in admissions at that time. Despite not completing sub-analysis on ethnic minorities, 46% of the sample was from ethnic minority groups.

The findings from the pilot study of joint crisis plans by Henderson\textsuperscript{155}, which preceded CRIMSON, indicated that significantly fewer people experienced compulsory admissions in the follow up period (12.5%) compared with those in the control group (26.5%), (OR=0.48, 95% CI= 0.24 - 0.95, p = 0.03); this is not consistent with the present findings within this thesis. The pilot study was conducted in London as a single site trial, therefore the researchers had more control and there were fewer changes in service provision during the trial. The findings can therefore not necessarily be generalised across the UK and across ethnic minority groups, as no specific efforts were made to recruit ethnic minorities into the trial. The author of the pilot study has confirmed that no sub-analysis was completed on any ethnic groups as, whilst the study team may have predicted a greater treatment effect for black service users, numbers were too small to complete analysis. The percentage of those with compulsory admissions in the control group was the same as those in the current study. It would have been predicted that rates would be higher for the sample from south Asian and black ethnic groups, given the previous hospital admission rates reported.

Due to small number in the pilot study (n=180) it is possible that the initial positive findings were due to chance or multiple testing. Alternatively, it is plausible that the implementation of intervention was more effective in the pilot study then in the current study; a theme which will be explored in part later within this chapter and one which has precedence in the primary CRIMSON paper. It is also possible that the poverty and deprivation found in current recruitment sites was not taken into consideration, in comparison to the sites in the pilot study. This is important to consider if, as in chapter 1, socio-economic status and culture can in any way be equated to ethnicity.
It is notable that through the pilot study and mental health admissions data, the percentage of compulsory admissions expected within the CRIMSON trial across all participants was predicted to be 30%, as detailed within Chapter 5. As the evidence suggests that the figure would be higher than this for ethnic minority groups, it would have been expected that the compulsory admissions data would be higher within this current study. Instead, the figures showed that only 26% of the control group experienced compulsory admissions within the follow up period. Lower than anticipated rates of compulsory admissions at the time of the trial may account for the findings relating to this hypothesis and may indicate that things have changed over time since the completion or previous research studies. In addition, changes to the services over the duration of the trial warrant consideration, as the recruitment settings were in all likelihood very different to the pilot study recruitment sites. Such transformation of services will be discussed later in this chapter.

Testing of hypothesis 2 found that when considering any hospital admission, south Asian and black service users allocated to receive a joint crisis plan were more likely to be admitted. One reason for the anomaly in the findings is, once again, that the number of people that were actually admitted to hospital when compared to the predicted figures was lower. It is possible that, as in Papageorgiou’s trial, current trends are reflected within previous admissions data and the current admissions to hospital, accounting for the differences; although this does not account for the apparent increase in admissions from those in the intervention group.

An explanation for this apparent increase in admissions for those who experience an admission (formal or informal) may be linked to the previous hypothesis which showed a lower proportion of formal admissions for those that were allocated to the intervention arm (although not significant). The joint crisis plans made by the service users frequently reported that they wanted to go into hospital under certain circumstances, as they felt they would be safer there and receive appropriate treatment in order to prevent mental health deterioration. Therefore the actual admission process may be in line with the service users’ wishes and the reduction in compulsory admissions may account in part for the higher proportions of informal admissions. The suggestion that joint crisis plans may help some service users get an admission when they want one may be valid at present, due to a decrease in bed numbers following budget cuts. Historically, at times where admissions have been easier to achieve due to greater bed numbers, this would be a far less likely explanation. Whilst this point is worth
consideration, it does not provide a reason for white British and south Asian service user groups are having increased admissions, whilst a reduction in admissions was observed for black service users. It is possible that this may be related to engagement and that joint crisis planning improved this for black participants, leading to fewer admissions. Whilst this argument may suggest that engagement was not improved for south Asian groups, if accepted it is still unclear why the white British group would have increased admissions for the same reasons.

The key comparison which can be made in relation to hypothesis 3 is between current findings and those of Swanson\textsuperscript{153}, who reported on working alliance within the randomised control trial on facilitated advance directives. Here a difference between the reported working alliance for those in the intervention arm was more positive than for those in the control arm (p<0.001). These findings were not specific to ethnic minority groups, although a much larger small sample (n=469) was used. This significant finding was supported by the CRIMSON trial, which suggested there was some evidence for an improvement in self-reported therapeutic relationship in the intervention arm and suggests that the current finding is valid.

This significant overall effect of joint crisis plans on working alliance was not replicated in the current study of ethnic minorities and the most likely explanation for this is the small sample size in this study, especially as the main CRIMSON finding was only of borderline significance. As the current study is so small a clinical significance cannot be ruled out as a non-significant trend was noted in favour of the intervention group. The difference in CRIMSON was so small and so did not show up in the analysis for this study. In summary, the findings on hypothesis 3 are valid for CRIMSON as a whole, although not for the current sub-analysis; no evidence of effect was found although it is likely that there may be a small effect which is too underpowered. The suggested improvement in working alliance for all ethnic subgroups does therefore not account for the aforementioned paradoxical effects of joint crisis plans on hospital admissions.

It is possible that changes in services over the duration of this trial may have impacted on the findings relating to working alliance. In particular the consistency of care coordinators over the duration of the trial was considered, as the mean number of care coordinators allocated to a participant (south Asian and black) was 1.63 with the range being from 1-5. A large number of changes of care coordinator within an 18 month period represented a great change for the service user in the treatment and support that they received. Whilst this is an important consideration, the number of changes of
care coordinator was frequent across the participants in the CRIMSON trial overall and not unique to those from ethnic minorities. That said, it could be argued that given the barriers to engagement that have been reported throughout this thesis, the impact of these changes may have been magnified for this sample. Alongside the more likely explanation of the differences in sample size, this may help account for the significant findings of an improvement in working alliance within the overall CRIMSON trial.

An opposing argument to the negative consequences of frequent changes of care coordinator is that the changes could actually be a positive factor and the transitions in teams could prove an optimum time to introduce the joint crisis plan. For this assumption to be true, an increase in working alliance would also be presumed to be significant for the ethnic minority subgroup analysed in this thesis. It is possible that the mechanism of the joint crisis plan intervention did not actively allow the opportunity for service users from ethnic minorities to improve their working relationship with their named clinician. Whilst the previous consideration warrants inclusion in this discussion, the most likely synthesis of findings in this hypothesis is that the intervention has, at best, a small effect on working alliance; hence when reducing the sample size by restricting it to ethnic minorities it becomes insignificant. Further support for this summary was seen earlier within this discussion, when a similar overall effect size for the ethnic minority sample (south Asian and black) was observed to that of the white group alone. Whilst neither was statistically significant, a larger sample size would have been likely to result in significant findings in line with the overall trial.

Structural reorganisation within community mental health services has taken place throughout this trial. Appendix 10 shows that out of the 59 teams (indicated in bold) that participants were recruited from, 33 (56%) have transformed; either by changing the areas that they cover or by merging with other teams that previously existed. It could be argued that the high number of changes of care coordinators could be attributed to such changes. However, this is actually unlikely as this turbulence was not uncommon before any structural service changes. It would seem to be the nature of the care coordinator function that care coordinators change roles and move to different areas, disciplines and teams, making changes in allocated care coordinator unavoidable. Services in the NHS are in constant transformation and any intervention that is introduced which is not robust to this will not work, therefore this is not deemed to be a major contributing factor in the negative findings of this study and indeed the wider CRIMSON trial. Rather than addressing the inevitable high number of care coordinators a service user may have, it would be appropriate to consider strategies to
ensure a smooth transition of care, in order that service users are not hindered by this process.

*Design considerations*

Chapter 5 detailed the methodology of the CRIMSON trial, documenting how randomisation was conducted at an individual level. Whilst the merit of this randomisation process was that it ensured that participants were matched evenly across the trial arms, a potential flaw in the design was noted. Within the promotion of the trial all team managers and clinicians were informed about the joint crisis planning intervention and the previous work carried out in this area. In addition the possible benefits of the intervention for the service users and clinicians were explored. Therefore exposure to trial information by all clinicians may have led to contamination of the intervention across trial arms. Whilst rare, on occasions a care coordinator may have had more than one service user under their case load involved in the trial, allocated to different arms. It is possible that their involvement in developing joint crisis plans could have impacted on the way in which they developed care plans with their service users in the control arm of the trial under CPA, treatment as usual. It is also plausible that care coordinators with only service users in the control group may change their care planning practice due to exposure to joint crisis planning information from researchers, promotional presentations and possibly from informal discussions with colleagues about the process.

Considering such potential for contamination of the intervention across trial arms, it was initially proposed that the CRIMSON trial may have been better positioned if a cluster level randomisation, either through site or through case manager, was selected. This would have been likely to reduce contamination issues, as each cluster would only be exposed to one arm of the trial. It is also possible that utilising a cluster design would have enabled a more focused training programme to develop clinicians’ motivation to effectively implement the intervention. The implementation of the joint crisis planning process could have been integrated within the supervision process, encouraging greater effort to be put into the use of joint crisis plans.

Whilst the above suggestions are valid, clustering in this trial would be problematic. A cluster design would require more sites within each area than individual level randomisation, so clustering at a site level would be ineffective with the numbers involved. If clustered at a caseload level, problems would be created as, when all
service users were screened, care coordinators often only had one or two eligible
service users under their case load. This, coupled with the probable outcome of high
rates of non-consenting service users, would have made this design impractical.

Whilst the concerns about the potential for contamination of the intervention in
CRIMSON are plausible and the author of this thesis has anecdotal evidence to
suggest that clinicians may have changed their practice to enhance care planning
across their caseloads, contradictory evidence is presented. There was no evidence of
the joint crisis plan changing clinicians' behaviour in the pilot trial\textsuperscript{155} and this did not
occur in CRIMSON either, as evidenced by analysis of care plans pre and post
CRIMSON, showing that exposure to the intervention had no effect on clinicians' 
behaviour\textsuperscript{310}. Contamination is also not a concern in this trial as evidenced by the
findings, as no improvement with the control group was found, which would be
expected should the practice has been transferred across trial arms. As the evidence
above shows no contamination and taking on board the recommendation that
individual level randomisation is utilised where possible, due to the drawbacks of
cluster allocation\textsuperscript{292} the randomisation design used within the CRIMSON trial is
supported.

Whilst cluster randomisation would not have seemed fruitful within this trial, the author
notes that a superior design may have included an active control. If it could be argued
that it is not the joint crisis planning intervention per se which may result in the positive
outcomes, but rather the act of actually doing something with the service user, then this
would be advisable. In this trial, instead of doing nothing beyond treatment as usual
with the control group, some additional time (equivalent to the time spent with service
users in the intervention group) could have been spent with service users in this group.
For example they could be accompanied to their routine care coordinator visit and CPA
review. In this case the person accompanying them would not have an active role,
other than attending the meetings; they would have no actual input. Had the study
revealed positive findings in favour of the joint crisis planning intervention then it could
be argued that it was simply the purposeful time spent with the participant and through
completing an active control design, such concerns could have been quashed. As this
was not the case in CRIMSON, it is not as significant at this stage, but an important
methodological consideration which should be utilised in future trials where
appropriate.
It is important to a different perspective to the lack of any evidence for contamination having been present within the trial and practice. This argument supposes that in this instance with the design selected, some contamination would be a positive thing, as whilst it would have showed methodological flaws and potentially impacted on the validity of findings, on a practice level; it would have evidenced that the clinicians were valuing the joint crisis planning way of doing things and applying this learning to their practice. The fact that there was no contamination noted in CRIMSON suggests that clinicians had not integrated this best practice into their work, therefore had not valued or taken much away from their involvement in the research, making it largely an artificial process. If this is to be the case the results presented within study 1 of this thesis may simply be random findings and whilst there are interesting conclusions inferred, it is possible that all of the suggested effects of joint crisis plans may be chance findings.

