Understanding Excessive Rates of Compulsory Hospital Admission amongst Black-Caribbean Patients, During First Episode Psychosis (FEP)

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Supplementary Information

Declarations

This thesis is my own original work and has not been published elsewhere or submitted to any other institute of higher education for the award of a degree, other than the University of Warwick.

Data was primarily collected by me with the assistance of other researchers as part of a larger program of work, entitled the ENRICH project. Further details of the connections between this thesis and the ENRICH project can be found on pages 96 and 148.

Compulsory hospital admission/ Compulsory detention/Detention/: the processes of

detaining a patient under sections II and III of the mental health act 1983

BME: Black Minority Ethnic

MHA: Mental Health Act

DRE: Delivering Race Equality

NHS: National Health Service

CQC: Care Quality Commission

NIHR: National institute of Health Research

IMD: Indices of Multiple Deprivation

EPAS: Early Psychosis Attribution Schedule

NOS: Nottingham Onset Schedule

MHRN: Mental Health Research Network

BSMHFT: Birmingham and Solihull Mental Health foundation Trust

EIS: Early Intervention Services

FEP: First Episode Psychosis

AESOP study: Aetiology and Ethnicity in Schizophrenia and Other Psychoses

DUP: Duration of Untreated Psychosis

DUI: Duration of Untreated Illness

Prodromal: the period of psychological disturbance prior to a first psychotic episode

CJA: Criminal Justice Agency Involvement

GPI: General Practitioner Involvement

LSOA: Lower Layer Super Output Area

CPN: Community Psychiatric Nurse

Abstract

Introduction: It has been consistently found that Black-Caribbean patients experience disproportionate rates of compulsory hospital admission during First Episode Psychosis (FEP). Existing research can only partially explain this phenomenon, which suggests that other more comprehensive explanations must exist. This thesis aims to address this limitation and develop both an empirical and theoretical understanding that explains ethnic variation in detention rates specific to FEP.

Thesis Aim: To identify new variables that account for excessive rates of detention amongst Black-Caribbean patients during FEP, which can help develop a theoretical explanatory model.

Method: A mixed method pathways to care study was conducted consisting of two parts. In the quantitative part, a multi-ethnic cohort of FEP patients was recruited at the point of entry into an Early Intervention Service (EIS) where socio-demographic, clinical, help seeking behaviours and symptom attributions during the pathway to care were collected. In a separate qualitative design, carers' narrative accounts of the processes leading to detention were also explored, comparing and contrasting ethnic difference between Black-Caribbean and other groups.

Results: From the quantitative arm, 122 FEP patients were recruited of which 46 were White-British (37.7%), 44 Black-Caribbean (36.06%) and 32 Asian-Pakistani (26.22%). Through the logistic regression analysis conducted, eight variables were found to attenuate the association between the Black-Caribbean sample and elevated rates of compulsory detention. In the qualitative work, 17 interviews were conducted and revealed many unique features in the process of detention for Black-Caribbean patients, such as; a lack of awareness of the early signs of psychosis, the influence of patients fragment living status and the importance of a psychotic episode manifesting itself through a crisis event.

Discussion: Through an iterative process, a theory is developed that married well key explanatory finding from both arms of the study, in accounting for ethnic differences in detention rates. This theory is named the 'crisis hypothesis', and is discussed in detail within.

Chapter One:

Introduction; Background to the Ethnicity and Excessive Rates of Compulsory Hospital Admission Problem

Background

Ethnic variation in the rates of compulsory hospital admission under the Mental Health Act (MHA) (Department of Health 1983) is a complex and historical topic in psychiatric care research. Since the 1960's epidemiological research has consistently found that specific ethnic minority groups in Britain are significantly overrepresented in their rates of compulsory hospital admission under the MHA, in comparison to their White-British counterparts (Sims and Symonds, 1975). Irish and Caribbean immigrants were some of the first to be identified as being subject to this phenomenon (Sims and Symonds, 1975), which subsequent studies have also found amongst second and third generation migrant groups (McGovern and Cope, 1991, Morgan et al., 2005a, Audini and Lelliott, 2002, Commander et al., 1999). In a meta-analysis exploring detention rates under the 1983 MHA, Singh et al. (2007) found that Black and Minority Ethnic (BME) patients were almost three and a half times more likely to be compulsorily detained in comparison to White-British patients. It is therefore well established that BME patients are disproportionately represented in their rates of compulsory hospital admission. Despite the extensive amount of research in this area, there remains a paucity of work clearly explaining why these differences exist. In a systematic review, Singh et al. (2007)

identified five groups of explanations that were frequently mentioned in the literature, however, the review also revealed that there was a lack of empirical evidence to support these postulations. Cantor-Graae (2008) argues that although we are aware that ethnic differences in detention rates exist, there is still no clear explanation as to why. This thesis aims to address this problem, and attempts to understand why certain ethnic minority groups in Britain are overrepresented in their rates of compulsory hospital admission.

Why Are Ethnic Difference In Detention Rates Important?

Compulsory hospital admission, unlike many other areas of health care, is most frequently used within Psychiatry. The Mental Health Act (MHA) is the legal document that oversees this process; detailing the specific circumstances where detention is lawful. Although the act is complex, it could be argued that the following two principles guide a clinician's choice to hospitalize a patient against their own volition. In some circumstances, psychiatric patients pose significant risk to themselves, in terms of deliberate self-harm, self-neglect and suicidal behaviour. Detaining a patient may be deemed necessary in these instances, in order to circumvent such risk and the potential negative longitudinal consequences to the individual. The second principle of the act is to safeguard the general-public. Occasionally, psychiatric patients are a risk to other members of society, when unwell and symptomatic. In such instances, health care professionals may feel compulsory hospitalisation is required to prevent the risks associated with illness-related behaviour and return the patient to good health.

Despite the benefits of the act, many have raised ethical concerns about the nature of detention, bringing into question the experiences associated with detaining an

individual against their will. In a qualitative study, Hanson (1995) found that family members often reported a variety of negative experiences in the process of compulsory detention, such as; conflicts with staff and staffing procedures, difficulty in relinquishing caring duties and upset in the discharge process. Jankovic et al. (2011) further demonstrated that family members experienced various emotional responses, such as worry, grief and distress. In the study conducted by Corcoran et al. (2007), caregivers also found the hospitalisation process problematic for a number of reasons and reported that it was a highly distressing life event. Moreover, similar findings have also been found for patients. Etheridge et al. (2004) reported the patients felt that the hospitalisation experience was unhelpful, while Jones and Mason (2002) qualitatively demonstrated that in-patients were dissatisfied with the quality of care by staff, often feeling isolated and neglected at a time of vulnerability. In a systematic review of patient experiences of detention, Newton-Howes and Mullen (2011) found the recurrent themes of personal violation, disrespect, distress and personal ostracization. However, the most common finding was that patients felt dehumanised, through a loss of normal human interaction and isolation. These findings have also been echoed in other studies (McGorry et al., 1991, Boydell et al., 2012).

In the era of patient centred care, the National Health Service (NHS) is committed to improve patients' experiences of the services it provides. The 2009 and 2010 NHS national strategic framework both emphasises the importance of this, and attempts to address the link between excessive rates of detention and greater negative experiences for BME patients. Moreover, negative experiences of compulsory hospitalisation are thought to lead to more serious outcomes. Both Singh (2001) and Morgan et al. (2004) have both argued that the initial negative experiences of treatment can lead to service

disengagement. In the event of a relapse, the reuse of compulsory treatment measures is often more readily required, as the patient is unwilling to engage with treatment on their own will. A vicious disengagement-relapse circle is thus created, where negative experiences of detention, leads to dissatisfaction with, and disengagement from, services; in turn increasing the use of compulsory treatment when the patient is unwell again. Furthermore, this cycle is likely to negatively impact the long-term recovery trajectories of the patient, as their level of treatment remains inconsistent. It therefore stands to reason that a better understanding of the causes of excessive detention rates is pivotal in the improved treatment of specific BME patient groups within the NHS.

The Politics

The very notion of ethnic disparities within the National Health Service (NHS) is an extremely controversial one. In 1998, an Afro-Caribbean man called David Bennett died whilst being restrained in a psychiatric hospital in Norwich. In addition to the usual medical inquiry, the Labour government commissioned an independent public one into his death. The findings brought to light the many claimed 'shortcomings' of services, including the unacceptable excess of BME patients that were compulsorily hospitalized. This report lead to the eventual establishment of the Delivering Race Equality (DRE) action plan, a government project aimed at reducing ethnic disparities in mental health care (Department of Health, 2005). The 100 million pound programme, set up in 2005, aimed to address a series of objectives related to ethnic inequalities in mental health care. This included the reduction in the disproportionate rates of compulsory detention for BME service users, over a five year period (Department of Health, 2005). Various social activist groups have also become concerned with the disproportionate rates of detention. In 2005 the "count me in census", a measure of inpatient usage in England

and Wales, demonstrated higher rates of detention for BME patients. In response, Lee Jasper, the chair of the African and Caribbean mental health charity, stated that these results confirmed once and for all that mental health services are 'institutionally racist" and 'overwhelmingly discriminatory' (Singh and Burns, 2006, p. 648).

In 2002, the Sainsbury's centre for mental health published the 'Breaking the circles of fear' report (Keating et al., 2002). The report highlighted many causal explanations surrounding the tensions between the Black-Caribbean community and psychiatry. One of the key findings suggested that there was a 'circle of fear' within the mental health system, which consisted of negative perceptions about Black people (stigma, racism and cultural ignorance) that undermined the way mental health services were accessed and responded to within the community. In addition the report also concluded that services were experienced inhumanly, unhelpfully and inappropriately; which further began to bring into question issues relating to human rights.

The place where this topic has seen the greatest amount of attention is within the psychiatry community itself. Often of a contentious nature, an array of current opinion pieces have been written by prominent academics in the area (Harrison, 1989, McKenzie and Bhui, 2007). From these exchanges it is clear that there is much disagreement within the psychiatric community about the true cause of this phenomenon. Although this debate is complex it could be argued that the many positions within are centralised around one of two themes. On one side exists the notion that the excess of compulsory hospitalisation for BME groups is the result of factors related to ethnicity. One argument within this position proposes that ethnic variation in clinical presentation legitimizes the need for differing rates of compulsory hospitalisation. It is therefore argued that

BME patients' psychiatric needs are of a different nature to the general population, more readily requiring compulsory care. Another argument suggests that although of the same type as their counterparts, severe psychiatric illness is much more common within the BME population, which attributes this to organic factors, malnutrition and aspects of their environment (Littlewood and Lipsedge, 1982). Another point within this notion is related to the differing ways that BME patients conceptualise mental illness and its treatment. Here, it is thought that BME patients in Britain have a concept of psychiatric services in line with the treatment in their country of origin, where services are typically less common and reserved for the more severely ill. A delay in voluntary help seeking occurs, as the patient is more likely to wait to seek help until he/she feels the course of the illness is more severe, thus increasing the likely hood of compulsory treatment and adverse routes (Littlewood and Lipsedge, 1982). Singh and Burns (2006) further postulate a series of claims built around this notion, stating that ethnic variation in help seeking behaviours and stigmatic views of mental illness services, acts as an barrier to voluntary modes of treatment. The authors also suggest that a lack of intermediaries may further lead to compulsory admission, as family members are likely to seek help early, pre-empt an acute crisis and provide community alternatives to detention.

At the other end of the spectrum lies the proposition that psychiatry, in its practices, creates ethnic variation in compulsory hospital admission. They argue that the excess amongst BME patients is the product of 'racism'; which inappropriately detain patients through prejudicial actions. Misdiagnosis, stereotyping, and discriminatory attitudes are the factors that contribute to this, as well as a societal level of discrimination, where by psychiatry acts as a 'social-political' form of control (Littlewood and Lipsedge, 1982).

Subscribing to this side of the debate, Sashidharan (2001) puts forward the notion of 'institutional racism'. Central to this is the idea of morality, in which he attempts to refocus our concept of 'treatment' from being solely about efficacy, to one about equality. Under this principle, the significance of the 'Black experience', imbued with its negative stereotypes, dissatisfaction and resistance to care, is crucial in our assessment. If an institution, through its activities, produce such diversity in its experiences and outcomes, he argues that it is clearly an agent of disadvantage and therefore 'racist'. McKenzie and Bhui (2007) argue that psychiatry can be construed as 'Institutionally' or 'structurally racist', when choices or service configuration inadvertently lead to disparities in health care outcomes for BME groups.