*Implementation issues affecting CRIMSON*

Prior to discussing implications of this study, there is merit is presenting a brief summary of implementation issues that were present in CRIMSON that were not anticipated. The first factor is the time delay in participants being offered the intervention and its adverse effect on the trial design. Whilst the pilot study of joint crisis plans saw a swift progression through the research process, the time taken from randomisation to the completion of the joint crisis planning process was much longer in CRIMSON (mean number of days between randomisation and intervention = 162).

There are a number of suggestions as to why the process was not as smooth in the current trial. The trial author within the pilot study is a consultant clinician in the NHS trust where the participants were recruited from and the trial had been well promoted with colleagues and senior managers. In addition, the recruitment site was in London and it could be argued that London trusts have a wealth of experience with conducting and participating in psychiatric research; so were well versed in processes, with clinicians being used to assisting with the required procedures.

It may have been predicted that the necessity for interpreters within the recruitment and joint crisis planning process would have caused a considerable delay to the completion of the intervention with those people from ethnic minorities that required interpreters, but this was not found to be the case. The time delay experienced was not attributed to this, and in practice was found to be due to limited cooperation from clinicians or the health of service users, regardless of any factors related to the ethnicity of the service user. The time delay was actually less for the south Asian and black services users.
compared to the overall CRIMSON trial sample (152 vs 162 days respectively). This has positive implications for future work in the recruitment of ethnic minorities, as historic negative perceptions of the exhaustive efforts needed for the inclusion of these groups were shown to be unfounded. With sufficient planning and resources, it was found that the effort in recruiting participants from ethnic minorities and completing the intervention with them was no more taxing than the recruitment of any other participant.

The discussions above relating generally to CRIMSON suggest that implementation issues were the same for ethnic minorities as for everyone else, therefore there is no evidence to suggest such issues were magnified or manifested themselves any differently within subgroups. Therefore this thesis does not support the supposition that CRIMSON did not find significant results because it was not effectively implemented, a view that is championed within the primary CRIMSON paper; instead, it supports the argument that joint crisis plan works differently in different ethnic groups. In the black subgroup it seemed to reduce admissions, in that the participants in the intervention arm were less likely to be admitted, although it is notable that these findings were not significant. Alternatively those participants from south Asian and white British ethnic groups who received the joint crisis planning intervention were more likely to be admitted than those in the control group. These findings were also not significant with the exception of a significant increase in compulsory hospital admissions for south Asian participants.

**Implications for future research, policy making and clinical practice**

Attention will initially be given to CRIMSON prior to considering the findings for ethnic minorities. The key point is that the findings of the main trial, whilst not consistent with the pilot study, are consistent with other research in the field.

The findings from hypothesis 1 consistently show no evidence of effect for all ethnic minority groups and therefore the implications for clinical practice, future research and policy are not consistent with those that would have been predicted prior to this study. There is insufficient evidence to suggest a positive treatment effect of joint crisis plans on compulsory hospital admissions for service users from ethnic minorities, therefore adoption of this intervention as it stands within standard clinical practice is not recommended at present. The analysis has highlighted some interesting findings, particularly in relation to black service users, as it would seem the intervention has
worked more effectively for them. This may be a chance finding and non-significant results imply, at best a possible trend in findings in favour of the intervention.

The assumption made prior to the findings was that the treatment effect on any hospital admissions may have been more pronounced for ethnic minority groups when compared to white participants, due to issues around engagement and disproportionate hospital admissions, as explored within the literature review. The findings for both groups were unsupportive of the hypothesis to the extent that they contradicted it, with south Asian sub-analysis showing a significant difference against the intervention. The analysis has highlighted some interesting findings, particularly in relation to south Asian service users, as it would seem the intervention had a paradoxical effect on this group of participants. More work is needed to fully understand the mechanism of the intervention in contributing to this result. Greater consideration given to the process of completing joint crisis plans, as well as the content of the plans for south Asian participants (and indeed ethnic minorities as whole), would add to current knowledge. This will be discussed later within this chapter as part of the discussion around the content analysis of joint crisis planning documents.

The findings suggest that there is a positive trend in perception of working alliance for ethnic minorities in the intervention arm of the trial. As previously discussed, findings are not significant and therefore caution must be taken when considering their implementation in practice. It is anticipated that the findings from CRIMSON focus groups will add qualitative data to support these quantitative findings. It is recommended that future work explores the experiences of people from ethnic minorities in completing joint crisis plans. How this has affected their working alliance with their care coordinator, and consequently their engagement with health services, should be investigated.

Within the sub-analysis across this study, although there is some suggestion of a difference in ethnic minorities, this is not significant. The most parsimonious explanation of the findings is that the intervention is not effective either for white participants or for the ethnic minority participants. In the pilot study there was no ethnic sub-analysis due to low numbers, it was assumed that it would work better in those groups that had higher rates of compulsory admission. Future research therefore needs to focus primarily on making the intervention work for anyone, rather than making it work for ethnic minorities per se. Nonetheless it is possible that some minorities may benefit more than others and future designs may have to take this into
account. It is possible that different ethnic minorities respond very differently indeed to joint crisis plans and this may therefore in effect be a culture bound intervention.

If this is deemed to be a culture bound intervention then it is important to consider the reasons why this may be. The two broad ethnic groups of interest within this thesis are black and south Asian and, when these are compared to white British service users, the similarities would be more apparent between white and black service users than between white and south Asian service users. From the literature reviews presented within this thesis it is argued that in general terms south Asians have less knowledge about their mental illness and circumstances around it and hence their ability to successfully formulate a joint crisis plans may be limited. It is clear that facilitators of joint crisis plans, and indeed to some extent clinicians, are not specifically trained to look at the needs of other cultures away from their own. However, regardless of their own ethnic group they are likely to have a good understanding of the cultural needs of white British service users. This knowledge and understanding will likely help clinicians when working with black service users, whose culture may be more closely aligned with that of the white British service user, in terms of language, religion and food taboos. If clinicians have less familiarity with cultural issues of south Asian service users then their knowledge of white British cultures may not be as easily transferable as it is when working with black service users. In addition, it is argued that external influences from family and the community are greater for south Asians as compared to white British and black groups.

The above concerns regarding the facilitators' training needs will be explored more fully within this chapter, although at this stage it is useful to raise the limitation of this study, which aims to promote working alliance and engagement with services, through effective planning for a future crisis. Within this research the process is begun by researchers contacting care coordinators and then subsequently the participants and then the facilitator who collaboratively works with the clinical team and service user to formulate the plan. Neither the facilitators nor care coordinators were offered specific training in cultural awareness despite their variable levels of cultural competence. So, for this intervention to be more effectively implemented in practice, the learning from this thesis needs to be carried forward to ensure that the research processes are more closely aligned with the aims and adequate training is provided to all involved. This theme will be picked up and elaborated on within the discussion in study 2.
Study 2: Strengths, limitations and implications

Summary of findings

The diary entries provided a compilation of barriers to the recruitment of south Asian participants from the Manchester/Lancashire site which were extracted into twelve themes. The diaries provided multi-perspective reflections on the recruitment from the principal investigator, researchers and interpreters. The themes which emerged have been used to propose strategies which are necessary to implement in order to minimise such barriers and aid the effective recruitment of ethnic minorities.

Strengths and limitations

One strength of this study is the unique nature of the diary entries which provide first-hand accounts of the recruitment processes of ethnic minorities in a mental health intervention trial. This study is deemed to have valid findings as they are consistent with the themes which have been extracted from the systematic review of barriers to recruitment. The diaries have added to existing knowledge and the findings may be transferred outside of the trial context and indeed away from the UK.

The limitations of the diary entries are presented as, whilst the findings may be generalised to other ethnic minority participants as a whole, it is clear that the focus of this study and the barriers reported relate to south Asian participants. The study also has a small sample size and the sample was taken from a small geographical area. Furthermore, the subjective nature of the methodology warrants consideration as, naturally, diary entries are written from the experiences and perspectives of individuals. In summary the main limitation of this study is that it was limited to south Asians in Manchester/Lancashire. It would have been valuable if similar diaries had been kept at the other recruitment sites, particularly in relation to the recruitment of black service users. This may have helped to tease out issues about family involvement in the consent and joint crisis planning processes also.

Validity of findings

Comparison of themes from diary entries and systematic review of barriers

These findings will be discussed in comparison to the literature review documented in Chapter 2, as similar themes have emerged, indicating the validity of current findings.
The limitations introduced above will be discussed and mitigated where appropriate with consideration given to the generalisability of current findings.

The diary accounts predominantly contained the same categories of barriers to the recruitment of ethnic minorities as the systematic literature review. It is important to state that the literature review included ethnic minority groups of any description whereas the diary entries only reported on the recruitment of south Asian participants in the UK. The practical and research process barriers to recruitment which emerged from the literature review were overcome by carefully considered methodology as described in Chapter 6, although some barriers reported, such as ‘medical insurance’, were not relevant to a UK population.

Reasons for refusal of participation mentioned in the diary entries often related to service users not feeling that it would be beneficial to them. They also often expressed the view that they are no longer ill and will never encounter mental illness again. This ties in with the explanatory model of illness as drawn from the systematic review and, due to the nature of mental illness, is one barrier which may prove difficult to overcome.

The main barriers emerging from the recruitment diaries, which were also found in the literature review, are those which fall under the broader category of ‘family related barriers’. The diary entries showed that the most frequent issue arising from the recruitment of south Asian participants was the necessity to include family members in visits and in decision making; a theme which mirrors the findings from the systematic review. One of the key issues which arose in both the review and in this study is the particular need to involve male family members when females were being approached for recruitment into the trial. This is an interesting moral issue as it could be argued that in doing this, compromises are being made on values such as autonomy and gender equality in order to boost trial recruitment.

The diary entries reported that gaining consent from female south Asian participants would have been more difficult without the consent of male family members. This raises the importance of considering the subtle difference between people wanting to participate and needing to gain their husband or family member’s consent to do so and them actually being pressurised into participating by male relatives. This subtle difference is difficult to detect through the diary entries and is worthy of further consideration. Should it be the case that male relatives are pressurising females into participating then their autonomy is undermined and the extent to which they are
consenting to participate in the research is questionable. This would also be likely to impact on the joint crisis planning process, which is designed to promote service user autonomy. If male relatives were present then they may have strongly influenced the joint crisis plans to the detriment of the service user’s true preferences, based on their perception of what their relative would want. This may even in part explain the raised admission rates in south Asian participants as the joint crisis plan gives family members a route into having a say on the service user’s care during future crises. The key issue to be raised from these findings is the difficulty with balancing the autonomy of women to make their own decision with cultural norms that may be perceived as being sexist.

The other perception of family member involvement is that male relatives would offer their agreement to their relative participating in the trial, once the relative had expressed their intention to become involved. This collaborative decision making would still promote the service user’s autonomy in the joint crisis planning process. This emphasises the need for cultural considerations within the recruitment strategy to be inclusive of family members. It is evident that in whatever form the decision making took place, family involvement was crucial to the recruitment process. Researchers should be mindful of such familial dynamics when recruiting ethnic minorities to ensure that even if family support for the trial is gained, they do not coerce the service user to participate if they express a preference to refuse consent. Whilst this discussion focuses on male relatives and female service users as these are themes which emerged from the diaries and systematic review, it is also important for researchers to be aware of the potential issue of family members pressurising male service users.

The diary entries also made reference to support from friends and family for service users attending appointments and the theme of such support also arose within the literature review. This is strongly linked to the joint crisis planning intervention as participants were encouraged to involve a nominated person in the process, who could contribute to the planning of the document and also hold a copy, so that they would be clear about the agreed actions in the event of a future crisis.

The findings support the need to include families within the recruitment of south Asian participants, although no differentiation has been made between different subgroups within this broader category or indeed between different religions within recruited participants. It is not argued that the issue of family inclusion is exclusively a requirement for Muslim participants as this is applicable across different cultures,
where family decision making is necessary. Researchers are presented with the difficult task of ensuring that participants are supported in their decision making and respect is shown to their cultural requirements, whilst preventing coercion from family members. The dilemma presented by this is clear and researchers should discuss such issues within their supervisory and research team meetings, seeking guidance with these culturally relevant issues. Researchers are advised to ensure that written consent is not obtained at the time if they deem coercion to be taking place, instead suggesting another meeting with the service user if they wish, in order to allow them to consider their participation. It is difficult, and in some respects would be foolish, to disregard familial support for research, especially where they can verbalise the benefits of research for their relative, where the service user may have little insight into their own mental health. It is, therefore, important to find balance. If service users are expressing their wishes to participate, and the researcher has doubts about any autonomous decision-making, more work may be required following recruitment, prior to the intervention stage. Such work would be best completed by the facilitator and, where applicable, an interpreter and would focus around the service users' views to create more autonomous decision making within the parameters of any cultural restrictions.

The advice given above could be transferred to clinicians working with service users from ethnic minorities in a broader sense, to enable them to develop their degree of cultural sensitivity within their practice. Firstly it is essential that all clinicians are aware that there are cultural differences between different minority groups. They need to understand the culture specific issues of minority subgroups within their clinical practice, and need to understand who the major groups that they will be working with within their geographical locations are, to try and understand the issues for these specific subgroups. There are a number of ways in which they can increase this knowledge, with the first being for them to simply read about such differences. Specific suggested reading could be distributed within training sessions as well as resources utilising different media. For example, beyond reading about cultural issues, the use of film has been suggested as a more meaningful method of transferring such learning.\textsuperscript{311,312}

Beyond the theoretical learning, it is important that clinicians are encouraged to actively learn about cultural intricacies within practice. Where challenges do arise they should endeavour to address these and develop their understanding of the specific issues. In instances where an interpreter is assisting, they can be key in helping the clinician
understand the importance of such issues. Clinicians are also advised to share their experiences and newly acquired knowledge with colleagues through shared problem solving with their teams.

It is important to give consideration to the range of issues which emerged from the diary entries during the recruitment period; as some can be categorised as solely applicable to ethnic minority groups (for example availability of bilingual information and the need for multilingual staff/interpreters), whilst the majority are relevant to all research participants. Whilst it is important to differentiate between these two over-arching categories, it is notable that diary entries were only included for those ethnic minority participants where ‘cultural issues’ arose during the recruitment process. Therefore whilst the issues may be applicable to white British participants, the way in which these issues manifested themselves and consequently the way they were addressed are distinct. An example of this is the need for family involvement. The ways in which this occurred with south Asian participants took a very different form than family involvement for white British participants, as previously explored.

The first theme which emerged from the diary entries is that of care coordinator involvement which was key to successful recruitment in CRIMSON. Whilst this involvement was crucial regardless of the ethnicity of service users, it is worthy of discussion as it can be directly linked to the aforementioned implementation issues within study 1 discussions. From the author’s experiences of working with teams in Lancashire, there were several barriers that needed to be broken down prior to the commencement of the recruitment processes. Care coordinators showed a limited level of trust towards research staff, who were met with suspicion throughout the early stages of the trial. Some care coordinators expressed the views that they did not see the need for ‘outsiders’ to come into their teams and look at their work and practice. There was a general concern that researchers were going to be criticising their work and make an assessment on performance. The researchers therefore had to constantly reassure the teams about the purpose of the research, the processes that would be undertaken throughout the duration, the funders of the trial and the dissemination of results. These barriers took time to eradicate and perhaps they were never truly overcome, although anecdotal evidence suggests that trust was built up over time as the researchers were slowly integrated within the teams, eventually being viewed more as colleagues rather than ‘outsiders’. Awareness of researchers of such potential issues with clinicians is important when planning for the research processes of any intervention into clinical practice.
The diary entries have supported the themes of the literature review in Chapter 2, which suggests that the barriers to recruitment are not specific to south Asians and may be generalised to other ethnic minority groups. The similarity in findings may also mitigate the limitations of the small sample size and geographical area of the sample, as the literature review included studies which were conducted across the USA, many of which had larger sample sizes.

The diary entries have added to the review through documenting current experiences of recruitment of ethnic minorities in mental health research and highlighting the importance of family inclusion and the dynamics of decision making within south Asian families. The entries have also included considerations that were not raised in the systematic review, including participants not attending appointments because they felt if they did so, they would be unable to refuse consent. This theme was present with a number of south Asian female service users who presented as highly motivated to research staff when they met and later withdrew their interest through non-attendance, sometimes followed by a text message to apologise.

**Implications for future research, policy making and clinical practice**

The supposition outlined above, that some south Asians may not have the autonomy required to make their own health care decisions due to cultural restrictions (for example family involvement in decision making and possible coercion), warrants further exploration. If this assumption is true then this raises questions as to the suitability of joint crisis plans for this group. The intervention is reliant upon some level of individual autonomy, which through the facilitation of the intervention can empower the service user through promoting more control in their treatment. If this autonomy is not present or indeed possible then the intervention would be invalid in that it would never be effective for south Asians; further supporting the previously explored notion of joint crisis plans being a culture bound intervention.

It is important to consider the extent to which healthcare services are capable of engaging with south Asians who want to participate, where autonomy is required. When considering the barriers that emerged with recruiting participants in this study, it is of note that such difficulties and issues arose when researchers were trying to access service users and gain informed consent for their participation in the research. The main factor that needed to be addressed throughout this period of time was the efforts made to gain the trust of the service users; this is true through the introductory
meeting, explanation of research and obtaining consent. As stated it was important to gain not only the trust of the service users but also their relatives. It is difficult to make direct comparisons between the issues encountered within the recruitment period and those encountered within the implementation of the intervention, as the author had no involvement with the formulation of the joint crisis plan. To the author’s knowledge, from consultations with facilitators across all three recruitment sites, there were no similar cultural barriers once approval for the study had been gained, such as those faced by the researchers upon initial meeting with the service user. It is therefore argued that these issues had been effectively dealt with to some extent within the recruitment period, so they may be resolved as service users had developed trust towards the researchers and the intervention. This is reinforced by anecdotal evidence from the author’s experiences during follow up, where south Asian participants and their families welcomed the researchers back after an 18 month period, even if they had received little contact through being in the control arm of the trial. This implies that the trust and good will forged during the initial stages was long lasting and not forgotten, despite the time lapse.

The argument that south Asians and in particular south Asian women cannot be truly autonomous, for the aforementioned reasons, is a worthy one and may account in part for the effects of the intervention for this group. That said, without the joint crisis planning intervention, these issues and barriers would still be present. It is therefore argued that the intervention may have gone some way towards addressing them and providing service users with the opportunity to make more autonomous decisions (albeit with the support and guidance of their relatives at times).

Awareness of potential barriers can assist with the design of future trials as issues can be highlighted and solutions to overcome barriers can be planned in advance. This is helpful at the trial design stage as it can assist with the writing of the protocol and the trial financial costing. The barriers that have emerged from the diary entries to successfully recruiting south Asian participants into research can be categorised into three broad groups, as described below. In order for the potential barriers to recruitment to be overcome, a priori mechanisms should be in place in advance of the recruitment period.

1) Those barriers that can be overcome without any extra effort should be resolved through routine good practice. These actual barriers are largely independent of ethnicity per se: front-line health professional involvement; senior staff involvement;
rapport with participants; repeated visits and timing. But still there is an ethnic variation in the way these barriers present, for example the response of the participants and the need for additional resources; hence cultural consideration is needed to overcome the barriers. A cultural understanding of the target sample will help in tailoring the initial approach made to the participants. This is evident within the recruitment process as it has been reported that 13 out of the 23 ethnic minority participants did not need any additional resources beyond the standard recruitment procedures. It is therefore essential to provide training for field staff to ensure that researchers follow best practice guidelines in their interactions with participants.

2) Resource based barriers: These refer to material resources and often require additional financial consideration in order to implement effectively. Bilingual information and interpreters are the most important resources to incorporate into trial design and recruitment processes. It is important in the costing of a study to consider the need for translation work to be undertaken and to cater for the provision of interpreters. It is also important in terms of the time allocated for the recruitment of participants and additional work that may need to be completed.

3) Training needs barriers: These include religious obligations; needs time to decide; family involvement; explanation of terms; research benefits and participants could not say no. These barriers may not be addressed through standard practice and it is important that they are addressed through training at every stage of trial design and implementation. It is beneficial to have expertise on board in the area of ethnic minority recruitment. Cultural sensitivity training should be provided to all people on the research team.

The three categories above are broad, with general factors noted. To develop these ideas further, Table 52 is presented below which clarifies the more general categories of barriers and gives consideration to the materials and skills that individuals need to acquire to overcome such barriers. Whilst research suggests that service users from ethnic minorities have questioned the value of pre-existing advocacy services, it is positive to note that they report to have felt more empowered when their ethnicity and culture was reflected by the advocate. This categorisation of barriers highlights the levels of awareness of cultural sensitivity that should be adhered to in order to avoid the unnecessary exclusion of minority groups. The barriers listed span the research process with specific barriers needing to be addressed prior to the research, others which need overcoming during the recruitment process and some barriers and
activities which are on-going and therefore necessary throughout the whole research process. Whilst the diary entries were taken only from the recruitment of south Asian participants, the comparison to the international literature review allows for the barriers to be presented in more general terms, demonstrating that these barriers are likely applicable to a wide range of ethnic minorities.

The previously reported concerns relating to clinicians’ defensiveness about their required engagement with the research and delivery of the intervention are important to consider alongside the training that has been highlighted in Table 52. In order to instil an ethos of practice development around this area then it is necessary to firstly address this at a policy level, as it is imperative that mental health trusts view research, and indeed cultural sensitivity within research and clinical practice, as being vital. With a clear direction in policy it is suggested that standard audits of routine clinical practice could address this. For example, within the supervision process the diversity of a clinician’s case load should be discussed and consultations around service users’ cultural requirements should take place. If an interpreter is required then an audit should be completed to confirm that one is being used and the clinician should be supported in ensuring that all strategies utilised are effective.
Table 52: Identification of barriers and recommended activities to overcome them

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Activity to overcome barrier</th>
<th>Person requiring the activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care coordinator promotion of the trial</td>
<td><strong>Research awareness training</strong>: This should not be aimed at developing practical research skills per se but should provide clinicians with knowledge about the research process. This should equip them with the skills to explain the purpose of research to the service users and to be competent in explaining simple research processes, prior to the full trial information being provided. This training would also promote the importance of the link between research and evidence based practice. This could be conducted as part of the trial promotion when accessing new teams. This is essential when working with a team who have not previously actively taken part in research.</td>
<td>Care coordinators. In addition: Team managers; support, time and recovery workers; student practitioners. All of the above may be tasked with the role of introducing the research to the service user.</td>
</tr>
</tbody>
</table>
| Language | **The translation of written trial documents and the arrangements made for interpreters** with knowledge of mental health to be involved in research processes. The time and financial costs should be factored in at the research protocol stage.  

**Research awareness training**: This is as highlighted above. Such training should include cultural awareness and encourage care coordinators to recognise the importance of considering the participant’s first language. This is linked to the above barrier, if care coordinators are providing the service users with research information, it is important that they ensure that there are no language barriers. This may be particularly important when recruiting south Asians, due to the diversity of languages spoken and the importance of providing the most appropriate interpreter and written materials. For example a person may be able to speak one language but not read it. | Principal investigators.  