What is apparent from the literature and discussions outlined above is that the notion of ethnic disparity in detention rates is highly politicised. The many sides of this on-going debate have raised some compelling arguments; however it is not the purpose of this thesis to contribute to this political debate.

The Influence of Psychiatric illness
Another important concept when understanding ethnic variations in detention rates is its connection with different psychiatric illnesses. Routes to compulsory detention are the consequence of behaviours associated with a range of psychiatric conditions. However, research has shown that individuals with specific disorders are more likely to be detained than others. In a study conducted in two sites in London, Bebbington et al. (1994) found that 72% and 73% of their samples were detained under the MHA with psychotic disorders; with the remainder of the sample experiencing other psychiatric conditions (22% affective and 5% other). It is therefore clear that when attempting to

understand ethnic variations in detention rates, one must also account for ethnic variation in psychotic disorders, as elevated rates of detention may simply be a function of elevated rates of psychosis. This argument has been the claim of many (Bebbington et al., 1994, Riordan et al., 2004, Anderson and Parrott, 1995) although there is much criticism of the research alluding to higher rates of psychosis for the BME community. Despite these claims, a recent robust study found that the incidence rates of all psychotic disorders were roughly nine and six times higher for the Black-Caribbean and Black-African population respectively, in comparison to White-British patients (Morgan et al., 2006b).

There therefore appears to be an interaction between the BME population, elevated rates of psychosis and elevated rates of compulsory hospital admission. However, existing research explaining ethnic differences in detention rates has been criticised as they failed to fully account for varying rates of diagnosis, by focusing on all patients detained at a given point in time (e.g. all patients on a specific hospital ward over a three month period), rather than focusing on specific clinical disorders (i.e. rates of detention in affective disorders vs. rates in psychotic disorders). This proves problematic, as the influence of ethnic variation in rates psychiatric illness cannot be fully accounted for in these methodological designs. New research has begun to address this issue, and showed that both Black-Caribbean and Black-African patients have elevated rates of detention exclusively within psychotic disorders (Morgan et al., 2005a). Other explanations for ethnic differences in detention rates must therefore exist which future research needs to take into account, in addition to the importance of ethnic variation in rates of psychosis.

How Can Excessive Rates Amongst Ethnic Minority Groups Be Reduced?

Despite all the attention drawn to this topic, the ability to reduce excessive rates of detention has been unsuccessful. In a systematic review of the literature, Sass et al. (2009) identified only six studies that had attempted to enhance the pathways to care for specific ethnic minority groups; one of which was conducted in the United Kingdom (UK) with no success. The Delivering Race Equality initiative (DRE) has also showed a lack of success in addressing this issue. The Care Quality Commission (CQC) a monitoring agent of the DRE reported an increase in detention rates amongst BME patients from 20% in 2005 to 23% in 2010. Furthermore, rates of compulsory detention were between 25 and 38 per cent higher for BME groups than those of White-British ethnicity (Care Quality Commission and National Mental Health Development Unit, 2010). It is therefore clear that existing strategies attempting to modify ethnic variation in detention rates are limited, which may be due to limited agreement in the ways best to deal with this problem or reflect the lack of understanding of the underlying causes of the phenomenon. Successful strategies are therefore unlikely to be reached, until the scientific community can agree on a model that adequately explains excess. However, before such aims can be reached, existing knowledge of key mechanisms needs to be improved, through more thorough investigation.

Summary

It is clear that ethnic minority groups are overrepresented in their rates of compulsory hospital admission. Although the purpose of compulsory admission is to help the patient, research suggests that both patients and carers often experience negative consequences as a result. For this and other associated reasons, compulsory routes to treatment are described as negative, coercive and adverse; as they are the non-

preferred routes to psychiatric care. Ethnic overrepresentation in detention rates is a controversial topic, in both the political, academic and social arena. Originally, it was thought that a diagnosis of psychosis was the only factor that explained ethnic differences in detention rates; however, new evidence suggests that variability in detention rates also occur exclusively within psychotic disorders; a fact that is seldom accounted for in previous studies. Our ability to reduce these disparities is therefore limited, which could reflect the lack of consensus about the specific cause of this phenomenon. Further research is therefore needed to improve our understanding by searching for the influence of other uncharted factors.

In addressing this topic, this thesis aims to increase existing knowledge of the factors that contribute to the overrepresentation of compulsory hospital admission for specific ethnic minority groups in Britain. In doing so, it will help begin to develop an empirically supported model, explaining BME excess through four main area;

1. The first is through identifying the contributory factors of BME excess over time. Within the literature, researchers have invariably attempted to understand BME excess in a cross-sectional way, by exploring the association between ethnicity, detention and associated factors at a fixed point in time. This proves problematic when attempting to develop a comprehensive view, as such approaches fail to account for ethnic variation in prior help seeking behaviours, previous clinical encounters, and various illness related factors (e.g. symptom development, length of illness and symptom presentation). In an attempt to obtain a fuller understanding of BME excess, this thesis will develop a more chronological understanding of the

factors which lead to compulsory hospital admission in addition to the cross-sectional approaches commonly used.

2. The second area that this thesis will increase understanding of BME excess is by focusing exclusively on First Episode Psychosis (FEP). In the past, previous research has often failed to take into account the importance of diagnostic and episodic differences in mental health problems (i.e. to make the distinction between those patients who present to services for the first time, in comparison to those who are known to services; and also those with affective disorders in comparison to those with psychotic disorders). As these two groups are qualitatively different in the routes that they come to care, an understandings of the factors that contribute to BME excess is limited where research fails to account for such difference. In addressing this, this work will only focus on factors that contribute to patients who present to services with psychosis for the first time (I.e. First Episode Psychosis).

3. The third area that this work will add to our existing knowledge, is through the exploration of cultural factors. In doing so this work will exclusively focus on the excess amongst specific and discrete ethnic groups (the rationale of which, will become clear through the literature review). In previous studies, researchers have often used loosely defined ethnic categorisation in their attempt to identify the factors that contribute to BME excess. This proves problematic, as the cultural processes in help seeking and illness experience may get overlooked, especially in methodologies where the boundaries between societal groups are loosely defined. Helman (2007) has suggested that specific ethnic groups have unique cultural ways

of dealing with sickness and help seeking. By being specific in the choice of the ethnic groups used, this work will be better able to develop a cultural understanding of factors involved, such as differences in beliefs about symptom causality, cultural help seeking resources and social network involvement.

4. The final way that this work will add to existing knowledge is by developing an empirically supported model. Morgan et al. (2004) has argued that our current knowledge surrounding this phenomenon is limited, due to the traditional epidemiological and survey based approaches used within psychiatric research. The effect of which is a static, mono-dimensional understanding, where by the associations between selected, fixed variables are taken to somehow capture the causal mechanisms. The authors further argue that our approach should move away from this, and attempt to develop dynamic theoretical models, exploring ethnic variation in the range of available treatment options, illness beliefs, social networks and other social processes.

Thesis Aims

1. To further identify the factors that best explain excessive rates of detention amongst Black-Caribbean patients exclusive to First Episode Psychosis (FEP).

2. To use the findings from aim 1 to develop a theoretical model of the processes which lead to excessive rates of detention amongst Black-Caribbean patients.

Thesis Outlines and Structure

In the first of the eight subsequent chapters, a systematic review and Meta-analysis will examine ethnic differences in the rates of compulsory detention during First Episode Psychosis (FEP). In addition, this chapter will identify the factors empirically shown to account for BME patient's association with compulsory hospital admission and identify influential factors and processes that navigate a patient to treatment. In the second (Chapter Three), the methodology of this work will be given, detailing both the quantitative and qualitative phases employed and how the methods were developed and interlinked. In chapters four and five, the results from the quantitative phase will be presented, followed by the qualitative results in chapter six. In the seventh chapter, a discussion of the results from the previous three empirical chapters will be given. In the eighth chapter, a synthesis of key finding will be brought together through the development of a new theoretical model. This thesis will then be concluded in the ninth and final chapter.

Chapter Two:

Literature Review; Ethnic differences In Detention Rates and the Pathways to Care during First Episode Psychosis (FEP)

Introduction

As established in Chapter One, ethnic minority groups in Britain are overrepresented in their rates of compulsory hospital admission under the Mental Health Act (1983). Various reviews have confirmed this (Singh et al., 2007, Morgan et al., 2004, Bhui et al., 2003, Littlewood, 1986, Spector, 2001), with the latest meta-analysis reporting that BME groups are three and a half times more likely to be detained as compared to their White-British counterparts (Singh et al., 2007). It has been argued by some, that ethnic variation in detention rates is simply the result of elevated rates of psychosis amongst specific ethnic minority groups (Bebbington et al., 1994, Riordan et al., 2004, Anderson and Parrott, 1995). However, if this were the only explanation, studies that control for psychosis should find no ethnic variation in the rates of detention. Despite this postulation, new research opposes this idea, and has found that ethnic differences persist exclusively during First Episode Psychosis (FEP) (Singh et al., 2007, Morgan et al., 2005a). It is therefore clear that existing explanations of why ethnic inequalities in detention rates exist are lacking, as no robust evidence-based explanations can fully account for the known differences in detention rates (Cantor-Graae, 2008, Singh et al., 2007).

Chapter Focus

The aim of this thesis is to identify the reasons behind higher rates of detention for specific ethnic minority groups in Britain. As new research has pointed to the importance of diagnosis, this chapter aims to review ethnic differences in detention rates specifically during First Episode Psychosis (FEP); identify known determinants and; explore how patients with FEP come to receive treatment.

Chapter Structure

This chapter is separated into the following four parts; two literature reviews exploring 1) the magnitude and determinants of ethnic differences in detention rates during FEP, and 2) important features of the 'pathway to care' for FEP patients and identify how ethnic groups vary within this. A discussion of the result of each of these reviews will be given in part 3, followed by a synthesis of key findings to conclude in part 4.

Figure 1: Structure of Literature Review Chapter

Review 1	Review 2
Ethnic variation in the rates of compulsory hospital admission during FEP	A review of the pathways to care during FEP
The determinants of ethnic variation in rates of compulsory hospital admission during FEP	Known ethnic variation in the pathway to care during FEP.

Discussion of key findings from reviews 1 and 2

Conclusions and Application
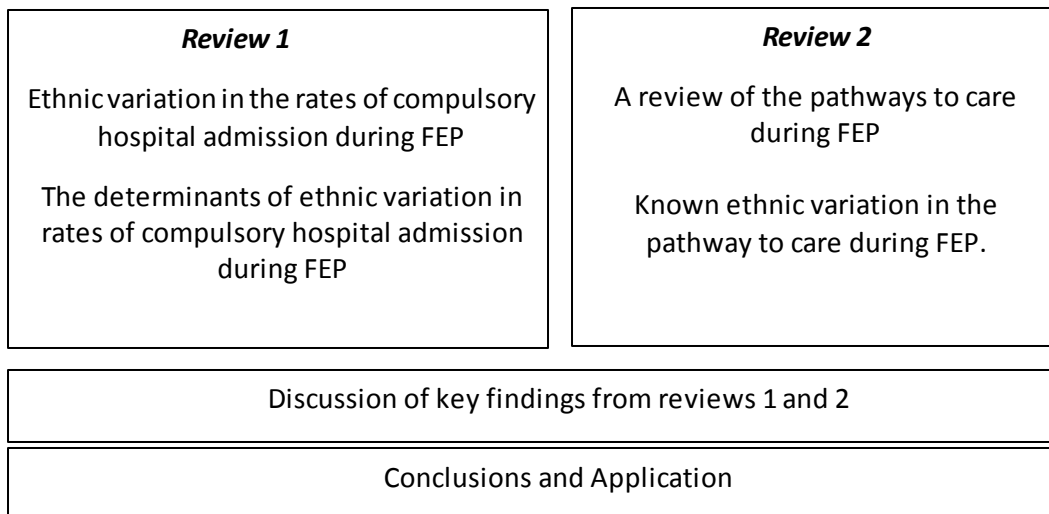
Review 1:

Ethnic Variation In Compulsory Hospital Admission During First Episode Psychosis (FEP): a review of the literature and Meta-Analysis

This review aims to systematically explore the literature to identify ethnic variation in the rates of compulsory hospital admission under the MHA, *specifically* during First Episode Psychosis (FEP). In order to facilitate this, a series of meta-analyses were conducted, comparing rates of detention between various ethnic groups. In addition, this review also attempts to identify the known determinants and associated evidence-based explanations of this phenomenon. Known determinants were therefore extracted from the relevant articles and reported in a narrative format.