Care coordinators. In addition: Team managers; support, time and recovery workers; student practitioners. All of the above may be tasked with the role of introducing the research to the service user. |
| Inappropriate timing of meetings with participants | **Cultural awareness training to research staff**. Through attending such training, research staff would develop an awareness of cultural issues that impact on the appropriate timing of appointments with participants from ethnic minorities. For example, research staff should be aware of recruiting around the times of religious festivals and consider obligations that may fall within that period. This training package should be delivered prior to the commencement of the recruitment period. | Research staff (researchers and clinicians conducting the intervention) |
| Lack of rapport with participant | **Cultural awareness training to research staff.** This would be addressed through the training above, which should give consideration to rapport building and how this could be increased through other factors on this table. For example through family involvement and through the utilisation of an interpreter. The training would develop rapport building through considering the practical issues of conducting research with an interpreter and provide an opportunity for research staff to practice developing their interpersonal skills in recruitment based scenarios. | Research staff (researchers and clinicians conducting the intervention) |
| Family involvement | **Cultural awareness training to research staff.** This is linked directly to the above barrier and the aforementioned training would consider the importance of family involvement in recruiting participants from ethnic minorities. The diary entries have shown that this would be particularly important when recruiting south Asian participants. The findings from this study would inform the content related to gender equality and autonomy to ensure research staff are equipped with a good understanding of the key issues and the balance between ensuring consent from the individual is obtained whilst balancing the need for cultural norms to be respected and adhered to. | Research staff (researchers and clinicians conducting the intervention) |
| Explanation of terms | **Cultural awareness training to research staff.** It is important that research staff develop their skills in explaining research in a culturally sensitive manner. They must develop their ability to show cultural awareness when explaining trial terms, gaining knowledge of potential words which could be misinterpreted. For example, within the recruitment in this study, the word ‘study’ caused some confusion with some participants from ethnic minorities. The word was associated with college and they voiced their concern that they would have to go and complete a qualification, rather than understand what the word study meant in relation to a research trial. Whilst this misinterpretation of the word could be made by any participant regardless of their ethnicity; the diary entries showed that it was made by south Asians and anecdotal evidence from researcher accounts does not recall any instances where the same misinterpretations were made by white British participants. Such terms are likely to be less familiar to people from ethnic minorities where language is noted as a barrier. The training to address this barrier is consistent with the previous barriers’ solution as it must be linked to the practical application of conducting research with an interpreter. | Research staff (researchers and clinicians conducting the intervention) |
| Understanding research benefits | **Cultural awareness training to research staff.** The training should include a component on encouraging participants to consider the possible personal benefits of participating. This barrier is not related to ethnicity per se, although the benefits of exploring such issues with service users with cultural needs in their treatment may take a different form. Researchers should be equipped with the understanding of issues that may be applicable to that individual in terms of their cultural needs, for example, having translated materials and an interpreter to allow them to devise a plan in their own words. | Research staff (researchers and clinicians conducting the intervention) |
| Participant did not attend appointments because they felt if they did they would be unable to refuse consent | **Cultural awareness training to research staff.** A component of this training (linked around discussions on gender issues) would be to cover potential challenges to recruiting service users into a trial once they have expressed their interest. It is possible that on occasions, service users may present as being highly motivated to be involved and then later retract their interest, resulting in a delayed refusal. This may be due to not wanting to disappoint the field staff in their initial interaction or them feeling that they could not say no. It is important for all researchers to be aware of this in order to avoid putting undue pressure on service users, which may diminish their perception of them being permitted to decline their participation | Research staff (researchers and clinicians conducting the intervention) |
| Repeated visits and participants needing time to decide | **Cultural awareness training to research staff.** In addition it is important that field staff are aware that it is probable that participants from ethnic minorities with cultural needs will require repeated visits to complete the recruitment process. This can be attributable to many of the aforementioned factors and training should incorporate this requirement to shape the expectations of field researchers prior to commencement of the recruitment process. | Research staff (researchers and clinicians conducting the intervention) |
| Senior staff involvement | **Cultural awareness training to research staff.** This should be standard in any research trial, although it may not always be the case directly. This is not specific to the recruitment of ethnic minorities, as it is a generic solution for the recruitment of all. This should be emphasised in the training package that is provided to research staff and should be adhered to throughout the entire recruitment process. Research staff should have the confidence to approach senior staff in practical recruitment issues. Following the literature review and diary entries it appears that this inclusion may have greater importance with ethnic minorities if the senior researcher is male. | Research staff (researchers and clinicians conducting the intervention) |
Reviewing the barriers raised can aid the training and supervision process, allowing researchers to be prepared in advance when conducting trials. For example, barriers that have been highlighted can be discussed and rectified immediately by finding appropriate solutions. This ensures an on-going learning process and can promote on-going training for the research team and across research trials.

*Utilisation of joint crisis plans*

Table 32 in Chapter 7 show that the utilisation of joint crisis plans was similar for the south Asian and black participants compared to the white-British participants (76% vs 80% respectively). This raises the issue that, despite incorporating efforts to recruit ethnic minority service users into psychiatric research, engagement throughout the trial cannot necessarily be maintained. It is still envisaged that ethnic minority participants will show non-engagement with the intervention and may withdraw from the trial.

*Summary*

The diary entries supported and added to existing literature regarding the barriers to recruitment of ethnic minorities in mental health research. A compilation of barriers with suggested activities to address them has been presented, which if addressed from the protocol stage of a trial should ensure that individuals from ethnic minorities are able to participate. This applies regardless of whether or not the research is focussed on ethnic minorities exclusively. The training of research staff and clinical staff within recruitment areas would equip attendees with the skills and knowledge to minimise those barriers where possible and to have a heightened awareness of the key issues with family inclusion in the recruitment process, as well as the consideration of gender issues and autonomy.
Study 3: Strengths, limitations and implications

Summary of findings

The main finding of this study was that 28% (20/71) of the people who completed joint crisis plans wanted to include culturally relevant statements. The figure was 44% (11/25) for south Asian participants and therefore much higher than the 20% (9/46) of black participants who made culturally relevant statements. The results from study 2 that found that of the 23 south Asian participants recruited within the Manchester/Lancashire site, 10 people (44%) were deemed to need cultural considerations in the recruitment process. As this thesis combines south Asian and black service users on the assumption that similar barriers may be present across ethnic groups, it could be assumed that approximately 44% of joint crisis plans completed in this sub-analysis would contain culturally relevant statements. There is recognition that this figure is taken from only south Asians in one recruitment site and so, to allow for generalisation, it is predicted that the percentage of participants making a culturally relevant statement would be between 40 and 50%.

Strengths and limitations

This study allows for the systematic analysis of the written joint crisis planning document. All joint crisis plans from south Asian and black participants were included and the content analysis was verified by an independent researcher to ensure the coding was consistent and ensure inter-rater reliability. The main weakness of the study is that the author, having been blinded to the allocation of participants, is reliant on the written documentation and has no additional information from the joint crisis planning meetings. This discussion therefore proposes the presence of three levels of culturally relevant statements, although without further information it is difficult to verify which of the arguments carries more weight.

Validity of findings

The literature reviewed within this thesis highlighted the importance of barriers for ethnic minorities in relation to their engagement with services. From this, we could assume that these issues would be drawn from collaborative discussion with the service users when formulating their joint crisis plans. It is important to consider reasons why culturally relevant statements were not as frequent as anticipated when
the south Asian and black ethnic minority groups were combined. The arguments are presented below in three categories, which relate to the questionable presence of culturally relevant statements and consider both ethnic groups separately, as well as combined.

**Culturally relevant statements not present**

This argument proposes that it may simply be the case that culturally relevant statements were not present as people do not feel the need to make such statements at the level anticipated. It is interesting that that 44% of the south Asian participants across the recruitment sites made culturally relevant statements, which mirrors exactly the figure of the percentage of south Asians’ in the Manchester/Lancashire site whose recruitment needed cultural considerations. To the contrary, the percentage of black service users making culturally relevant statements was much lower at just 20%. It is therefore suggested that the assumption of treating the two groups the same in this study was misjudged and the two distinct groups have different needs when crisis planning. This implies that the limited engagement with services by both groups, as reported in the literature, may not equally be enhanced by the joint crisis planning process. The differences in the analysis between south Asian and black participants are reported in study 1, although such small sample sizes make any differences inconclusive, as no evidence of effect were observed.

**Culturally relevant statements present but not raised in discussions**

This argument utilises the evidence to suggest that people from ethnic minority groups may have previously made culturally relevant statements even though these were not raised in joint crisis planning meetings. It is suggested that the limited amount of time allocated for the joint crisis planning meeting may have inhibited some discussions and meetings may have been rushed to ensure that all sections were completed within the limited time limits. This may also be the case when considering joint crisis planning meetings that were tacked onto the end of standard reviews, as time would be limited for the clinicians and service users, so exploration of preferences may have been prematurely terminated.

The findings from working alliance measures shows that unlike the full sample for CRIMSON, participants from south Asian and black groups who were allocated to receive a joint crisis plan did not show an improvement in working alliance when
compared to those in the control group. The limited number of culturally relevant statements within joint crisis plans warrants consideration of the participants’ working alliance with their clinician. It is plausible that participants may not have trusted their clinician with personal information about their cultural or religious beliefs or even felt that they would not understand their cultural needs. In addition, anecdotal evidence suggested participants sometimes voiced their concerns regarding their reluctance to share their true feelings with their care coordinators. Such evidence is taken from researchers’ informal interactions with service users during the recruitment and assessment procedure. The author can recall many instances where service users have made a statement and then followed this with a retraction, stating that they would not want their care coordinator to have that information. This type of scenario was corroborated by informal accounts from other researchers across the trial, although there is no formal written evidence to support this.

It could be argued that the facilitation process of the intervention meant service users did not readily make culturally relevant statements. Joint crisis plans are a standardised research intervention to date and within their derivation there is no specific section for the inclusion of cultural or ethnicity related comments. The facilitators who assisted the service users with the formulation of their plans did not prompt service users to consider culturally related concerns or effective aids to their recovery, instead keeping the questioning very generalised. It is therefore suggested that is not that culturally related factors were not important to the participants, more that the process did not actively promote discussion around such issues. It is also possible that the facilitators did not have full awareness of the cultural issues that may be important to the service user and hence may be another barrier to the inclusion of culturally relevant statements on the plans for ethnic minorities.

The counterargument to the above discussion would be that service users did not make culturally relevant statements as they did not consider such statements to be necessary for themselves. This would suggest that the research staff aiming to explore cultural sensitivity may be overly concerned with such issues and may therefore predict that they would be a priority for people from black and south Asian groups, when in reality they are not within this context. Whilst this explanation is plausible, it is difficult to ascertain the validity in it without further exploratory work, which would be best placed focusing on the experiences of those that completed the intervention. Anecdotal evidence suggests that there may be things that service users need but feel that they are not worth raising with their clinical teams; possibly for fear that they would
be making unrealistic demands, or that explaining their thoughts may not have any bearing on their clinical outcome. With the clinicians and service users often having competing views on the treatment, such issues may be held back by the service user. In line with the other arguments, this could be true of all service users, regardless of their ethnicity. However, given the concerns about autonomy raised previously, the effect may be more pronounced for this group; providing further support for the argument that cultural differences must be considered when testing the effects of interventions.

_Culturally relevant statements raised but not recorded_

This argument proposes that it is possible that service users did make culturally relevant statements within discussions; however they were not recorded on the joint crisis planning document. The evidence provided below is plausible based on previously reported anecdotal evidence; although it has limitations. Due to blinding procedures the author had no direct input within the facilitation process, nor did they have access to audio or written transcripts from the meetings. Therefore they are reliant on the final written documentation which formed the finalised joint crisis plan.

It is conceivable that service users’ care coordinators may have a limited awareness of cultural issues which may be relevant to them. Generally the service user’s care coordinator would be the person in the planning meeting that knew them best and therefore may take a lead in helping the discussion evolve in conjunction with the facilitator. If the care coordinator was not actively encouraging the participants to think about the issues specific to their illness and specific preferences they have, then such culturally relevant statements that may have warranted being on the plan may have been side-lined, in favour of more generic issues, for example medication. If it is the case that care coordinators were not actively encouraging participants’ to consider cultural preferences then perhaps a more worrying rationale for this may simply be related to their willingness to consider such issues.