Aims of Review 1

1. To compare ethnic differences in compulsory hospitalisation during FEP in England and Wales, since 1983 (the introduction of the MHA).

2. To establish the socio-demographic, clinical and help-seeking correlates of MHA detention and determine whether these fully explain ethnic differences in detention rates.

Method

Search Strategy

A systematic literature search was conducted to explore the rates of BME excess in compulsory hospitalisation during First Episode Psychosis (FEP). The CONSORT guidelines for the conduct of systematic reviews and meta-analyses of observational

studies were adhered to (Stroup et al., 2000). A comprehensive search strategy was utilised to identify all studies in England and Wales that had explored ethnic variation in pathways to care during FEP. Studies from England and Wales were selected, as these were the regions where the jurisdiction of the MHA was applied. Three recent systematic reviews had previously been conducted in this area, one on ethnicity and detention (Singh et al., 2007) and two others on pathways to care during FEP (Anderson et al., 2010, Schaffner et al., 2012). As these three reviews overlapped the purpose of the current review, but did not specifically focus on making ethnic comparisons during FEP, each was read and cross-referenced for relevant articles meeting the inclusion/exclusion criteria.

In addition, bibliographic databases (ISI Web of Science, OVID-Medline and AMED) were searched for articles published between May 2007-September 2013, to account for contemporary research following a similar approach to one used in the review by Singh et al. (2007). The literature on ethnicity and psychiatric care is both vast and diverse, and hence narrow terms were used to ensure that retrieved literature only focused on a first episode population. A comprehensive keyword and title search strategy was employed where combinations of the following sets of words were used;

1. Mental health Act related terms (e.g. sectioned, MHA, mental health act, legal detention),
2. First Episode Psychosis terms (e.g. schizophrenia, early psychosis, first episode schizo$),
3. Ethnicity and race related terms (e.g. Black, BME, Ethnic Minority, Non White, Afro-Caribbean, Asian and Black-Caribbean)

Boolean search operators were used where possible, in addition to explosion terms predefined by some of the databases used. Grey literature was also sought, including conference abstracts and data from unpublished theses (Web of Knowledge and Ethos-British Library). Finally, Google Scholar was also utilised using the phrase 'pathways to care in first episode psychosis' in the 'anywhere in text' field using the same time frame as previous stated. Once key articles had been retrieved, the bibliographies of each of the papers were read for additional studies. Personal endnote libraries were also searched and contact was made with other authors in the area for additional research missed.

Inclusion Criteria

1.   First Episode Psychosis only (FEP) cohorts.

2.   Conducted in England and Wales (the jurisdiction of MHA)

3.   Ethnic comparison between two or more groups.

4.   Comparison of rates of compulsory hospital admission under the Mental Health Act 1983 or 2007

Exclusion Criteria

1.   Data used in previously retrieved articles.

2.   Data from 'first contact with services' studies, with no specification of episode.

3.   Qualitative papers.

4.   Studies not in English.

Data Extraction

The author of this thesis extracted all key information from each of the papers, which was subsequently entered into a database via Endnote. Titles of all relevant papers were reviewed for possible inclusion and were read for further information. Of all the potential papers, key information was extracted, including; overall sample size, ethnic specific sample size, measurement of ethnicity, method of ethnic comparison and rates of detention. Articles were also read to identify instances where the determinants of ethnic disparities in detention rates were reported.

Appraisal of Literature Methodology

A quality review of the included studies was conducted using the approach described by Bhui et al. (2003). Essentially this approach is a scoring system appraising each study on the domains: sample size, adjustment for confounders, measurement of ethnicity and choice in ethnic comparison (Appendix 1). Each article was given a series of scores that totalled up to a maximum of 11. Higher scores reflect better methodological quality.

Heterogeneity

Chi squared and I^2 statistics were used to assess statistical heterogeneity within each analysis. The convention set out by Higgins et al. (2003) was used to qualitatively rate heterogeneity.

Meta-Analyses Design

Meta-analyses were conducted to compare distinct ethnic minority groups to one another. In all, four separate meta-analyses were conducted, in which the following four

categories were used, as they were the most consistent groups compared between the papers;

1. Broad-Black (Unspecified Black, Black-Caribbean, Black-African and Black-Other),

2. Black-Caribbean (Black-Caribbean only)

3. Broad South-Asian (Unspecified Asian, Asian-Indian and Asian-Pakistani).

These three ethnic categories were chosen, as they were the lowest common denominator by which multiple studies could be combined. Black-Caribbean ethnicity was most frequently used within the literature and so this warranted its inclusion in the Meta analyses as a unique category. The Broad-Black group used a mixture of other Black ethnicities (African, Other and Unspecified) as they were less frequently used in the literature. This approach was also used for the south-Asian group. Studies that compared rates in Afro-Caribbean patients were included in both the Black-Caribbean specific meta-analyses as well as that of the Broad Black analysis.

Comparative sample groups were chosen as they reflected distinct categories in which the three target ethnic groups could be compared against. The four comparative samples were;

1. Broad White (Unspecified White and White-British),

2. White-British (White-British Only),

3. Non Broad-Black (all ethnic groups other than Broad-Black, see above)

4. Non Black-Caribbean (all ethnic groups other than Black Caribbean see above).

The estimation of excess was therefore calculated for the Broad-Black, Black-Caribbean and South-Asian population independently. In addition, studies that explored compulsory detention in more than one ethnic group were included multiple times *within* each analysis, as multiple comparisons could be made. All analyses were conducted using Review Manager 5.1 for Windows 7.

Results (Part 1)

In total 1820 journal articles retrieved from both the previous systematic reviews and the new contemporary review. Only three new studies met the overall inclusion/ exclusion criteria of this review (see Figure 2 for further details). These were added to the eight articles identified through the three previous reviews. However, on further examination one was a conference abstract of an article already retrieved, and therefore excluded. The final tally consisted of 10 studies.

There was variation between studies in terms of methodological quality (See Table 1). The majority were of 'moderate quality', with eight of the eleven articles scoring between 4 and 7. The studies by Birchwood et al. (1992) and Morgan et al. (2005a) were both rated 'high in quality', scoring 8 and 10 respectively. Throughout, ethnic comparison of detention rates was rarely a primary research objective and many studies gave narrative accounts of difference in detention rates rather than actual numbers. Of the 10 studies, 6 had data that could be extracted and pooled (See Figure 2). The studies by King et al. (1994), Goater et al. (1999) and Cole et al. (1995) used the same data set, but extractable data was only found in the article by Cole et al. (1995).

The individual meta-analysis ranged from low to moderate in their levels of heterogeneity using the convention set out by Higgins et al. (2003). The results further revealed that the analyses in figures 3 and 4 were more heterogeneous than the ones conducted in 5 and 6.

Outcome of Meta-Analyses

In total, four separate meta-analyses were conducted, comparing one ethnic category to another. Figures 3 and 4 show that Black-Caribbean patients were significantly more likely to experience compulsory hospital admission, when compared to both White-British (2.39, 95% CI 1.62-3.52, p < 0.0001), and Non-Black Caribbean patients (2.10, 95% CI 1.62-2.73, p < 0.0001). This was also true for the Broad-Black group in comparison to Non Broad-Black patients (2.57 95% CI 2.05-3.24 p < 0.0001) (Figure 5). Conversely, no difference was found between South-Asian patients in comparison to White-British patients (0.59, 95% 0.25-1.39, p < 0.22) (Figure 6).

Figure 2: Flow Chart Showing the Different Steps in the Amalgamated and Updated

Search Strategy

Previous Systematic Review Included

- Singh et al., (2007) =28
- Anderson et al., (2010) =49
- Schaffner et al., (2012) =25

Total =102

Articles Retrieved Through

Contemporary Review n= 1718

Studies Excluded From Previous Reviews

Not clearly define their cohort as FEP =42

FEP cohorts but not conducted in the United Kingdom (UK) =41

Duplicated studies = 9

FEP studies with no ethnic comparison = 2

Studies Excluded

Non pathway to care studies =1660

Not meeting one or more of the inclusion criteria = 41

FEP studies with no ethnic comparison = 2

Systematic reviews already obtain =2

Abstract of Already Obtained Article = 1.

Studies Taken Forward From Previous Reviews =08

Studied Taken Forward =02

Overall Studies Included In Review 1 = 10

Table 1: Articles Used In Systematic Review of the Literature and Meta-Analysis With Scoring System Adapted From Bhui et al. (2003)

Author, year	Group size (n)	Sample size (n)	City	Adjustment for confounders	Ethnic Categorization Quality	Ethnicity Use in analysis	Score
Harrison et al. (1989)*	African-Caribbean (42) Non African-Caribbean (89)	131	Nottingham	Diagnosis, Gender & Age	Third party reports	Inappropriate ethnic groups combined /poor Collection of ethnicity data.	5
Chen et al. (1991)	Afro- Caribbean (40) Non African-Caribbean (40)	80	Nottingham	Diagnosis	Medical records, Source not specified	Inappropriate ethnic groups combined /poor Collection of ethnicity data.	4
Birchwood et al. (1992)*	White British (74) Asian British (30) African-Caribbean British (50)	154	Birmingham	Diagnosis	Census rated	Lumping of groups	6
(King et al., 1994)	White (39) Asian (11) Black (38)	93	London	Diagnosis	self-reported/census categorisation	Lumping of groups	4
Cole et al. (1995)*	White (39) Black (39) Other (16)	93	London	Diagnosis, Absence of a help seeker, Lack of GP involvement	Census rated	Lumping of groups	8
Goater et al. (1999)	White (39) Black (38) Other (16)	93	London	Age, gender, Unemployment, Risk to others, Criminal Justice referrals, Self-initiated help seeking & Diagnosis	Self-reported/census categorisation	Lumping of groups	6
Burnett et al. (1999)*	White (38) African-Caribbean (38) Asian (24)	100	London	Diagnosis	Self-reported/census categorisation	Lumping of groups	7
Williams et al. (2000)	Black (20) White (88)	108	Nottingham	Diagnosis	Self-reported/census categorisation	Lumping of groups	4
Brunet (2003)*	White (15) Black (32) Asian (25)	79	Birmingham	Diagnosis	Not reported	Inappropriate ethnic groups combined /poor Collection of ethnicity data.	5
Morgan et al. (2005a)*	White British (237) African-Caribbean (128) Black African (64) White Other (33)	462	London & Nottingham	Age, gender, Unemployment, Risk to others, Criminal Justice referrals, Self-initiated help seeking & Diagnosis	Self-reported/census categorisation	All analysis done without amalgamation of data.	10

Scoring system key (Bhui et al., 2003): Low quality 0-3, Moderate quality 4-7; High quality 8-11

Figure 3: Comparison In Rates of Compulsory Hospital Admission between Black-Caribbean and Non Black-Caribbean patients

Study or Subgroup	Black–Caribbean Events	Total	Non Black–Caribbean Events	Total	Weight	Odds Ratio M–H, Fixed, 95% CI	Odds Ratio M–H, Fixed, 95% CI
Birchwood et al (1992)	16	50	19	74	13.5%	1.36 [0.62, 3.00]	
Birchwood et al (1992b)	16	50	4	30	4.4%	3.06 [0.91, 10.25]	
Chen et al (1991)	20	40	9	40	5.8%	3.44 [1.31, 9.06]	
Harisson et al (1989)	19	42	19	89	8.7%	3.04 [1.38, 6.72]	
Morgan et al (2005)	66	128	64	237	28.2%	2.88 [1.84, 4.51]	
Morgan et al (2005b)	66	128	10	33	10.0%	2.45 [1.08, 5.56]	
Morgan et al (2005c)	66	128	35	64	29.3%	0.88 [0.48, 1.61]	
Total (95% CI)		566		567	100.0%	2.10 [1.62, 2.73]	
Total events	269		160				

Heterogeneity: Chi² = 13.37, df = 6 (P = 0.04); I² = 55%
Test for overall effect: Z = 5.55 (P < 0.00001)

Figure 4: Comparison In Rates of Compulsory Hospital Admission between Black-Caribbean and White-British patients

Study or Subgroup	Black–Caribbean Events	Total	White–British Events	Total	Weight	Odds Ratio M–H, Fixed, 95% CI	Odds Ratio M–H, Fixed, 95% CI
Birchwood et al (1992)	16	50	19	74	32.4%	1.36 [0.62, 3.00]	
Morgan et al (2005)	66	128	64	237	67.6%	2.88 [1.84, 4.51]	
Total (95% CI)		178		311	100.0%	2.39 [1.62, 3.52]	
Total events	82		83				