There is evidence from the trial to suggest care coordinators presented the potential problem of imposing their own views of the trial onto the service users. Whilst this could be positive and there is clear evidence of care coordinators actively encouraging service users to consider how joint crisis planning may be useful to them within their care, it is probable that this was often not the case. The suspicion that care coordinators treated the research with could be connected to their perception that their
work was to be criticised. When discussing the trial, many clinicians became defensive in their approach, expressing their views that the intervention did not differ from their current practice. They stated that they do take service users’ views into consideration when planning for future treatment and they take a collaborative approach within their interactions. This lack of enthusiasm towards the intervention from some clinicians may have undermined the joint crisis plan, as it may have limited discussions and discouraged service users from exploring issues more personal to their own illness, even if culturally relevant statements were raised.

*Nature of the culturally relevant statements*

Whilst the frequency of culturally related statements was lower than anticipated, when south Asian and black service users’ plans were analysed as a collective, the south Asians’ plans produced the anticipated level of culturally related statements. This suggests that for south Asian service users, cultural issues do have a strong influence in relation to their illness and crisis treatment. Within this section, it is also important to differentiate between the types of cultural relevance in the statements made within the joint crisis plan. The inclusion criteria for content to be highlighted as having cultural relevance has been previously highlighted and there was no distinction made between how the factors manifested in the build-up, escalation or treatment and recovery of mental illness.

The section of the plan that most often had culturally relevant statements made within it is ‘circumstance that may lead me to becoming unwell or have done in the past’. Within this section of the joint crisis plan, 17% (12/71) of south Asian and black service users made a culturally relevant statement and of those that made such a statements within any part of the plan (n=20), 12 (60%) made it within this section. This suggests that there may be cultural indicators and relapse signs that, if detected, may allow early intervention in order to reduce escalation of the illness. The section of the joint crisis plan which had the next highest number of culturally relevant statements within it is ‘what happens when I first become unwell?’ Within this part of the plan, 10% (7/71) of south Asian and black service users made a culturally relevant statement and of those that made such a statement within any part of the plan (n=20), 7(35%) made it within this section.
Key issues raised following analysis of the culturally relevant statements relate to the importance of religion and food in both the circumstances leading to illness and treatment during and following a crisis. Religious beliefs and worshipping practice may be intensified in a period preceding a crisis and it is important that clinicians are aware of such factors and how they can be recognised and addressed to prevent escalation of the illness. Religion is also a key issue warranting consideration during and after treatment and beliefs must be respected during potential stays in hospital and recovery periods. Within the section of the joint crisis plan which offered service users the opportunity to make any other statements related to their treatment preferences, the most frequently used statements referred to food. Food related habits were often altered in unique ways indicating the start of a relapse and in addition to the presence of such issues contributing to illness; preferences were stated for the event of a crisis and the period following illness. The most comment statements related to diet in hospital and getting support with eating when unwell in the home.

The degree and type of cultural relevance of the statement made within each section of the joint crisis plan warrant consideration. The results chapter documented the statements verbatim, although more exploration into these categories reveals a distinction between relapse signs, times that service users are more susceptible to crises, relations with services and ethnic minority subcultures. When verbalising the circumstances which lead to them becoming unwell, all of the culturally relevant statements included some reference to relapse signs and particular times when they may be more susceptible to a mental health crisis; for example, around an anniversary of a relative’s death. Whilst many of these relapse signs or specific periods of times that have been highlighted are relevant to service users regardless of their ethnicity, the specific nuances in how they manifest themselves are particular to minority subcultures. For example, the subcultures commensurate with the service users’ religion were referred to, with particular circumstances that would not apply to white British service users, such as experiences with Jinns. This same pattern is observed when service users documented what happened when they first became unwell. Whilst this gives details regarding particular relapse signs, the type of experiences documented were specific to the ethnic subculture relevant to that service user.

Within the joint crisis plan, service users were able to document any other information that they would like to be known by clinicians, providing them with the opportunity to capture anything that was missing on the plan that was important to them. All responses coded within this section related to minority subcultures, suggesting the
importance of this inclusion on the joint crisis planning document. It is argued that without this option, service users may not have the opportunity to formally record such important considerations to them, which included food taboos and their faith. It is interesting that the culturally relevant statements that emerged from analysis of the plans placed little emphasis on the service users' relations with services, with only three statements making reference to this. It is not argued that these issues are not important to the service user but perhaps some increased autonomy and the collaborative nature and the focus of the intervention allowed them to shift the emphasis in their responses to consider their particular personal needs.

It is important to consider why black participants made fewer culturally relevant statements compared to south Asians. One explanation that may account for the difference in frequency is that in some respects the culture of black African/black Caribbeans in the UK is closer to white British culture than south Asian culture is. For example, within the black subgroup, it is presumed that if participants are religious, then they are likely to be Christian and hence do not have food taboos. They may also be more likely to have English as their first language. As it has been shown that culturally relevant statements have predominantly contained references to food and religion, then this may be why the black subgroup made fewer such statements. Furthermore it can be summarised that the prevailing cultural practices within the psychiatric services are closer to their norms than those cultural norms of south Asians.

**Implications for future research, policy making and clinical practice**

It is recommended that a future addition within the joint crisis planning document should place emphasis on culturally relevant factors for the service users; it is possible that if service users were prompted to consider the wider factors of importance across their lives, more of them may have made culturally relevant statements within their plans. This in turn may assist their clinical team in understanding more about such considerations and allow them to support the service users in ways which may not have been previously discussed. A section related to cultural issues may be provided within the menu document given to service users with examples of issues that may be relevant and important to them.

In addition it is argued that the training provided for clinicians and researchers should have greater emphasis on cultural awareness, in line with the recommendations in
study 2. This would ensure that they would be better equipped to develop the service users’ exploration of issues that are pertinent to their own mental illness.

Future work around implementing joint crisis plans with ethnic minorities would benefit from closer exploration of the joint crisis plan discussions, which was not possible by the author in this trial. The effects of the presence of an interpreter on the service user and their perception of the joint crisis planning process is also worthy of further investigation.

**The role of the researcher**

The discussions in this study and study 2 are somewhat limited in that they refer to the processes and experiences of the trial and so large generalisations are made. The assumptions that are made and the experiences provided are largely from the research across the Manchester/Lancashire sites. A change in research staff across the other sites has made the generalisability of these experiences unclear.

It is important to reflect on the ethnicity of the researcher, when considering the findings and analysis of studies 2 and 3. The biases of a white British researcher when considered alongside their limited shared experiences of ethnic minority participants will influence the reporting of the research. Chapter 3 makes reference to the importance of distinguishing between culturally matched and culturally competent researchers, concluding that culturally competent researchers were as effective. Therefore the researcher’s training and cultural awareness would mean that the research was not inhibited. There are limitations to the researcher’s true understanding of the marginalisation that ethnic minorities may encounter within health services. This knowledge and understanding is limited to the existing literature and first-hand accounts from participants, which may influence the analysis of the study.

The professional position of the researcher, as a chartered psychologist, is also worthy of consideration. Entering the mental health clinical teams and integrating into their work systems to complete this research has been challenging at times. Judgements made on the appropriateness of professional approaches and the researcher’s limited knowledge in this professional area may have impacted on the reporting of such experiences of conducting the research.
Conclusion- wider implications of the three component studies

This final discussion brings together all three component studies to consider broader implications for research, policy and clinical practice.

Cross cultural research methods

As highlighted within the methodology chapter of this thesis, the CRIMSON trial endeavoured to incorporate culturally sensitive research methods into the trial design. The inclusion of translated materials, interpreters and efforts to understand, and therefore try and overcome barriers to recruitment of ethnic minorities, were considered from the outset. These methodological considerations appeared to help the recruitment of service users from ethnic minority groups and the experiences of researchers can be used to aid future research. The compilation of barriers found in the literature review within Chapter 2 and the synthesis of diary entries in Chapter 7 provide future researchers with a framework to enhance the recruitment of ethnic minorities into their research.

Intervention development

This is the only known study to date that has focussed on the effectiveness of an advance decision making intervention for people from ethnic minority groups with severe mental illness. As previously stated, the intervention was tested within a wider trial that was not limited to the inclusion of service users from ethnic minorities. The document therefore did not reflect some of the potential preferences from service users in relation to cultural considerations; it is recommended that joint crisis plans are adapted to include a section for cultural considerations. Should users be prompted by the joint crisis planning menu and the actual intervention document, it would be anticipated that the inclusion of culturally relevant statements would increase. Further research on the facilitation of the intervention with service users from ethnic minorities would add to the information available to support this. This would be particularly important for south Asian females, to add to the existing knowledge regarding gender and autonomy issues which have been discussed in detail.
Clinical implications

There is a need to complete further work in this area on ethnic minority groups to further understand what it is about the joint crisis planning process that has shown potentially promising findings for black participants. Once the mechanisms of the intervention and how it can be implemented more effectively are understood, the findings would be more comprehensive and there would be a stronger case for the plans to be incorporated into standard practice; with the joint crisis plan progressing beyond being simply a research intervention. Whilst further work in implementing the intervention would be encouraged, the paradoxical effects for south Asians compared with black participants warrant further exploration. It would seem that in study 1, south Asians responded to the intervention in a similar way to the white British group, which suggested an increase in hospital admissions. To date potential reasons to account for this finding against the prediction have been presented, although these are lacking in their evidence base and a greater understanding of the different treatment effects is necessary to make any definitive conclusions about clinical effects or to inform policy.

It is plausible, considering the evidence presented that joint crisis plans, through their collaborative facilitation processes, do not have any influence on hospital admission rates, either on a voluntary or involuntary basis. Explanations that have been presented within this thesis focus on the severity of service users’ illness alongside their poor insight. The additional factors presented when this intervention is focussed on service users from ethnic minority groups bring in new variables which may limit the effectiveness, to the extent that it may never work for such groups. This argument holds more weight when considering the effects for south Asian participants, who may never gain true autonomy within their planning for future crises given the concerns about possible coercion from their families that have been highlighted.

Joint crisis plans aim to reduce compulsory hospital admissions by ensuring that adequate treatment is administered, through considering the circumstances raised with reference to the service users’ wishes at time of plan formulation. Circumstances are dynamic and it is difficult for service users to document what these circumstances could be in advance, due to often chaotic lifestyles. Therefore at the time when the joint crisis plans are needed, the circumstance may not match those at the time of writing. Hence at present, when faced with the choice of utilising a joint crisis plan over a more current crisis plan, clinicians may focus on using the latter and ignore the joint crisis plan. In summary, for the joint crisis plans to be valued more and increase their
utilisation within practice, it is essential that currency of information is retained over time through updating service user circumstances and wishes. This was not conducted within this trial, so mechanisms would need to be in place for this to happen should they be trialled in the future or indeed implemented into practice.

As there is inherently something about the planning process that may have positive effects on service users from ethnic minorities, particularly in terms of an improved working alliance, it is possible that this process could be adapted and trialled in other areas away from severe mental illness and the reduction of hospital admissions. There are other groups of people for whom capacity may fluctuate and the potential for joint crisis plans to be used with people with learning disabilities, for example, is strong.

**Conclusion**

The thesis has presented promising findings in relation to the successful recruitment of ethnic minorities into a psychiatric research trial. The strategies employed can be used to assist future researchers and the compilation of barriers reported can act as a framework from which to work when planning for and conducting research with ethnic minorities.

The effectiveness of joint crisis plans for people from ethnic minorities with severe mental illness is questionable. Statistical analysis has not revealed significant results. Overall the CRIMSON trial showed that joint crisis plans have no clinically significant effect on any primary outcomes. This thesis has suggested that there is a differential effect on people from ethnic minorities on hospital admissions with south Asians having more admissions (significantly so) and black service users having fewer admissions; although this is too small a sample to show this definitively. The case is far from proven, although on balance it would appear that there is something about the joint crisis plan which may affect hospital admissions, in opposing directions, and this possibility should not be dismissed.