Heterogeneity: Chi² = 2.60, df = 1 (P = 0.11); I² = 61%
Test for overall effect: Z = 4.39 (P < 0.0001)
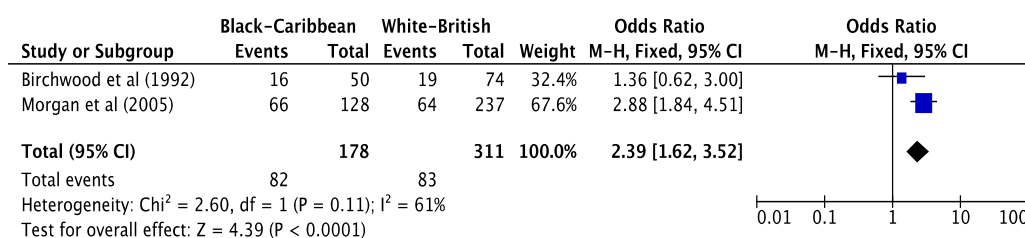
Figure 5: Comparison in Rates of Compulsory Hospital Admission between Broad-Black and Non Broad-Black Patients

Study or Subgroup	Broad–Black Events	Total	Non Broad–Black Events	Total	Weight	Odds Ratio M–H, Fixed, 95% CI	Odds Ratio M–H, Fixed, 95% CI
Birchwood et al (1992)	16	50	19	74	11.5%	1.36 [0.62, 3.00]	
Birchwood et al (1992b)	16	50	4	30	3.7%	3.06 [0.91, 10.25]	
Brunet et al (2003)	16	36	5	16	4.2%	1.76 [0.51, 6.11]	
Brunet et al (2003b)	16	36	8	28	5.5%	2.00 [0.70, 5.72]	
Chen et al (1991)	20	40	9	40	5.0%	3.44 [1.31, 9.06]	
Cole et al (1995)	15	38	11	39	7.2%	1.66 [0.64, 4.31]	
Cole et al (1995b)	15	38	3	16	2.8%	2.83 [0.69, 11.62]	
Harisson et al (1989)	19	42	19	89	7.4%	3.04 [1.38, 6.72]	
Morgan et al (2005)	66	128	64	237	24.0%	2.88 [1.84, 4.51]	
Morgan et al (2005b)	66	128	10	33	8.5%	2.45 [1.08, 5.56]	
Morgan et al (2005c)	35	64	64	237	13.6%	3.26 [1.85, 5.77]	
Morgan et al (2005d)	35	64	10	33	6.6%	2.78 [1.14, 6.76]	
Total (95% CI)		714		872	100.0%	2.57 [2.05, 3.24]	
Total events	335		226				

Heterogeneity: Chi² = 5.44, df = 11 (P = 0.91); I² = 0%
Test for overall effect: Z = 8.07 (P < 0.00001)

Figure 6: Comparison in Rates of Compulsory Hospital Admission between South-Asian and White-British Patients

Study or Subgroup	South–Asian Events	Total	White–British Events	Total	Weight	Odds Ratio M–H, Fixed, 95% CI	Odds Ratio M–H, Fixed, 95% CI
Birchwood et al (1992)	4	30	19	74	67.6%	0.45 [0.14, 1.44]	
Brunet et al (2003)	8	28	5	16	32.4%	0.88 [0.23, 3.35]	
Total (95% CI)		58		90	100.0%	0.59 [0.25, 1.39]	
Total events	12		24				

Heterogeneity: Chi² = 0.56, df = 1 (P = 0.45); I² = 0%
Test for overall effect: Z = 1.21 (P = 0.22)

0.01 0.1 1 10 100
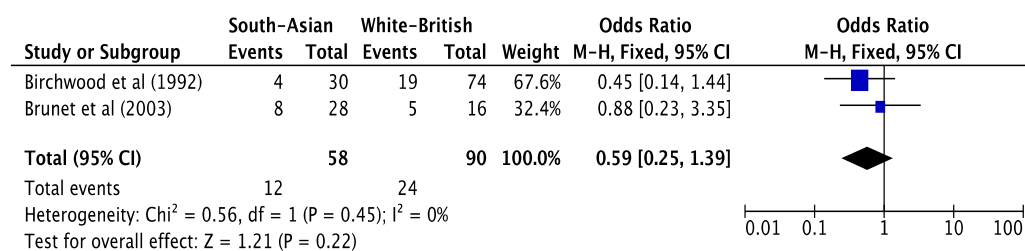
Determinants of Ethnic Differences in Detention Rates from Studies

Factors shown to influence the relationship between ethnicity and compulsory hospital admission were also extracted from the articles identified above. Of these, only two of the ten studies attempted to provide some empirical explanation of why BME groups were more likely to be detained during FEP. These findings fell into one of the two categories 1) Age and gender and 2) the influence of other factors.

1) Age and Gender

Both articles explored the role of socio-demographic factors in accounting for BME excess during FEP. With regards to gender, Harrison et al. (1989) reported that the excess of Afro-Caribbean patients disappeared when comparisons were made between men only. The authors also explored the influence of age, in conjunction with gender. When ethnic comparisons in detention rates were made between both males and females under the age of 30, a reduction in BME excess was also observed. The authors concluded that excess amongst the Afro-Caribbean group was the result of a disproportionate number of older age Afro-Caribbean patients being detained.

Morgan et al. (2005a) also explored the effects of age and gender on detention rates but found differing results to that of Harrison et al. (1989). When comparisons were made solely between males, African-Caribbean patients were 4.75 times more likely to experience compulsory hospital admission in comparison to White-British patients (95% CI 2.41-9.38 p < 0.0001). Conversely, this association was not found for either Afro-Caribbean females or the entire Black-African group. In relation to age, the authors found an increase in the odds of compulsory admission for younger African-Caribbean patients. Those patients aged 16-29 years old were 4.36 times more likely to be detained, as compared to 3.64 times more likely for the whole group overall. A reduction in the odds of detention was also observed for those African-Caribbean patients aged 30-65 years old. It was therefore evident from this study that both gender and age influenced the rates of compulsory detention, with younger African-Caribbean men being at greater risk.

2) The influence of other factors (clinical, social and help seeking variables)
Morgan et al. (2005a) also explored the role of other factors in accounting for excessive rates of detention. Firstly, the unadjusted odds ratios for all measured variables were calculated against compulsory admission. In addition to ethnicity; being unemployed; male; having a manic or depressive psychotic disorders; perceived as a risk to others; having criminal justice agency referral; living alone; not being referred by a General Practitioner (GP); and patient-initiated help seeking, all increased the likelihood of being compulsory detained. In an attempt to assess the interaction between these factors, ethnicity and detention, the authors developed two logistic regression models. In addition to ethnicity, the first model included employment status, criminal justice referral, perceived risk to others, self-initiated help seeking and diagnosis. In the second,

the same variables were used; however, the interaction effects term 'African-Caribbean ethnicity' against 'gender' was also created. The binary outcome of these models was compulsory hospital admission (detained vs. non detained).

The results of the first analysis demonstrated that in addition to African-Caribbean and Black-African ethnicity, unemployment, manic-psychosis, perceived risk to others, criminal justice agency and self-initiated help seeking, all predicted compulsory hospital admission. It was therefore found that ethnicity's relationship with detention remained, even after controlling for these other key factors. In the second analyses, with the interaction effects term included, Afro-Caribbean men were 3.52 times more likely to be detained; a rate higher than its unadjusted overall level. Being unemployed, perceived as a risk by others, manic and depressive psychosis and self-initiated help seeking also remained significant in the model.

Explaining Ethnic Differences in Detention Rates during FEP

The discussion sections of both articles were read to obtain the authors interpretations of significant determinants. In total, four explanations emerged, which attempted to account for ethnic differences in detention rates specific to First Episode Psychosis (FEP). The first highlighted the importance of age and gender; however, there was conflict between studies as to how these variables actually led to excessive detention rates. The second set of explanations encompassed ethnic differences in clinical presentation. It was suggested that excessive detention rates were due to a significant proportion of Black-Caribbean patients presenting to services with greater clinical disturbance. The third set of explanations were related to living status, and suggested that help seeking was complicated when patients lived in isolation. The final set of explanations identified

through the review, was related to ethnic differences in the route to psychiatric care (also known as the pathway to care). It was argued that excessive rates of detention amongst Black-Caribbean patients were related to their involvement in the criminal justice system. In summary, it was clear that although there were many explanations put forward, none could completely account for the excessive rates of detention specific to FEP.

Review 2:

Pathways to Psychiatric Care during First Episode Psychosis (FEP); a Review of the Literature from England and Wales

Introduction

As established in review 1, ethnic differences in detention rates during FEP can only be partly explained. It is therefore likely that other yet charted factors must exist, which this thesis aims to comprehensively address. However, before embarking on the pursuit of such factors, a literature review is required to identify other key factors known to influence a patients' journey to care during FEP, which can further be applied to understand ethnic difference in detention rates. In the literature the journey to psychiatric intervention is referred to as the *'pathway to care'*, which Rogler and Cortes (1993) define as;

"The sequence of contacts with individuals and organisations, prompted by the distressed person's efforts, and those of his or her significant others, to seek help as well as the help that is supplied in response to such efforts".

From this perspective the pathway to care is a complex processes involving both a structure and flow. Contact with the various help-providers is the direct result of the efforts of the ill person and their significant others. Furthermore, this process is a dynamic one, as help-seeking behaviours, the role of services and a non-voluntary routes to care, are all deemed equally as important as each other (Singh and Grange, 2006). The purpose of this objective in the literature review is to identify key features and influential factors of the pathway to care, specific to FEP, and reveal how ethnic groups differ within it. It is hoped that through this discovery new insights into the

pathway to care would be revealed, which can help influence future research attempting to understand ethnic differences in detention rates.

Theoretical Perspectives of Ethnic Variation in the Pathways to Care

Health care utilization is partially mediated by social and cultural factors. These processes are closely interconnected; and incorporate how individuals respond to, and understand their illness, as well as the institutions within the individuals' social world (Morgan et al., 2004). In the context of mental health care, Morgan et al. (2004) draws on the work of Kleinman (1980) who articulates the importance of the Health Care System (HCS), an arena where illness and disease is experienced (see figure 7 for diagrammatic representation of this model). This arena consists of three sectors of care, which Kleinman (1980) designates the popular, folk and professional sector. Firstly, the 'Popular Sector' comprises of all freely available help within one's own social network and community, without the consultation of medical doctors or folk healers. This includes self-medication and informal advice and support from family and friends. The second sphere is the 'Folk Sector' (i.e. spiritual, religious and cultural). This comprises of those individuals not a part of the established medical system that employs traditional approaches to treatment, often using the values of the community in which they serve. Finally, the 'Professional Sector' is usually the medical establishment (i.e. psychiatric services and allied health professionals).

Essentially, Kleinman (1980) theory states that social processes, such as beliefs about the cause of illness, cultural norms that govern health care choices, and the evaluation of available treatment, all mediate the ways in which a patient moves between these spheres of care. It is therefore the interaction between socio-cultural factors and these

treatment sectors that influence the pathway to mental health care; and not solely the severity, frequency and nature of symptoms alone.

Ethnic diversity in the pathway to care is likely to occur when there is cultural variation in the availability of these sectors and the processes involved in help seeking. For example, ethnic differences in beliefs about psychological distress may impede psychiatric help seeking, and in some cases, blur the visibility of medical care as being a viable treatment option (Takeuchi et al., 1988). Ethnic variations in the availability of 'Folk Sector' alternatives may also mediate psychiatric help seeking in a similar way. In addition, those ethnic groups with fewer Popular and Folk sector resources may rely more heavily on mental health services (professional sector). Conversely, help seeking may become less specific for those with multiple treatment avenues available, delaying and even preventing the involvement of medical care. From this perspective Morgan et al. (2004) argue that ethnic specific healthcare outcomes, such as treatment delays, compulsory admission and coercive referral routes are a by-product of these social processes, unique to each ethnic group.

Review Aim

1. To identify key determinants of pathways to care during FEP in the UK
2. To explore ethnic variation in these pathways to care for FEP.

Figure 7: Morgan et al. (2004) preliminary framework for the study of pathways to care and ethnicity, based on (Kleinman, 1980).p 40) Health Care systems model.