This thesis suggests that joint crisis plans may have a differential effect on people from different ethnic groups, for reasons that at present we do not understand. This is interesting because it emphasises the importance of analyses that look at ethnic minorities, and the way that they may help elucidate the effects of complex interventions. It also suggests that different ethnic minorities may react in different ways, and it certainly supports the value of efforts to recruit ethnic minorities.
Understanding why joint crisis plans have a differential impact may be one of the best hopes for making the intervention work and it is suggested that future research focuses on qualitative work exploring what lies behind these apparent differential effects.
References


65. The NHS Information Centre, Mental Health and Community Team. Mental health bulletin. Fifth report from mental health minimum dataset (MHMDS) annual returns, 2011.


75. Quirk A, Lelliott P. What do we know about life on acute psychiatric wards in the UK? A review of the research evidence. Social Science and Medicine 2001;


100. Maden A, Friendship C, McClintock T, Rutter S. Outcome of admission to a medium secure psychiatric unit. 2. Role of ethnic origin. *British Journal of*


253. Lancashire Care Foundation Trust. *Location Map*.  


308. NVivo Qualitative Data Analysis Software; QSR International Pty Ltd. Version 9, 2010.


Appendices

Appendix 1 Joint crisis plan example ................................................................. 276
Appendix 2 Staff information sheet ................................................................. 278
Appendix 3 Staff consent form ...................................................................... 281
Appendix 4 Participant information sheet ....................................................... 282
Appendix 5 Participant consent form ............................................................... 285
Appendix 6 CRIMSON pen, mug and post-it ................................................. 286
Appendix 7 CRIMSON leaflet ...................................................................... 287
Appendix 8 Joint crisis planning menu ......................................................... 289
Appendix 9 Participant contact form ............................................................... 294
Appendix 10 Transformation of teams recruited from in the trial .............. 295
This Joint Crisis Plan has been developed by agreement between Christopher Jones, Lorraine Parvez, sister, Dr Robertson, consultant psychiatrist, and Thandie Smith CPN on 17/3/08

Please make every effort to fulfil this agreement in the event of a crisis.

Advance statements regarding preferences for care included in a Joint Crisis Plan are not legally binding. Where a Joint Crisis Plan includes a valid advance refusal of treatment, that specific statement is legally binding, but may be overruled in certain circumstances such as treatment under the Mental Health Act.

Appendix 1 Joint crisis plan example

<table>
<thead>
<tr>
<th>My name</th>
<th>Christopher Jones</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td>82 Paxton House</td>
</tr>
<tr>
<td></td>
<td>Joiners lane</td>
</tr>
<tr>
<td></td>
<td>Peckham</td>
</tr>
<tr>
<td></td>
<td>London SE15</td>
</tr>
<tr>
<td>Tel No</td>
<td>xxxxxxxxxxxxxxx</td>
</tr>
<tr>
<td>GP</td>
<td>Dr Anju</td>
</tr>
<tr>
<td>Address</td>
<td>Kings Rd Medical Practice</td>
</tr>
<tr>
<td></td>
<td>Kings Rd, Peckham SE15</td>
</tr>
<tr>
<td>Tel No</td>
<td>xxxxxxxxxxxxxxx</td>
</tr>
<tr>
<td>Consultant</td>
<td>Dr Robertson</td>
</tr>
<tr>
<td>Address</td>
<td>Eastways Resource Centre</td>
</tr>
<tr>
<td></td>
<td>21 Dover St, Peckham SE15</td>
</tr>
<tr>
<td>Tel No</td>
<td>xxxxxxxxxxxxxxx</td>
</tr>
<tr>
<td>CPN</td>
<td>Thandie Smith</td>
</tr>
<tr>
<td>Address</td>
<td>Eastways Resource Centre</td>
</tr>
<tr>
<td></td>
<td>21 Dover St, Peckham SE15</td>
</tr>
<tr>
<td>Tel No</td>
<td>xxxxxxxxxxxxxxx</td>
</tr>
</tbody>
</table>

If I appear to anybody to be experiencing “mental health” difficulties that require decisions to be taken either against my wishes or in the absence of my agreement then I request that my nominee, below, be contacted immediately, informed of what is happening and requested to attend as a matter of urgency. My nominee is:

<table>
<thead>
<tr>
<th>Name</th>
<th>Lorraine Parvez</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td>23 Latimer House, Wickford</td>
</tr>
<tr>
<td></td>
<td>Walk, Greenwich, SE10 5BD</td>
</tr>
<tr>
<td>Tel No</td>
<td>xxxxxxxxxxxxxxx</td>
</tr>
</tbody>
</table>

© Institute of Psychiatry
Current Care and Treatment Plan

My mental health problem or diagnosis
Paranoia and mental health problems.

Physical illnesses or allergies
My asthma can be bad when I’m stressed and I may need to go to casualty. I carry an inhaler.

Current Medication & dosage
Olanzapine: 10mg at night
Ventolin inhaler: 2 puffs 3-4 daily as needed

Circumstances that may lead to me becoming unwell or have done in the past
Problems with money or with my ex-partner.

What happens when I first start to become unwell
I have trouble sleeping. I get suspicious of things and feel persecuted by people. Sometimes I can also get angry and shout at people.

Treatments or other things that have been helpful during crises or relapses in the past
I like to have a quiet space, to be treated at home if possible and have support from my CPN, my sister and my brother. Increasing night time dose of Olanzapine.

Preferred treatment or social care during a crisis or relapse
I’d like a quiet room if possible as noise makes me more stressed and more likely to get angry.

Circumstances in which I would wish to be admitted to hospital for treatment
I would like to be admitted when it is still my decision.

Specific refusals regarding treatment during a crisis – see legal statement overleaf
I don’t want an injection.

Practical Help in a Crisis

If I am admitted to hospital please contact the person named below and ask them if they would carry out the following tasks for me.

Name Lorraine Parvez
Address 23 Latimer House, Wickford Walk, Greenwich, SE10 5BD

Tel No xxxxxxxxxxxxxxxx
- check my home is secure, i.e. doors and windows locked, cooker and fires turned off;
- water my bonsai trees
- dispose of perishable food;
- collect my mail

Agencies or people that have copies of this card or agreement
- myself
- treatment team
- GP
- my nominee, Lorraine Parvez
- copy to go on electronic records

Care in a Crisis

What I would like to be done when I first start to become unwell
I’d like to have a quiet space, to be treated at home if possible and have support from my CPN, my sister and my brother. Increasing night time dose of Olanzapine.

Preferred treatment or social care during a crisis or relapse
I’d like to stay on Olanzapine and to have Clonazepam to help me keep calm and avoid the need for an injection.

Specific refusals regarding treatment during a crisis – see legal statement overleaf
I don’t want an injection.

Circumstances in which I would wish to be admitted to hospital for treatment
I would like to be admitted when it is still my decision.

If my brother, Robert, or sister, Lorraine, thought I needed to.

My brother, Robert, can be contacted via my nominee, Lorraine.
We would like to invite you to take part in the CRIMSON study. Before you decide you need to understand why CRIMSON is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about CRIMSON 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 study of ‘Joint Crisis Plans’. The Joint Crisis Plan is an agreement between a service user and their mental health team about what to do if the service user becomes unwell in the future. An independent person (or “facilitator”) helps the service user and the team to reach agreement and makes sure that all voices are heard.

This information sheet is to help you decide if you want to take part. Please read it carefully. Feel free to discuss the study with friends, relatives or staff.

What is the purpose of the study?

We want to find out if people who have a Joint Crisis Plan are less likely to be ‘sectioned’ under the Mental Health Act. We would also like to know if they are happier with their treatment, and feel more involved in their care. We also want to know if people with Joint Crisis Plans get on better with mental health staff. The best way to find this out is to conduct a trial and compare what happens to two groups of people, one with the Joint Crisis Plan and another without.

Why have I been invited?

We want you to take part because you are a care co-ordinator for a service user that has agreed to take part in the study. We are interested in your relationship with the service user and would like to look at factors that may affect this relationship.

Do I have to take part?

No. If you decide not to take part, your rights will not change in any way. Even if you decide to take part, you may leave the study at any time, without giving a reason.

What will happen if I choose to take part?

To make sure the Joint Crisis Plan is effective we wish to compare two groups. The first group will have a Joint Crisis Plan and the second ("control") group will not. Once a service user and their
care coordinator agree to take part, the service user will be placed in one of these two groups. To make sure this comparison is fair, and the groups are similar, a computer will decide which group the service user is in at random. They will have a fifty-fifty chance of being in the group with the Joint Crisis Plan.

If you take part in the study, you will be interviewed twice. The first interview will be as soon as you agree to take part. The second will be 18 months later. Each interview will take a maximum of 20 minutes. You will be asked some basic demographic questions, and be asked to complete two questionnaires regarding your relationship with the service user involved in CRIMSON. The answers you give will be confidential to the study and will not be shared with the service user.

**Control Group:**

If the CRIMSON participant you work with is in the Control group, he/she will not make a Joint Crisis Plan and treatment will continue as normal.

**Joint Crisis Plan Group:**

If the service user you work with is in the Joint Crisis Plan group, then as well as being interviewed, you will have two meetings to develop his/her Joint Crisis Plan. You may also be asked to attend a discussion group.

**At the first meeting:** An independent person (“the facilitator”) will meet with you and the service user for half an hour to discuss what the service user might want on the Joint Crisis Plan. This could include information about what treatment has been helpful and what has not, and what he/she would like to happen in the event of a future crisis. If the service user already has an advance decision, this can be incorporated into your Joint Crisis Plan.

**At the second meeting:** The facilitator will meet with you and the service user and psychiatrist. This meeting will take one hour and will give the service user an opportunity to discuss what they would like to happen if they were to have a mental health crisis. If you do not agree with the service user’s wishes (e.g. with any medication refusals that may be made), you will be asked to explain why, and to suggest other options. The facilitator will be there to help the discussion, and to ensure that what is included on the Joint Crisis Plan is of the service user’s choice. These meetings will be audio taped so that we can make sure that everyone is getting the same amount of help.

Once the plan has been finalised, the facilitator will send a copy of the Joint Crisis Plan to you, if agreed by the service user. You and the treatment team should then endeavour to follow the agreement reached. However, the service user will be informed that there may be situations in which the team may not follow the agreement, for example in situations when the Mental Health Act is used. During the study the Joint Crisis Plan can be updated if necessary. If the group is unable to agree with an aspect of the plan, a plan could still be completed, but it will be a statement of treatment preferences or wishes which we call a ‘Crisis Card’. If the service user then becomes unwell again this ‘Crisis Card’ would remind the treatment team of the service user’s wishes, and would carry some weight, however the team would not have to follow these wishes.

**Discussion Group:** About 1 in 5 service users and their care coordinators will be asked to take part in discussion groups about the Joint Crisis Plan. The discussion will help the researchers to understand what worked and didn’t work with Joint Crisis Plans. You will therefore only be invited to participate in these groups if a service user you are working with is in the intervention group and develops a Joint Crisis Plan. If you are invited, there will be two separate groups: one with other care coordinators and a combined group of service users and care coordinators. The discussions will be audio-taped, but will be kept confidential and used only for research purposes. Each group

---

11 Recent legislation, the Mental Capacity Act 2005, means that patients may make ‘advance decisions’ setting out treatment refusals which must be respected unless the Mental Health Act is used to override a person’s wishes. Other treatment preferences can also be stated but do not carry the same force of law. Your Trust can provide you with information about this. A Joint Crisis Plan differs from an ‘advance decision’ in being an agreement between you and your treatment team about what should happen. The Joint Crisis Plan may be able to include what you would have chosen to put in an ‘advance decision’.
member will be paid £20 to thank them for their time. You can take part in the study but refuse to
take part in the group discussion.

**What are the possible risks of taking part?**

There are no foreseeable risks to taking part in the study.

**What are the possible benefits of taking part?**

You may or may not experience some benefit from taking part in this research. The Joint Crisis
Plan discussions may improve your relationship with the service user.