Folk Sector

Popular Sector

Beliefs
Choices and Decisions
Roles
Relationships
Interaction Settings
Institutions

The popular sector is the context within which mental illness (onset and relapse) is experienced, made sense of and responded to.

Key features of the popular sector that may be important in shaping variations in pathways to mental health services between ethnic groups include:
- Social Networks
- Beliefs about Mental Illness
- Racism
- The Overall Content and Structure of the Local Health Care System

Contacts in the folk sector may further delay or hinder entry into the professional sector

Professional Sector

Previous experiences of folk and professional services will modify the popular sector and influence subsequent entry into the folk and professional sectors

Method

Search Strategy

Although various systematic reviews have explored some aspects of the 'pathways to care' exclusively during FEP (Anderson et al., 2010, Boydell et al., 2010, Schaffner et al., 2012, Singh and Grange, 2006), none had made ethnic comparisons in this process. For the purpose of this review, the articles from these previous reviews were obtained through snowballing. Furthermore, a new systematic literature search strategy was conducted to ensure that no recent articles were missed.

Contemporary Literature Search Strategy

A replication of the key word search strategy in the article by Schaffner et al. (2012) was used, in the bibliographic databases ISI Web of Science, OVID-Medline and AMED. In doing so, variations of the following key title search terms were used; Pathways to care, First Episode Psychosis (FEP), Help seeking, and Duration of Untreated Psychosis (DUP). Boolean search operators were used to optimise this, where available.

Inclusion Criteria

1. Only studies conducted in England and Wales.

2. Studies with explicit mention of First Episode Psychosis /Schizophrenia cohorts.

3. Studies exploring some feature of the pathway to care.

4. Qualitative or quantitative methodologies.

Exclusion Criteria

1. Non- empirical based papers

2. Studies conducted outside of England and Wales (Jurisprudence of NHS England and Wales)

3. Multinational studies, where UK sample data could not be separated out.

Results (Part 2)

Of the total articles retrieved from the six sources (Figure 7), 337 were non-FEP pathway to care studies, 97 were non-UK studies, 12 duplicates and 1 non-peer review. In total, 17 articles were retrieved, which were combined with a further 6 articles obtained from the bibliographies of the other articles. In all, 23 articles were included in the review. Three articles (Morgan et al., 2006a, Morgan et al., 2005a, Morgan et al., 2005b) used data from a single study (The Aetiology and Ethnicity in Schizophrenia and Other Psychoses- AESOP study), while two (Fisher et al., 2008, Ghali et al., 2012) used the same data from the MiData project. Results were not amalgamated from the latter project as they had different sample sizes from one another.

Description of Studies Included

All articles were published over roughly a three-decade period, between 1986 and 2013. Studies were conducted predominantly in urban settings, with the majority from London, Birmingham and Nottingham. Quantitative designs were mainly employed, however, two qualitative studies were found and one mixed-method design. Studies also varied in their sample size, recruiting between 7 to 775 participants, the majority however had between 50 and 100 participants. These studies also varied in their

categorisation of ethnicity, however most used measurements that included both racial and cultural designation (e.g. Black-Caribbean rather than just Black). Overall, White-British, Black-Caribbean and Asian patients were the most common ethnic categories referenced.

Figure 8: Flow Chart Showing the Amalgamation of Systematic Reviews Included In the Synthesis

Systematic review by (Anderson et al., 2010) n	→	Non UK studies n = 24 **Articles carried forward into the review n= 7**
Systematic review by (Schaffner et al., 2012) n =	→	Non UK studies n = 20 Articles already retrieved n = 1 **Articles carried forward into the review n= 3**
Descriptive qualitative review by (Boydell et al., 2010) n = 27	→	Non UK studies n = 27 **Articles carried forward into the review n= 0**
Review by (Singh and Grange, 2006) n = 15	→	Non UK studies n =9 Articles already retrieved n = 4 **Articles carried forward n = 1**
Ethnicity, compulsory hospitalisation and First episode Psychosis meta-analysis n = 10	→	Excluded non peer review articles n =1 Excluded articles already retrieved n = 4 **Articles carried forward into the review n= 5**
Updated search 2012-september 2013 n = 367	→	Irrelevant articles n = 337 Discarded articles after abstract appraisal n = 8 Non UK studies n = 17 Duplicated articles from previous reviews n = 3 **Articles carried forward into the review n =2**
		Articles from personal files n = 6 **Total articles in review n = 23**

Table 2: Studies Included In Systematic Review of Pathways to Care during FEP

	Authors	Sample Size (n)	City	Ethnic demographic of sample (n)*	Key general findings	Ethnic comparisons
1	(Johnstone et al., 1986)	253	London	White European = 166 West Indian Negro = 41 African Negro = 12 Asian = 25 Chinese = 1 Mixed = 8	- At first contact, patients were likely to be admitted to hospital followed by General Practitioner (GP) involvement. - Overall, GP involvement was the most common help-seeking agency. - Religious organisations were consulted in 33 cases and marriage guidance councillors in 21. - 73 patients were admitted after two help seeking contacts or less. - 46 patients were admitted after nine contacts or more.	- No ethnic comparison reported.
2	(Skeate et al., 2002)	48	Birmingham	Caucasian = 16 African-Caribbean = 26	- Median Duration of Untreated Psychosis (DUP) of 15.4 weeks was found. - Patients, who more frequently consulted their GP before the onset of psychosis, were more likely to have shorter DUPs. - Patients with long DUPs were more likely to use avoidant illness coping strategies and were less likely to visit their GP.	- No ethnic comparison reported.
3	(Morgan et al., 2006a, Morgan et al., 2005a, Morgan et al., 2005b)	462	London and Nottingham	White British = 237 African Caribbean = 128 Black African = 64 Other White = 33	- Overall, patients had a median DUP of 9 weeks and Mean DUP of 58 weeks. - The majority of patients made contact with services within 10 weeks of psychosis emergence. - An insidious mode of onset and non-affective psychosis was correlated with	- Black African and African-Caribbean patients were significantly (sig.) more likely to have compulsory hospital admission, criminal justice involvement, come to services with violent clinical presentation,

					longer DUPs.	and to be perceived as a risk to others than White patients.
					- Patients with acute onset, presented to services within 10 weeks.	- They were also less likely to have, GP and family involvement in the pathway to care.
					- Those patients unemployed and did not have family involvement in their pathways had longer DUP.	- No difference was found between groups in DUP length, self-initiated help seeking or Accident and Emergency referral.
4	(Bhugra et al., 2000)	38	London	All African-Caribbean	- 9 patients (25%) came to services via the police, and 5 (13.8%) by their psychiatrist.	- No ethnic comparison reported.
					- At first contact, 14 patients (37.2%) saw their GP, with the remainder seeing other professionals, such as social workers, nurses and community mental health centers.	
					- The majority of patients conceptualized their illness as 'mental illness', followed by 'not conceptualizing' the illness at all.	
					- In relation to the cause of the problem, 'substance abuse' was often given. No patient mentioned 'supernatural causes'.	
5	(Harrison et al., 1989)	131	Nottingham	African Caribbean = 42 General population = 89	- Only ethnic comparisons were reported.	- Higher levels of compulsory hospital admission for African Caribbean patients.
						- There was a similar length of symptom duration between groups.
						- 40% of Afro-Caribbean patients made 'first contact' with services less than one week prior to

						presentation to psychiatric services in comparison to 2% of the general population sample.
						- Lower levels of family contact prior to illness onset in Black Caribbean patients.
						- Ethnic variation in beliefs about the cause of illness between carers.
						- Ethnic differences in types of presentation to services
6	(Cole et al., 1995)	93	London	White = 38 Black = 11 Other =16	- At 'first contact' patients were likely to see health or social services. - Those who made first non-medical contact most often lived alone. - First mental health contact was most likely to be an on duty psychiatrist. - Factors that predicted compulsory admission were, living alone, living in public housing, absence of a GP, absence of a family or friend in help seeking, and living away from their family. - Factors that predicted the use of section 136 of the MHA were, absence of a friend or family member in help seeking, absence of GP and living alone. - Factors that predicted police involvement were, absence of family and friends during help seeking and no GP involvement. - Lack of GP involvement was associated with not having a family or friend in help seeking,	- No ethnic differences were at first contact in the use of; section 136 of the Mental Health Act (MHA), police involvement, religious encounters or GP referral. - White patients were significantly more likely to make first contact with an on-duty psychiatrist. - Black patients had higher rates of compulsory hospital admission. - A trend was found suggesting that Black patients came to services later than the other two groups.

					living alone and, living in public housing. Consultation with alternative help seeking agencies (religious and non-orthodox) had no association with GP involvement. - 18% of patients had alternative help seeking (faith healers, psychic mediums). - Being single and unemployed predicted later presentation to services as did diagnosis (affective psychosis vs. non affective psychosis).	
					-	-
7	(Burnett et al., 1999)	100	London	African Caribbean = 33 Asian = 24 White = 38	- 28% of patients were compulsory admitted under the MHA. - Patients referred via their GP and visited their GP on their own volition, were less likely to be sectioned, than those who took alternative routes to care. - Police involvement predicted compulsory hospital admission (however, ethnicity and unemployment controlled for that association).	- African Caribbean patients were sig. less likely to have GP involvement and sig. more likely to have domiciliary visits in their pathways to care. - No differences in compulsory hospital admission between the three groups were found. - African Caribbean patients had higher levels of police involvement in comparison to the other groups. - 2.6% of the Afro Caribbean sample, and 8.3% of the Asian sample sought help from a 'priest', in comparison to 0% in the White group. However this difference was not significant.
8	(Garety and	21	London	White/White Other = 12	- 62% of patients had initial treatment at an	- No ethnic comparison reported.

	Rigg, 2001)			Black = 9	acute hospital vs. 38% in the community. - 54% accessed treatment via the police (136 & informal police escort). - 31% via informal routes (Self-initiated/A&E departments). - 8% via compulsory detention (MHA). - 8% via the criminal justice system.	
9	(Cratsley et al., 2008)	59	London	Not reported	- Patients with Children and Adolescent Mental Health Service contacts (CAMHS) had a shorter DUP. - FEP patients referred to adult psychiatric services came predominantly via Community Mental Health teams (CMHTs) (23 cases), In-patient units (9), home treatment services (6), A&E departments (3), other (3). No patient was referred directly via their GP. - Patients referred to CAMHS came through GP (2 cases), A&E (2), inpatients units (1), youth offending team (1) educational psychologist (1) and social services (1). - Shorter DUP was associated with earlier age at psychosis onset and also referral through A&E and home treatment teams.	- No ethnic comparison reported.
10	(Chen et al., 1991)	80	Nottingham	Afro- Caribbean =40 Non Arican- Caribbean =40	- The majority of the sample was hospitalized within 3 months of making initial contact with services.	- No sig. differences between the groups in time between initial contact and admission. - Afro-Caribbean patients had sig. longer ward stays. - Afro Caribbean patients were sig. more likely to be compulsory detained.

						-	Ethnic differences in the reported presentation to services were also found.
11	(Birchwood et al., 1992)	154	Birmingham	White British = 74 Asian British = 30 African-Caribbean British = 50	- Of the 90 patients detained, 70 had criminal justice agency involvement in their pathways. - 73 patients came to care through self-referral or through family help seeking via the GP.	- No difference in detention rates under the MHA. - Afro Caribbean patients were sig. more likely to come to services through criminal justice agency.
12	(King et al., 1994)	38	London	White = 39 Asian = 11 Black = 38	- Only ethnic comparisons reported.	- No differences between groups in admission under the MHA or Criminal justice agency involvement.
13	(Goater et al., 1999)	93	London	White = 39 Black = 38 Other = 16	- Only ethnic comparisons reported.	- No differences in compulsory hospital admission.
14	(Williams et al., 2000)	108	Nottingham	Black = 20 White = 88	- Only ethnic comparisons reported.	- The majority of both groups were registered with their GP. Although not being registered was sig. more common in the Black group. - Black patients were 1.9 times more likely to be subject to MHA detention.
16	(Tanskanen et al., 2011)	30	London	Patient sample (21): White British = 3 White other = 4 Black African = 3 Black Caribbean = 5 Asian Bangladeshi = 4	- **Qualitative Methodology** -------------------- - *Patients reported:* - The majority of patients did not think their psychological distress was a mental health issue. - Unawareness of symptoms lead to prolonged and complicated help seeking,	- ----------------------------------- - No ethnic comparison reported.

					Mixed Raced = 2	through various sources.	
						- Many had alternative explanation for symptoms.	
					Carers sample (9)	- Patients thought symptoms were transient and would pass overtime. Such beliefs were linked to longer DUP and alternative explanations for illness.	
					White British = 5		
					White Other = 2		
					Black Caribbean = 1		
					Mixed Race = 1	- Some patients described concealing their symptoms from others.	
						- Attributing the problem to mental illness facilitated medical help seeking in times of crisis.	
						- Alternative beliefs promoted help seeking from alternative sources (religious, vocational institutions and youth groups).	
						- Stigma, fear and a lack of knowledge about the availability of mental health services, all prevented help seeking.	
						- Social network were reported to both impede and facilitate help seeking.	
						- Alternative help seeking agencies facilitated medical help seeking in some cases.	
						- *Carers reported:*	
						- The difficulty in the recognition of symptoms, which delayed help seeking.	
						- Alternative attributions of symptoms were sometimes given, relating 'psychological distress' to typical teenage behaviors.	
						- Such attributions and unawareness of	

					mental health problems prevented help seeking. - Bizarre uncharacteristic behaviors often promoted medical help seeking. - While trying to seek help, family members were often faced with denial, anger and stigma related worries from the ill patients, which delayed help seeking. - Carers also had stigmatic beliefs about treatment and health services. - Reported on the usefulness of alternative help seeking agencies. - Felt the responses from professionals were sometimes insensitive. - Non-disclosure of symptoms by patients also inhibited the pathways to care process.	
17	(Chaudhry et al., 2008a)	48	Lancashire	South Asian = 24 White British = 24	- Only ethnic comparisons reported.	- South Asian patients were sig. more likely to come to service via community mental health teams. - More White British patients required hospital admission. - However, compulsory hospital admission was similar between the two groups.
18	(Johnson and Weich, 2010)	7	Birmingham	African Caribbean = 4 White European = 3	**Qualitative Methodology** ------------------------ - The majority of patients sought help from their GP early on in their illness. - Two participants felt they were not listened	- -- - African Caribbean patients described dissatisfaction with GP consultations, which prevented further help seeking.

					- to by their GP. - Lack of communication between GP and patient was felt to be a barrier to further treatment. - 6 participants who sought GP help reported that they were sent home without medication.	- All 3 White British patients were referred to mental health services from their GP, in comparison to only 1 African Caribbean patient. - 3 African Caribbean patients received in-patient treatment in comparison to no White European patients.
19	(Brunet et al., 2007)	80	Birmingham	South Asian =38 White =30 Black =5 Dual ethnicity =6	- Mean DUP length 53.1 weeks, with a median 11.1 weeks. - Help seeking delays 29.8, median 2.6. - Referral delays 4.7 weeks, median 0.3. - Delays in mental health services 18.8, median 2.1. - 24% of patients sought help in the pre-psychotic period of illness.	- No ethnic comparison reported.
20	(Drake et al., 2000)	248	Manchester, Liverpool, and North Nottingham-shire	White =215 African-Caribbean =19 South Asian =4 Other =10	- Median DUP of 12 weeks and mean 38 weeks. - 16 patients had a DUP between 2-12 years. - Longer DUP was associated with more severe symptoms at presentation, worse social integration and better coping daily activities.	- No ethnic comparison reported.
21	(Etheridge et al., 2004)	30	Rotherham	All White British (Carers = 12 and patients = 18)	- **Qualitative and Quantitative Methodology** - *Patients reported:* - The change was often first noticed by family members, followed by themselves, friends, teacher and the GP. - 10 patients initially went to their family members of help, 4 to GP, and the remainder to other avenues.	- -- - No ethnic comparison made

| | | | | | - Reasons for not seeking help were, lack of information (8 participants), embarrassment (6), too ill to seek help (6), fear (5), stigma (4) uncertainty who to approach (4), belief that the problem would go away by itself (2), feeling overpowered (1), and not realizing that there was an illness (1).
- *Carers reported:*
- On average 3 professionals were contacted before they received assessment.
- GP contact was the most common first port of call, followed by school staff, and police/A&E services.
- Those gaining early treatment did so through acute admission (including referrals from CAMHS services, private psychiatrists and police).
- Delays occurred when inappropriate treatment was given by GP, referral through prison and forensic services, and repeat involuntary admission.
- Lack of knowledge of where to go for help and not being listened to by professionals all delayed help seeking.
- 5 carers reported help seeking in the prodromal phase of illness, however they felt this was often futile, as they were told that the patients symptom behaviors was likely due to teenage antics. | |

| 22 | (Fisher et al., 2008) | 533 | London | Black Caribbean (27%), White British (22%), Asian (13%), White Other (10%), Mixed (9%) and Black-African (4%). | - Patients tended to see their GP first for their psychosis (44%). However, a significant minority of patients had initial contact with emergency services (26%) or the police (16%).
- Similarly, the main eventual referral route into mental health services was through primary care (39%), followed by A&E departments (24%), and the police (16%).
- Most referrals to care came from community mental health teams (34%) or psychiatric wards (32%).
- The median length of time between 'first contact' with any service to the referral with Early Intervention Service (EIS, a specialized service for FEP treatment) was 1 month (range 0–80 months).
- Across the sample there was a median DUP of 2 months.
- The median length of patients' pathways from first contact with any service to referral to EIS was 1 month (range 0–80 months).
- Whilst referral to EIS following the appearance of psychosis, took a median of 4 months (range 0–195 months).
- The median length of DUI was one year (range 0–158 months) with a range of 13 years. | - No ethnic comparison reported. |

| 23 | (Ghali et al., 2012) | 775 | London | White British = 215
White Other = 123
South Asian = 90
Black British = 169
Black Caribbean = 28
Black African = 150 | - 46% of the sample made contact with a GP on the pathway to care.
- Emergency medical services were used by 45% & criminal justice agencies 24% of the sample during the pathway to care. | - Compared to the White-British group, South Asian, Black-British and Black-African patients experience shorter treatment DUP.
- All but the Black-Caribbean group experienced significantly briefer service DUP than White-British patients.
- All but the South-Asian and Black-African groups were less likely than White British patients to make contact with a GP during their pathway to care.
- All except the Black-African group were more likely to come into contact with emergency medical services. This was especially true for Black-Caribbean patients.
- All three Black groups underwent higher rates of criminal justice agency involvement in their pathway. This was especially true of Black African patients. |

* Ethnic categorisation as described in the original article

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Narrative Review of the Pathway to Care and its Variation between Different Ethnic Groups

Across the studies, there was variation in the type of data captured, however, the literature could be categorised into eight categorical themes: 1) The chronology of illness development 2) General Practitioner involvement, 3) Criminal Justice Agency Involvement 4) Informal and Compulsory Hospital admission 5) Emergency medical contact, 6) Other pathway encounters 7) Help seeking behaviours and 8) Clinical presentation. Meta-analyses were used to compare ethnic variation in specific pathway to care outcomes. Meta-analyses and forest plots were created using a similar method to the one detailed in objective one of this chapter. Analysis was conducted using Review Manager 5 for Mac. Other data are presented in a narrative format, via theme.

1) *The Chronology Of illness Development (DUP and DUI)*

The Duration of Untreated Psychosis (DUP) is the length of time between the onset of frank psychotic symptoms to the start of psychiatric treatment. From the articles retrieved 5 out of the 21 studies capture this variable, showing a range in reported outcomes. In Birmingham Skeate et al. (2002) reported a median DUP of 15.4 weeks, while Brunet et al. (2007) reported a median DUP 11.1 weeks. In London, Morgan et al. (2006a) found a median DUP of 9 weeks and Fisher et al. (2008) a median DUP of 4 weeks. One multisite study (Manchester, Nottinghamshire and Liverpool) reported a DUP of 12 weeks (Drake et al., 2000). Two studies explored ethnic variation in DUP length, however both found no evidence of ethnic difference (Morgan et al., 2005a, Ghali et al., 2012).

Four studies attempted to understand the factors that predicted DUP length. Skeate et al. (2002) found that patients who consulted their General Practitioner (GP) more frequently before the onset of psychosis had significantly shorter DUPs. Morgan et al. (2006a) found that those patients who, had an insidious mode of illness onset, were unemployed and did not have family involvement in their pathways to care, had longer DUPs in comparison to those who did not. In a qualitative study, Tanskanen et al. (2011) reported that patients felt their DUP was longer when they believed their symptoms to be 'transient' or gave alternative explanations for the cause of illness. Drake et al. (2000) reported that long DUPs were associated with greater severity in symptom presentation, worse social integration and better coping in daily activities.

Only one study attempted to measure the Duration of Untreated illness (DUI). The DUI is the length of time between the onset of non-specific disturbances in mood thinking and behaviour to the start of psychiatric treatment. This variable includes the DUP and its preceding (prodromal) phase. Fisher et al. (2008) reported a medium DUI of roughly 1 year in their sample of FEP patients.

Although the DUP is a unitary variable, it consists of various sub-components (Brunet et al., 2007, Bechard-Evans et al., 2007, O'Callaghan et al., 2010), including; 1) a *Help Seeking Delay;* referring to the length of time between the onset of psychosis to the first contact with services, 2) a *Referral Delay:* the length of time between the 'first contact' and first referral to mental health service and 3) a *Delay within mental health services;* the length between the first referral received by mental health services to the start of anti-psychotic medication.

Brunet et al. (2007) found that 'help seeking delays' and 'mental health service delays' were approximately equal to each other. Ethnic variation in help seeking delays has also been explored. In the work of Harrison et al. (1989). Their study reported that 40% of African-Caribbean patients had a delay in help seeking; contacting services less than 1 week before entry into psychiatric services, as compared to 1% of the non-Black-Caribbean sample. There was no difference in symptom duration between the two groups, but once African-Caribbean patients had made contact with services, psychiatric intervention occurred much sooner in comparison to the non-African Caribbean sample, suggestive of firstly a delay in help seeking, and secondly a crisis referral. Ghali et al. (2012) found that compared to the White-British group, South-Asian, Black-British and Black-African patients experience shorter delay within mental health services. Likewise, all but the Black-Caribbean group experienced significantly briefer service DUP than White-British patients.

Data from three qualitative studies attempted to explain the delay within services. Patients reported that delays occurred when they were given wrong medication by their GP (anti-depressants), came through forensic or prison services, and had repeat assessments through involuntary admission (Etheridge et al., 2004). In another study, patients reported that a lack of communication with their GP was a barrier to further treatment. Other problems with the GP were also reported to caused difficultly in help seeking, such as not being listened to and being sent away without medication (Johnson and Weich, 2010). Similarly carers thought that patients' non-disclosure of symptoms in clinical consultation also hindered further treatment. Few ethnic differences in this were found, however, Johnson and Weich (2010) reported that African Caribbean patients described being dissatisfied with their GP consultation.

2) General Practitioner Involvement (GPI)

The significance of the General Practitioner (GP) in the pathways to care was quite evident in the literature. Of the 21 articles, 12 explored some aspect of GP involvement. Two studies reported that GPs were the most common contact during the pathway to care (Johnstone et al., 1986, Fisher et al., 2008), and two studies showed that GPs were where first contact most likely to be made (Johnstone et al., 1986, Etheridge et al., 2004, Bhugra et al., 2000). This was also true for FEP patients in Children and Adolescent Mental Health services (CAMHS) (Cratsley et al., 2008). Conversely, one study found that no patients in their study were referred directly into adult psychiatric services by their GP (Cratsley et al., 2008). Cole et al. (1995) further explored that factors which predicted GP involvement. Lack of family or friends in help seeking, living alone and living in public housing all predicted non-GP involvement. However, no association was found with alternative help seeking attempts (e.g. faith organisations).

2.1) Ethnic Variation in GP Involvement (GPI)

Five studies compared rates of GP usage between the ethnic groups. Data from these studies were pooled and a meta-analysis compared rates of GPI between Black (broadly defined) and non-Black patient groups. The study by Burnett et al. (1999) used two measurements of GP referral, one by family members and the other by the patient themselves. It was therefore excluded from the analyses, as there was a lack of clarity surrounding how GP referral was measured in this study. The results of the meta-analysis demonstrated that Black and Black-Caribbean Patients were significantly less likely to have GP involvement in their pathways to care than non-Black and non-Black-Caribbean patients (Figures 9 and 10).

Figure 9: Forest Plot Demonstrating Ethnic Variation In General Practitioner Involvement (GPI) Between Black vs. Non Black patients.