**What if there are any problems?**

If you are worried about any part of this study, please speak to the researchers who will do their
best to answer your questions (contact details below). If you have complaints about the study you
can complain formally through the NHS Complaints Procedure (details can be obtained from the
Trust).

**Will my taking part in the study be kept confidential?**

All information collected about you will be kept strictly confidential to the study (unless it gives rise
to concerns about your safety or that of other people). Any information about you that we store on
computer will have your name and address removed so that you cannot be recognised. Written
records of interviews will be stored in locked files in the researchers’ office. All databases will be
password protected. Information collected in the study will only be available to research staff and
research regulators.

**What will happen to the findings of the study?**

Results from the study may be published in medical or psychiatric journals, without the use of any
information that could identify individuals. We will send you information about the study once it has
finished.

**Who is organising and funding the research?**

This research is being run and organised by three groups: the Institute of Psychiatry, Kings College
London; the University of Birmingham; and the University of Manchester. The research is funded
by the Medical Research Council (MRC).

**Who has approved the study?**

This study has been reviewed and given favourable opinion by Kings College Hospital Research
Ethics Committee.

**Further information and contact details**

If you have any questions regarding the study, you can contact Professor Graham Thornicroft
(Chief Investigator) on 0207 848 0735 or Ms. Simone Farrelly (Scientific Coordinator) on 0207 848
5098.

You may also contact your local site lead.
- Dr George Szmukler for London site on 0207 848 0096
- Professor Max Birchwood for Birmingham site on 0121 301 1850
- Professor Max Marshall for Manchester site on 01772 773500
CONSENT FORM
CRIMSON Study: A Study of Joint Crisis Plans to reduce compulsory treatment for people with psychosis.
Staff
(Version 2, 29 July 2009)

Centre number:
Participant 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 interviews and JCP facilitation sessions may be tape recorded

4. I agree to take part in the above study

<table>
<thead>
<tr>
<th>Name of Participant/Staff Member</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Person taking consent</td>
<td>Date</td>
<td>Signature</td>
</tr>
<tr>
<td>(if different from researcher)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name of Researcher</td>
<td>Date</td>
<td>Signature</td>
</tr>
</tbody>
</table>

When completed, 1 for participant; 1 for researcher site file; 1 (original)
Appendix 4 Participant information sheet

You are invited to take part in a study of ‘Joint Crisis Plans’. The Joint Crisis Plan is an agreement between you and your mental health team about what to do if you become unwell in the future. An independent person (or “facilitator”) helps you and the team to reach agreement and makes sure that your voice is heard.

This information sheet is to help you decide if you want to take part. Please read it carefully. Feel free to discuss the study with friends, relatives or staff.

**What is the purpose of the study?**
We want to find out if people who have a Joint Crisis Plan are less likely to be admitted to hospital against their will (in other words ‘sectioned’ under the Mental Health Act). We would also like to know if they are happier with their treatment, and feel more involved in their care. We also want to know if people with Joint Crisis Plans get on better with mental health staff. The best way to find this out is to conduct a trial and compare what happens to two groups of people, one with the Joint Crisis Plan and another without.

**Why have I been invited?**
We want you to take part because you have been admitted to hospital due to mental health problems.

**Do I have to take part?**
No. If you decide not to take part, your care will not change in any way. Even if you decide to take part, you may leave the study at any time, without giving a reason.

**What will happen if I choose to take part?**
To make sure the Joint Crisis Plan is effective we wish to compare two groups. The first group will have a Joint Crisis Plan and the second (“control”) group will not. To make sure this comparison is fair, and the groups are similar, a computer will decide which group you are in at random. You will have a fifty-fifty chance of being in the group with the Joint Crisis Plan. If you take part in the study, you will be interviewed twice. The first interview will be as soon as you agree to take part. The second will be 18 months later. Each interview will take one hour. You will be asked questions about your treatment and how you get along with your mental health team. The answers you give will be confidential to the study and will not be shared with your mental health team. The interviewer will read your medical records to check your diagnosis and history of admissions, and may also contact your GP or mental health care team to check your contact details. At the end of each interview you will be given £20 as a thank-you for the time and thought you have given to this study.
Control Group:
If you are in the Control Group, you will not make a Joint Crisis Plan and your treatment will continue as normal.

Joint Crisis Plan Group:
If you are in the Joint Crisis Plan group, then as well as being interviewed, you will have two meetings to develop your Joint Crisis Plan. You may also be asked to attend a discussion group.

At the first meeting: An independent person ("the facilitator") will meet with you and your care coordinator for half an hour to discuss what you might want on the Joint Crisis Plan. This could include information about what treatment has been helpful and what has not, and what you would like to happen if you become unwell in the future. If you have already made an advance decision this can be incorporated into your Joint Crisis Plan.

At the second meeting: The facilitator will meet with you and your care coordinator and psychiatrist. You will be encouraged to bring a relative or friend. This meeting will take one hour and will give you an opportunity to discuss what you would like to happen if you were to have a mental health crisis. If your treatment team does not agree with your wishes (e.g. with any medication refusals you may make), they will be asked to explain why, and to suggest other options. The facilitator will be there to help the discussion, and to ensure that what is included on your Joint Crisis Plan is your choice. These meetings will be audio taped so that we can make sure that everyone is getting the same amount of help.

Once the plan has been finalised with you, the facilitator will send a copy of your Joint Crisis Plan to you, and everyone you would like to have a copy. Your treatment team will endeavour, but can not guarantee, to follow the agreement reached, for example in situations when the Mental Health Act is used. During the study the Joint Crisis Plan can be updated if necessary. As this is your plan, you may withdraw your Joint Crisis Plan at any time or keep it even after the study finishes. If your team is unable to agree with an aspect of your plan, we could still complete a plan for you, but it will be a statement of your treatment preferences or wishes which we call a ‘Crisis Card’. If you become unwell again this ‘Crisis Card’ would remind your treatment team of your wishes, and would carry some weight, however the team would not have to follow your wishes.

Discussion Group: About 1 in 5 people will be asked to take part in a discussion group about the Joint Crisis Plan. The discussion will help the researchers to understand what worked and didn’t work with Joint Crisis Plans. The discussions will be audio-taped, but will be kept confidential and used only for research purposes. Each group member will be paid £20 to thank them for their time. You can take part in the study but refuse to take part in the group discussion.

What are the possible risks of taking part?
You could find it upsetting to discuss your experiences of mental illness and treatment. If this happens you can ask for the meeting or interview to stop, and we will make sure you

---

12 Recent legislation, the Mental Capacity Act 2005, means that patients may make ‘advance decisions’ setting out treatment refusals which must be respected unless the Mental Health Act is used to override a person’s wishes. Other treatment preferences can also be stated but do not carry the same force of law. Your Trust can provide you with information about this. A Joint Crisis Plan differs from an ‘advance decision’ in being an agreement between you and your treatment team about what should happen. The Joint Crisis Plan may be able to include what you would have chosen to put in an ‘advance decision’.
receive support. The meeting can then be rearranged if you wish. You might be worried that someone could find and read your Joint Crisis Plan. If you are worried about this we can help you find a safe place to keep it, or make sure that only your care team has a copy. We will take very careful precautions, to make sure that your confidential information is not disclosed outside the study.

What are the possible benefits of taking part?
You may or may not experience some benefit from taking part in this research. The Joint Crisis Plan may provide important information about you during a crisis or relapse. Previous research suggests that people with Joint Crisis Plans are less likely to be “sectioned”, but we do not know this for certain.

What if there are any problems?
If you are worried about any part of this study, please speak to the researchers who will do their best to answer your questions (contact details below). If you have complaints about the study you can complain formally through the NHS Complaints Procedure (details can be obtained from the Trust).

Will my taking part in the study be kept confidential?
All information collected about you will be kept strictly confidential to the study (unless it gives rise to concerns about your safety or that of other people). Any information about you that we store on computer will have your name and address removed so that you cannot be recognised. Written records of interviews will be stored in locked files in the researchers’ office. All databases will be password protected. Information collected in the study will only be available to research staff and research regulators.

What will happen to the findings of the study?
Results from the study may be published in medical or psychiatric journals, without the use of any information that could identify individual patients. We will send you information about the study once it has finished.

Who is organising and funding the research?
This research is being run and organised by three groups: the Institute of Psychiatry, Kings College London; the University of Birmingham; and the University of Manchester. The research is funded by the Medical Research Council (MRC).

Who has approved the study?
This study has been reviewed and given favourable opinion by Kings College Hospital Research Ethics Committee.

Further information and contact details
If you have any questions regarding the study, you can contact Professor Graham Thornicroft (Chief Investigator) on 0207 848 0735 or Ms. Simone Farrelly (Scientific Coordinator) on 0207 848 5098. You may also contact your local site lead.
- Dr George Szmukler for London site on 0207 848 0096
- Professor Max Birchwood for Birmingham site on 0121 301 1850
- Professor Max Marshall for Manchester site on 01772 77350
Appendix 5 Participant consent form

CONSENT FORM
CRIMSON study: A Study of Joint Crisis Plans to reduce compulsory treatment for people with psychosis.
(Version 4, 18 December 2007)

Centre number:
Patient 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 relevant sections of my medical notes and data collected during the study, may be looked at by in the study team. I give permission for these individuals to have access to my records.

4. I understand that my GP may be contacted to inform them of my participation in this study. I give permission for this.

5. I understand that interviews and JCP facilitation sessions may be tape recorded

6. 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 ........................................

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical note
Appendix 6 CRIMSON pen, mug and post-it
Appendix 7 CRIMSON leaflet

Do you have experience of hospitalisation due to mental health problems?

Would you like to have more influence over the care you receive in a crisis?

If so, you might be interested in crim/on.

Where can I find out more?

If you have any questions about CRIMSON, please call Ms. Simone Farrelly (Coordinator) on 020 7848 5098 or visit www.iop.kcl.ac.uk/crimson
**What is crimson?**

Crimson is a research study that would like to find out if people who develop a Joint Crisis Plan are less likely to be admitted to hospital against their will (in other words ‘sectioned’ under the Mental Health Act).

We would also like to know if people who develop a Joint Crisis Plan:
- are happier with their treatment
- feel more involved in their care
- get on better with mental health staff

**What is a Joint Crisis Plan?**

The Joint Crisis Plan is developed by seeking agreement between you and your mental health team about what to do if you become unwell in the future.

An independent person (or “facilitator”) helps you and the team to reach agreement and makes sure that your voice is heard. The Joint Crisis Plan can include things like the name of someone you would like to be contacted in a crisis; treatments that have been helpful or unhelpful for you in the past; treatment preferences or refusals; and practical arrangements like asking someone to feed your pet if you are admitted to hospital.

**What will happen if I choose to participate?**

If you take part in the study, you will be interviewed twice. The first interview will be as soon as you agree to take part. The second will be 18 months later. Each interview will take one hour. You will be asked questions about your treatment and how you get along with your mental health team.

The answers you give will be confidential to the study and will not be shared with your mental health team. At the end of each interview you will be given £20 as a thank you for the time and thought you have given to this study.

**What else will happen?**

The best way to find out if the Joint Crisis Plan is effective is to compare what happens to two groups: one which makes a Joint Crisis Plan and one which continues with Usual Treatment.

To make sure this comparison is fair, and the groups are similar, a computer will decide which group you are in at random. You will have a fifty-fifty chance of being in the group who makes the Joint Crisis Plan.

**Usual Treatment Group:**

If you are in the Usual Treatment Group, you will not make a Joint Crisis Plan and your treatment will continue as normal.

**Joint Crisis Plan Group:**

If you are in the Joint Crisis Plan Group, then as well as being interviewed, you will have two meetings with a facilitator and your mental health care team. You may also be asked to attend a discussion group.
Appendix 8 Joint crisis planning menu

This menu is to help you decide what you would like on your crisis card or joint crisis plan. Some sections can be simply filled in by you if you want them included. Elsewhere you may want to select an item but wait to discuss the details with your treatment team at your crisis planning meeting.