Study or Subgroup	Black-Caribbean Events	Total	Non Black-Caribbean Events	Total	Weight	Odds Ratio M-H, Fixed, 95% CI
Ghali et al (2012)	7	28	99	215	12.2%	0.39 [0.16, 0.96]
Ghali et al (2012b)	7	28	40	215	4.9%	1.46 [0.58, 3.67]
Ghali et al (2012c)	7	28	60	150	10.1%	0.50 [0.20, 1.25]
Harisson et al (1989)	25	42	67	89	12.4%	0.48 [0.22, 1.06]
Morgan et al (2005)	32	128	99	237	37.3%	0.46 [0.29, 0.75]
Morgan et al (2005b)	32	128	14	62	10.1%	1.14 [0.56, 2.34]
Morgan et al (2005d)	32	128	15	33	12.8%	0.40 [0.18, 0.88]
Total (95% CI)		510		1001	100.0%	0.57 [0.43, 0.75]
Total events	142		394			

Heterogeneity: Chi^2 = 10.01, df = 6 (P = 0.12); I^2 = 40%
Test for overall effect: Z = 4.03 (P < 0.0001)

Odds Ratio M-H, Fixed, 95% CI
0.01 0.1 1 10 100

Figure 10 Comparison In Rates Of GP Involvement Between Broad-Black And Non Broad-Black Patients.

Study or Subgroup	Broad Black Events	Total	Non Broad-Black Events	Total	Weight	Odds Ratio M-H, Fixed, 95% CI
Cole et al (1995)	26	38	27	39	2.6%	0.96 [0.37, 2.53]
Cole et al (1995b)	26	38	13	16	1.8%	0.50 [0.12, 2.09]
Ghali et al (2012)	7	28	99	215	5.3%	0.39 [0.16, 0.96]
Ghali et al (2012b)	60	150	99	215	15.2%	0.78 [0.51, 1.19]
Ghali et al (2012c)	63	169	99	215	17.1%	0.70 [0.46, 1.05]
Ghali et al (2012d)	7	28	40	215	2.2%	1.46 [0.58, 3.67]
Ghali et al (2012e)	60	150	40	215	6.2%	2.92 [1.82, 4.69]
Ghali et al (2012f)	63	169	40	215	6.9%	2.60 [1.64, 4.14]
Harisson et al (1989)	25	42	67	89	5.4%	0.48 [0.22, 1.06]
Morgan et al (2005)	32	128	99	237	16.3%	0.46 [0.29, 0.75]
Morgan et al (2005b)	13	64	99	237	10.5%	0.36 [0.18, 0.69]
Morgan et al (2005c)	32	128	15	33	5.6%	0.40 [0.18, 0.88]
Morgan et al (2005d)	13	64	15	33	4.9%	0.31 [0.12, 0.77]
Total (95% CI)		1196		1974	100.0%	0.86 [0.73, 1.01]
Total events	427		752			

Heterogeneity: Chi^2 = 77.24, df = 12 (P < 0.00001); I^2 = 84%
Test for overall effect: Z = 1.83 (P = 0.07)

Odds Ratio M-H, Fixed, 95% CI
0.01 0.1 1 10 100
Favours experimental Favours control

Anderson and Parrot (1995) found that living circumstances, gender, self-initiated help seeking and family involvement were all associated to GP under-involvement. Williams et al. (2000) reported that Black patients were significantly less likely to be registered with their GP in comparison to White patients, which may again further explain this finding. However, no other explanation from the literature was found.

3) Criminal Justice Agency Involvement (CJA)

Eight studies mentioned the involvement of Criminal Justice Agency (CJA) in the pathway to care (Morgan et al., 2005a, Cole et al., 1995, Burnett et al., 1999, Garety and Rigg, 2001, Cratsley et al., 2008, Etheridge et al., 2004, Fisher et al., 2008, Ghali et al., 2012). In these studies CJA was defined as contact with police services under sections 136/135 of the mental health act and referrals from courts. However it is worth noting that some studies failed to give any definition of what CJA was at all. Cole et al. (1995) reported that the absence of a GP, living alone and the absences of family or friends in help seeking, were all predictors of having the police involved in the pathway to care.

3.1) Ethnic variation in Criminal Justice Agency Involvement (CJA)

Five articles explored ethnic differences in relation to criminal justice agency involvement (CJA). A meta-analysis was conducted pooling the data from studies. Two separate sources of data were extracted from both the articles by Cole et al. (1995) and Burnett et al. (1999) as they used two independent measurements of CJA (e.g. Cole et al 1995 explored police section 136 of the MHA and police involvement separately). Two separate meta-analyses were conducted, exploring ethnic variations in CJA between in 1) Black-Caribbean vs. non-Black-Caribbean patients; and 2) Broad Black (i.e. Black-African, Black-Caribbean and Black Other) vs. non-Broad Black patients. In addition, all articles bar Harrison et al. (1989) were included multiple times, as the authors made comparisons between multiple ethnic groups.

The results of the meta-analyses revealed that Black-African patients (2.84, 95% CI 1.90-4.23, p<.001) and Black patients (broadly defined) were approximately twice as likely (2.43, 95% CI 2.02-2.92, p <.001) to experience CJA in their pathways to care during FEP

(Figures 11 and 12) to other and White British patients. Conversely, no difference was found between South-Asian groups and Asian-Pakistani (Figures 13).

Figure 11: Comparison in rates of criminal justice agency involvement between Broad-Black and Non Broad-Black Patients.

Study or Subgroup	Broad Black Events	Total	Non Broad-Black Events	Total	Weight	Odds Ratio M-H, Fixed, 95% CI	Odds Ratio M-H, Fixed, 95% CI
Birchwood et al (1992)	10	50	5	74	2.2%	3.45 [1.10, 10.81]	
Burnett (1999)	10	38	1	24	0.6%	8.21 [0.98, 69.01]	
Burnett (1999b)	10	38	6	38	3.0%	1.90 [0.61, 5.91]	
Cole et al (1995)	17	39	15	38	5.9%	1.18 [0.48, 2.94]	
Cole et al (1995b)	17	39	7	16	3.9%	0.99 [0.31, 3.21]	
Ghali et al (2012)	9	28	31	215	3.3%	2.81 [1.17, 6.78]	
Ghali et al (2012b)	41	169	31	215	14.3%	1.90 [1.13, 3.19]	
Ghali et al (2012c)	48	150	31	215	12.0%	2.79 [1.67, 4.66]	
Ghali et al (2012d)	9	28	23	215	2.5%	3.95 [1.60, 9.76]	
Ghali et al (2012e)	41	169	23	215	10.6%	2.67 [1.53, 4.67]	
Ghali et al (2012f)	48	150	23	215	8.9%	3.93 [2.26, 6.82]	
Harisson et al (1989)	8	42	6	89	2.1%	3.25 [1.05, 10.09]	
Morgan et al (2005)	38	128	34	237	11.6%	2.52 [1.49, 4.26]	
Morgan et al (2005b)	21	64	34	237	6.7%	2.92 [1.54, 5.51]	
Morgan et al (2005c)	38	128	9	33	6.9%	1.13 [0.48, 2.65]	
Morgan et al (2005d)	21	64	9	33	5.5%	1.30 [0.52, 3.29]	
Total (95% CI)		1324		2109	100.0%	2.43 [2.02, 2.92]	
Total events	386		288				

Heterogeneity: Chi² = 17.27, df = 15 (P = 0.30); I² = 13%
Test for overall effect: Z = 9.48 (P < 0.00001)

Figure 12: Comparison in rates of criminal justice agency involvement between Black African and White-British patients.

Study or Subgroup	Black-African Events	Total	White-British Events	Total	Weight	Odds Ratio M-H, Fixed, 95% CI	Odds Ratio M-H, Fixed, 95% CI
Ghali et al (2012)	48	150	31	215	64.1%	2.79 [1.67, 4.66]	
Morgan et al (2005)	21	64	34	237	35.9%	2.92 [1.54, 5.51]	
Total (95% CI)		214		452	100.0%	2.84 [1.90, 4.23]	
Total events	69		65				

Heterogeneity: Chi² = 0.01, df = 1 (P = 0.92); I² = 0%
Test for overall effect: Z = 5.11 (P < 0.00001)

Favours experimental Favours control

Figure 13: Comparison in rates of criminal justice agency involvement between South-Asian and White-British patients.

Study or Subgroup	South-Asian Events	Total	White-British Events	Total	Weight	Odds Ratio M-H, Fixed, 95% CI	Odds Ratio M-H, Fixed, 95% CI
Birchwood et al (1992)	2	30	5	74	11.7%	0.99 [0.18, 5.38]	
Burnett (1999)	1	24	6	38	19.4%	0.23 [0.03, 2.06]	
Ghali et al (2012)	12	90	31	215	68.9%	0.91 [0.45, 1.87]	
Total (95% CI)		144		327	100.0%	0.79 [0.42, 1.48]	
Total events	15		42				

Heterogeneity: Chi² = 1.43, df = 2 (P = 0.49); I² = 0%
Test for overall effect: Z = 0.74 (P = 0.46)
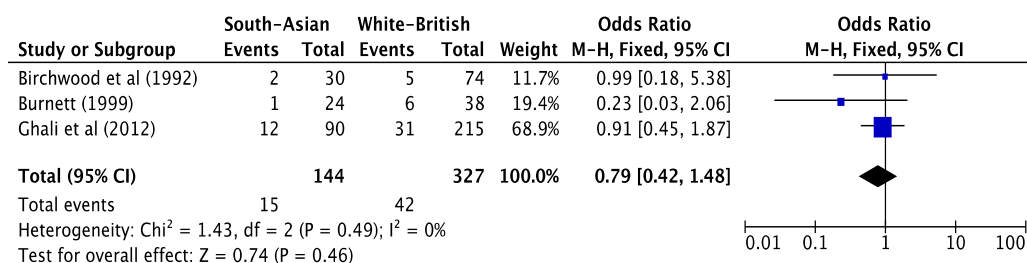
Morgan et al. (2005b) calculated the unadjusted odds ratios for all variables that predicted criminal justice agency involvement. The results showed that unemployment, living status, diagnosis and family involvement were all associated with CJA. In a multiple regression model, Black African ethnicity no longer remained significant, suggesting that these variables accounted for the excess amongst this group. Cole et al. (1995) found that those patients who had no relatives or friends involved in their help seeking attempt or GP involvement, were at significantly greater risk of having police involvement. When a logistic regression model was fitted, the lack of GP contact in their pathway to care was the only independent predictor of police involvement (OR = 4, CI = 1.5-12.6, p =0.004).

4) Informal and Compulsory Hospital Admission

16 of the 21 studies reported the use of either informal or compulsory in-patient hospital admission in the pathway to care. The proportion of such routes did however vary between studies, as one found the rates of compulsory admission to be 28% (Burnett et al., 1999), while another reported 52% (Chen et al., 1991). Cole et al. (1995) reported that those patients living alone, living in public housing, had the absence of GP involvement, lack of family or friends in help seeking, and were living away from their family, were significantly more likely to have compulsory admission in their pathways to care. The review also compared rates of detention between groups, suggesting that minority groups were often overrepresented in this (see previous review for further details).

5) Emergency Medical Contact

From the review, only two studies captured information about the emergency medical service contact during the pathway to care. With regards to ethnic differences two Meta-Analyses were conducted comparing ethnic differences in the rates of emergency services referral (i.e. contact with Accident and emergency department). The results demonstrated (Figure 14) that Black-Caribbean patients were significantly more likely to have emergency medical services involved in their pathway to care during FEP than White-British patients (1.79, 95% CI 1.20-2.625, p < 0.0001). The same was also true for the Broad-Black group (Figure 15) in comparison to Non Black-patients (1.63, 95% CI 1.38-1.92, p < 0.00001). No other comparisons were made.

Figure 14: Comparison in rates of emergency medical services involvement between Black Caribbean and White British patient's patients.