You can include as much or as little information as you wish. Whatever you have chosen or agreed at your crisis planning meeting will then be made up into your own personal card or plan.

It is important that your Crisis Card or Joint Crisis Plan is kept up to date. If you feel that it needs to be updated at any time please contact your treatment team.

Please tick which of the following you would like on your crisis card or plan. Please provide details if at all possible.

☐ My name .................................................................
   Address ................................................................
   Tel no. ..................................................................

☐ GP's name ...............................................................
   Address ................................................................
   Tel no. ...................................................................

☐ Consultant's name ...................................................
   Address ................................................................
   Tel no. ..................................................................

☐ CPN's name ............................................................
   Address ................................................................
   Tel no. ..................................................................

☐ Social Worker's name ..............................................
   Address ................................................................
   Tel no. ..................................................................

☐ Other (please name) .................................................
   Address ................................................................
   Tel no. ..................................................................

Please provide details if at all possible.
If there is someone you would like to be called in a crisis, please tick the following paragraph and ask this person (your nominee) if they would be willing to help and support you in an emergency. This person could be a relative, a friend, or an advocacy worker. It would be helpful to invite them to be present at your crisis planning meeting when you discuss your crisis card or joint crisis plan so that they can understand what you would want done in an emergency.

- "If I appear to anybody to be experiencing "mental health" difficulties that require decisions to be taken either against my wishes or in the absence of my agreement then I request that my nominee, below, be contacted immediately, informed of what is happening and requested to attend as a matter of urgency. My nominee is:"  

Name ..............................................................................................................
Address ...........................................................................................................
......................................................................................................................
Tel no: Home.................................Work..............................................

Current Care and Treatment Plan

Please tick which of the following you would like on your crisis card or plan. You may want to fill in the details yourself or you can discuss them with your treatment team at your crisis planning meeting.

- My mental health problem or diagnosis

..............................................................................................................................

- Physical illnesses or allergies eg. diabetes, sickle cell, epilepsy, allergic to penicillin

..............................................................................................................................

- My Current Care/Treatment Plan Here you can include details such as regular arrangements to see your psychiatrist, CPN or social worker, plans to attend a day centre, plans for rehousing or for greater support in the community

..............................................................................................................................
..............................................................................................................................
..............................................................................................................................

- Current Medication & dosage

..............................................................................................................................
..............................................................................................................................
..............................................................................................................................


Circumstances that may lead to me becoming unwell or have done in the past
This may help you, or a relative, friend or nominee to recognise when you are becoming unwell and need help, or help prevent this happening. eg. being on my own at weekends, forgetting to take my medication
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

What happens when I first start to become unwell
This may help you, or a relative, friend or nominee to recognise the first signs that you are becoming unwell and need help. eg. not sleeping, becoming restless, feeling suspicious, voices becoming louder
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

Treatments or other things that have been helpful during crises or relapses in the past
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

Treatments or other things that have not been helpful during crises or relapses in the past
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

Care in a Crisis
Here you can make plans in advance for the care or treatment you would prefer in a crisis.

What I would like to be done when I first start to become unwell Here you can describe what you want done when you first become unwell, to help prevent you from becoming fully unwell eg. make an appointment to see your keyworker or psychiatrist urgently, start some medication that you know has helped you in the past.
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

291
Preferred treatment or social care during a crisis or relapse Here you can describe what you want done if you do become fully unwell. This may be helpful if it is difficult to make decisions for yourself when you are fully unwell.

............................................................................................................................................................................................
............................................................................................................................................................................................
............................................................................................................................................................................................

Specific refusals regarding treatment during a crisis or relapse Here you can describe what you do not want done if you become fully unwell.

............................................................................................................................................................................................................................................................
............................................................................................................................................................................................................................................................
............................................................................................................................................................................................................................................................

Circumstances in which I would wish to be admitted to hospital for treatment This may be useful if you recognise that there are times when it would be helpful to be treated in hospital, but find it difficult to accept that you need this help when you are becoming unwell.

............................................................................................................................................................................................................................................................
............................................................................................................................................................................................................................................................
............................................................................................................................................................................................................................................................

Practical Help in a Crisis

If you live alone you may wish to have the following tasks undertaken should you have to be admitted to hospital. You will need to give details of who you would like to carry out these tasks and where they can be contacted. You will need to ask their permission, give them information such as the phone numbers to cancel services, and may wish to leave them a spare set of keys to your home in case of an emergency.

If I am admitted to hospital please contact the person named below and ask them if they would carry out the following tasks for me.

Name ..............................................................
Address ......................................................................................
......................................................................................
......................................................................................
......................................................................................
Tel no: Home..............................................................Work..............................................................

tick whichever are required

☐ check my home is secure. ie. doors locked, cooker and fires turned off.
☐ dispose of perishable food
☐ cancel services eg. milk deliveries, paper deliveries, home help.
☐ water plants or garden
☐ look after my pet
☐ let my work (or college or day centre) know
☐ other (please describe the task you need carried out)

☐ If I am admitted to hospital I would like the following arrangements for my children/dependent relative If you have young children, or an elderly/disabled relative at home you may want to give details about who you would like to look after them if you are in hospital. For children you may want to say whether you would like them to continue at school, nursery or with the childminder, and what you would like them to be told.

............................................................................................................
............................................................................................................
............................................................................................................
............................................................................................................
............................................................................................................

☐ Other information I would like to be known or taken into account
  eg. special diets, people I would or would not like to be told, people I would or would not like to visit me

............................................................................................................
............................................................................................................
............................................................................................................
............................................................................................................
............................................................................................................
............................................................................................................

Agencies or people that I would like to have copies of this card or agreement
(please tick)

☐ myself
☐ treatment team
☐ emergency clinic
☐ GP
☐ my nominee
☐ other (please name) .................................................................

Date of Crisis Planning Meeting  .................

Present at meeting:

<table>
<thead>
<tr>
<th>Name</th>
<th>Role or profession</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>eg. friend, relative, keyworker/CPN</td>
</tr>
</tbody>
</table>

PRiSM, Institute of Psychiatry, De Crespigny Park, London, SE5 8AF. Tel. 020-7848-0732/0714
Participant contact form

Participant contact details 18 February 2008

Participant ID: ___________

Your contact details:

Home Phone: ______________________

Mobile: _________________________

Work Phone: ______________________

e-mail address: ______________________

Address: ________________________________

Contact details of a relative or friend

(someone we could contact if we are having trouble getting in touch with you):

Name: ______________________

Relationship to you: ______________________

Telephone number: ______________________

Address: ________________________________

Your GP’s contact details

G.P. name: ______________________

Telephone number: ______________________

Address: ________________________________
### Appendix 10 Transformation of teams recruited from in the trial

<table>
<thead>
<tr>
<th>Trust</th>
<th>Original team name at recruitment</th>
<th>Team name at the end of the trial</th>
</tr>
</thead>
<tbody>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Croydon Adult - COAST</td>
<td>Early Intervention Service (Croydon)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Croydon Adult AOT</td>
<td>Assertive Outreach Service (Croydon)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Croydon Adult Central CMHT</td>
<td>Community Mental Health Team (Croydon Central)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Croydon Adult North CMHT</td>
<td>Community Mental Health Team (Croydon North)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Croydon Adult West CMHT</td>
<td>Community Mental Health Team (Croydon West)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Lambeth AOS</td>
<td>Assertive Outreach Service (Lambeth)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Lewisham Early Intervention Service</td>
<td>Early Intervention Service (Lewisham)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>North Lambeth R&amp;S</td>
<td>Support and Recovery Service (Lambeth North)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Northover Assertive Outreach Team</td>
<td>Support and Recovery Service (Lewisham South)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Northover CC South West</td>
<td>Support and Recovery Service (Lewisham South)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>South East Lambeth R&amp;S</td>
<td>Support and Recovery Service (Lambeth South East)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Southbrook Central CC</td>
<td>Support and Recovery Service (Lewisham Central)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Southbrook East CC</td>
<td>Support and Recovery Service (Lewisham Central)</td>
</tr>
<tr>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
<td>Southbrook Road AOT</td>
<td>Support and Recovery Service (Lewisham Central)</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Aston CMHT</td>
<td>Harry Watton CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>East AOT</td>
<td>East AOT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>EIS BEN</td>
<td>EIS BEN</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>EIS East</td>
<td>EIS HoB</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>EIS South</td>
<td>EIS South</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>EIS West</td>
<td>EIS HoB</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Erdington/Stockland Green CMHT</td>
<td>Erdington/Stockland Green CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Handsworth CMHT</td>
<td>Handsworth CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Kingstanding CMHT</td>
<td>Kingstanding CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Ladywood AOT</td>
<td>Ladywood AOT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Ladywood CMHT</td>
<td>Ladywood CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Longbridge/Northfield CMHT</td>
<td>Longbridge/Northfield CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Main Street CMHT</td>
<td>Zinnia CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>NAS AOT</td>
<td>NAS AOT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Scarborough House AOT</td>
<td>Scarborough House AOT</td>
</tr>
<tr>
<td>Trust</td>
<td>CMHT Name</td>
<td>CMHT Name</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>----------------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Sheldon &amp; Shard End CMHT</td>
<td>Riverside CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Shenley Fields CMHT</td>
<td>Longbridge CMHT (shenley)</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Soho CMHT</td>
<td>Handsworth CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Solihull Early Intervention Team</td>
<td>Solihull Early Intervention Team</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Solihull North CMHT</td>
<td>Newington CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Solihull South CMHT</td>
<td>Lyndon CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>South Locality AOT</td>
<td>South AOT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Spring Road CMHT</td>
<td>Spring Road CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Stratford Road CMHT</td>
<td>Zinnia CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Sutton CMHT</td>
<td>Patrick House CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Ten Acres</td>
<td>Ten Acres CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Warstock Lane CMHT</td>
<td>Warstock Lane CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Washwood Heath CMHT</td>
<td>Riverside CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>Yardley &amp; Acocks Green CMHT</td>
<td>Riverside CMHT</td>
</tr>
<tr>
<td>Birmingham and Solihull Mental Health Foundation Trust</td>
<td>East Rehab &amp; Recovery Team</td>
<td>n/a</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Pendle CMHT</td>
<td>Burnley and Pendle CCTT</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Blackburn and Pendle AOT</td>
<td>Burnley and Pendle CCTT</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Blackburn CMHT</td>
<td>Blackburn and Darwen CCTT</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Blackburn and Darwen AOT</td>
<td>Blackburn and Darwen CCTT</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Hyndburn CMHT</td>
<td>Hyndburn, Ribble Valley and Rossendale CCTT</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Hyndburn AOT</td>
<td>Hyndburn, Ribble Valley and Rossendale CCTT</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Darwen CMHT</td>
<td>Blackburn and Darwen CCTT</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Ribble Valley CMHT</td>
<td>Hyndburn, Ribble Valley and Rossendale CCTT</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Rossendale CMHT</td>
<td>Hyndburn, Ribble Valley and Rossendale CCTT</td>
</tr>
<tr>
<td>Lancashire Care Foundation Trust</td>
<td>Burnley CMHT</td>
<td>Burnley and Pendle CCTT</td>
</tr>
<tr>
<td>Rotherham Doncaster and South Humber NHS Foundation Trust</td>
<td>Manchester EIS</td>
<td>Manchester EIS</td>
</tr>
<tr>
<td>Manchester Mental Health and Social Care Trust</td>
<td>CMHT South 1</td>
<td>CMHT South Mersey</td>
</tr>
<tr>
<td>Manchester Mental Health and Social Care Trust</td>
<td>CMHT South 3</td>
<td>CMHT South Mersey</td>
</tr>
<tr>
<td>Manchester Mental Health and Social Care Trust</td>
<td>CMHT Central/ East</td>
<td>CMHT Central/East</td>
</tr>
<tr>
<td>Manchester Mental Health and Social Care Trust</td>
<td>CMHT North C</td>
<td>CMHT North Mersey</td>
</tr>
</tbody>
</table>