Study or Subgroup	Black-Caribbean Events	Total	White-British Events	Total	Weight	Odds Ratio M-H, Fixed, 95% CI
Ghali et al (2012)	20	28	60	215	11.3%	6.46 [2.70, 15.45]
Morgan et al (2005)	33	128	74	327	88.7%	1.19 [0.74, 1.91]
Total (95% CI)		156		542	100.0%	1.79 [1.20, 2.65]
Total events	53		134			

Heterogeneity: Chi² = 11.19, df = 1 (P = 0.0008); I² = 91%
Test for overall effect: Z = 2.86 (P = 0.004)
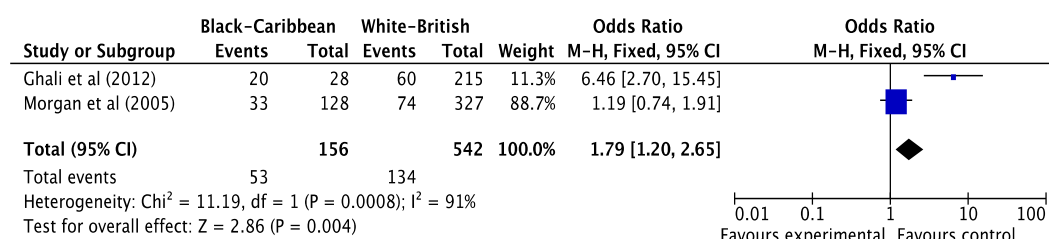
Figure 15: Comparison in rates of emergency medical services involvement between Broad-Black and-non Broad-Black patient's patients.

Study or Subgroup	Broad-Black Events	Total	Non Broad-Black Events	Total	Weight	Odds Ratio M-H, Fixed, 95% CI
Ghali et al (2012)	20	28	60	215	1.8%	6.46 [2.70, 15.45]
Ghali et al (2012b)	74	169	60	215	13.7%	2.01 [1.31, 3.08]
Ghali et al (2012c)	58	150	60	215	14.0%	1.63 [1.05, 2.54]
Ghali et al (2012d)	20	28	55	215	1.7%	7.27 [3.03, 17.45]
Ghali et al (2012e)	74	169	55	215	12.6%	2.27 [1.47, 3.49]
Ghali et al (2012f)	58	150	55	215	12.8%	1.83 [1.17, 2.87]
Morgan et al (2005)	33	128	74	237	17.8%	0.77 [0.47, 1.24]
Morgan et al (2005b)	22	64	10	33	4.0%	1.20 [0.49, 2.98]
Morgan et al (2005c)	33	128	74	237	17.8%	0.77 [0.47, 1.24]
Morgan et al (2005d)	22	64	10	33	4.0%	1.20 [0.49, 2.98]
Total (95% CI)		1078		1830	100.0%	1.63 [1.38, 1.92]
Total events	414		513			

Heterogeneity: Chi² = 44.00, df = 9 (P < 0.00001); I² = 80%
Test for overall effect: Z = 5.77 (P < 0.00001)

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6) Other Pathway Encounters

The review also found the importance of other clinical and non-clinical encounters in the pathways to care. Seven studies reported the involvement of Community Mental Health Teams (CMHT), teachers, private psychiatrists, Home Treatment Teams, Psychologist, marriage counsellors and youth offending teams (Johnstone et al., 1986, Cole et al., 1995, Tanskanen et al., 2011, Etheridge et al., 2004, Morgan et al., 2005a, Garety and Rigg, 2001, Cratsley et al., 2008). In addition, four studies mentioned the involvement of faith-based institutions in the pathway to care, such as the consultation with priests and religious leaders (Johnstone et al., 1986, Cole et al., 1995, Tanskanen et al., 2011, Burnett et al., 1999). Tanskanen et al. (2011), study found that patients' alternative beliefs about the cause of symptoms lead to faith based help seeking. In addition the study demonstrated that alternative help seeking both facilitated and impeded medical help seeking.

6.1) Ethnic Differences in Other Pathway Encounters

Cole et al. (1995) found no difference in faith based or other organisation involvement at first contact, however, White patients were significantly more likely to have first contact with an on-duty psychiatrist. Burnett et al. (1999) reported that Asian patients had a higher number of domiciliary visits in comparison to White and African-Caribbean patients. Conversely, in a study conducted in Lancashire, Chaudhry et al. (2008b) found that South Asian patients were significantly more likely to come to services through community mental health teams, and White patients were significantly more likely to have hospital admission (informal and compulsory).

7) Help Seeking Behaviour

Seven studies explored various aspects in help seeking behaviours and the factors likely to influence it (Morgan et al., 2005a, Birchwood et al., 1992, Garety and Rigg, 2001, Tanskanen et al., 2011, Etheridge et al., 2004, Cole et al., 1995, Johnson and Weich, 2010). Of these, 4 explored some aspect of self (patient) and family initiated help seeking. Morgan et al. (2005b) found that self-initiated help seeking was poor in their sample, as roughly two thirds had help seeking initiated by 'others', however no ethnic differences in this were found. Other studies had mentioned the lack of family and friends in help seeking had led to adverse and coercive routes to care (Cole et al., 1995, Morgan et al., 2005a).

Three qualitative studies comprehensively explored the process of help seeking (Tanskanen et al., 2011, Johnson and Weich, 2010, Etheridge et al., 2004). These studies highlighted how the beliefs about the cause of psychosis influenced the pathway that participants took to care. Several studies reported that patients and carers often misattributed the cause of symptoms or were unaware of their problems as being a 'mental health concern'. Such beliefs were further linked to prolonged and complicated help seeking. These studies also revealed a series of other factors which prevented help seeking, including stigmatising views about services and treatment, the negative perceived social consequences of being involved with mental health care, fear of treatment, dissatisfaction with their GP, embarrassment and a lack of knowledge of how and where to help seek from.

Finally, the review also demonstrated that patients sought help early on in the illness. Roughly a quarter of patients sought help during the prodromal phase of the illness

(Brunet et al., 2007), however, parent-carers thought this was often futile, as they were told that their relatives behaviour was likely due to teenage antics (Etheridge et al., 2004).

7.1) Ethnic Differences in Factors Relating To Help Seeking Behaviour

Harrison et al. (1989) further explored ethnic differences in carers' attribution of symptoms. In their study, carers were asked to explain the cause of their relative's current problems (referring to the patient's mental health). Relatives of Black-Caribbean patients were significantly more likely to attribute the cause to illness to *"Faulty Biology"* or *"Substance Misuse"* in comparison to non African-Caribbean patients. About a third (35%) of African-Caribbean carers viewed the illness as the result of personal character/lifestyle choices, in comparison to 50% of non Black-Caribbean carers. However this difference was not statistically significant. Only one Black-Caribbean carer mentioned a supernatural cause, compared to three non Black Caribbean patients. When carers were asked what they thought the nature of the problem was, both groups frequently cited mental illness.

8) Clinical Presentation

Studies also explored the influence of clinical factors in the pathway to care (i.e. symptoms and symptom related behaviours). Harrison et al. (1989) found that African-Caribbean informants (family, friends and clinicians) were more likely to report that their patient showed signs of neglect in social functioning, personal appearance and hygiene; suggesting greater clinical impairment. The study further demonstrated that African-Caribbean patients were more likely to be perceived as being a danger to themselves and more likely to commit violent attacks, as compared to patients from

other ethnic groups. Chen et al. (1991) reported that Black-Caribbean patients

presented to services with behavioural disturbances (a collective term for violence,

extreme bizarre behaviour, threatening behaviour, absconding and agitation), as

compared to non-African-Caribbean patients. Morgan et al. (2005a) reported that

African-Caribbean patients were significantly more likely than other ethnic groups to be

involved in a violent incident and/or perceived as threatening by others leading to

inpatient admission.

Chapter Discussion

It is well established that Black Minority Ethnic (BME) groups in Britain are overrepresented in their rates of compulsory hospital admission under the Mental Health Act (MHA). Although various reviews have established this (Singh et al., 2007, Morgan et al., 2004, Bhui et al., 2003, Littlewood, 1986), very little is known about the actual causal mechanisms at play (Cantor-Graae, 2008, Singh et al., 2007). First Episode Psychosis (FEP) is one area where this fact is particularly true. FEP patients are unique in that a substantial part of their journey to psychiatric intervention occurs outside of the influence of psychiatric services. The pathway to care for this group is therefore qualitatively different to those patients with chronic psychiatric conditions, who are managed within services. In an attempt to understand this topic further, this chapter aimed to review the literature in two ways; 1) to identify overall ethnic differences in the rates of compulsory hospital admission during FEP and known determinants; 2) to identify key factors and influential processes in the pathway to care during FEP and also highlight ethnic differences.

Review 1: Rates and Determinants of Ethnic Differences in Detention Rates

In relation to the first objective, the review identified several key insights. Firstly, the meta-analysis and systematic review re-established that certain ethnic minority groups were overrepresented in their rates of detention specific to FEP. Black patients, in particular, Black-Caribbean patients, were shown to be approximately 2.5 times more likely to be detained than White-British and other comparative samples. Conversely, this association was not found for the South-Asian population, and limited evidence was found for the Black-African group. In comparison to the findings from the review by Singh et al. (2007), the observed excess for Black-Caribbean patients was lower. It is

likely that this was due to a difference in the clinical group under observation, as the review by Singh et al. (2007) explored ethnic difference in detention rates in both first and multiple episode disorders collectively and did not focus on diagnosis. Nonetheless, the association between ethnicity and detention did remain, which confirmed that excess occurred even during first episode psychosis. The review also identified all the known determinants of excess and the associated explanations found in the empirical research retrieved. However, as these findings could only partially account for ethnic variation in detention rates, it became apparent that more comprehensive explanations must exist.

Despite this, the review has highlighted several important insights that may prove useful for the purposes of this doctoral research. The first was that excess in detention rates appeared to be associated with specific ethnic groups. The review demonstrated that although Black-Caribbean patients were significantly more likely to be detained, the same was not true for South-Asian patients. In addition, only two studies explored this phenomenon in the Black-African community, which limited the conclusions drawn about this particular group. Although the need to further explore these findings is required, this review clearly demonstrated that the disproportionate rates of detention could not solely be explained by ethnic minority status alone, but rather something more unique to particular ethnic minority communities.

From this standpoint, the notion of ethnic grouping should remain a core consideration in future research; however, it is often the case that the distinction between ethnicity, race and culture are methodologically blurred in social science research. Fernando (2001) and Witherspoon et al. (2007) both state that the notion of race is primarily a

biological one; grouping individuals on physical similarity, such as skin pigmentation, facial features, hair consistency and stature. Culture, according to Tylor (1889) and Brody (1964) have been used to describe differences between people on shared psychological traits. Rack (1982) has argued that ethnicity fills in the gap between race and culture, comprising elements of both. Future research may therefore attempt to be sensitive in their selection of an ethnic group and should try to use a measurement that captures all facets of ethnicity, whilst being able to uniquely distinguish between different ethnic communities.

Secondly, the review highlights the importance of symptomatology, in specific how a manic clinical presentation, partially accounts for the association between African-Caribbean patients and their elevated rates of compulsory detention (Morgan et al., 2005b). It is therefore clear that future models of understanding should also attempt to account for the effects of clinical presentation. This may take the form of exploring ethnic variation in symptom related risk (e.g. self-harm, aggression and violence), or by capturing the types of symptoms or sub psychotic diagnoses that are apparent upon service entry (e.g. the types of positive and negative symptoms or affective psychosis vs. Schizophrenia).

Thirdly, the review confirmed the importance of other socio-demographic influences. In particular, age, gender and employment status were all shown to have an association with detention rates. There was a suggestion that social isolation may also play an important role, however, this had yet to be empirically tested. What was evident from these findings was that other social factors also predicted detention in addition to ethnicity. In the multivariate analysis conducted, age and gender both interacted with

ethnicity, by either increasing or decreasing the odds of detention. These proximal social variables were therefore important in understanding the excessive rates of detention demonstrated.

Although ethnicity is used as a primary explanatory variable to understand social inequality in detention rates, it is important to acknowledge other social markers. The historical and political context of this debate has put ethnicity in the foreground, as this has been a relatively easy marker to accurately measure. Over time we have become aware that migrant groups in Britain are often of low social economic status and often experience greater social adversity. It may be important for future research to account for these social variables, to ensure that ethnicity is not a proximal variable of a deeper and more important sociological process. Future research should therefore actively attempt to capture and include a range of descriptive factors, such as personal traits and information about their social positioning.

Finally, the review pointed to the importance of help seeking behaviour and the encounters that individuals made with different services. Of all the variables included in the logistic regression model, criminal Justice agency referral remained the strongest predictor (Morgan et al., 2005a). Patients who had such encounters, were roughly 7 times more likely to be detained, after controlling for other factors, including ethnicity. When ethnic comparisons were made, 33% of the African-Caribbean sample experienced such encounters in their pathways to care, in comparison to only 12% in the White-British group. To a lesser extent, a similar association was also shown between patient-Initiated help seeking. Although it remained clear that these factors *were* important, what remains unclear is *how* they were important. Future research should

therefore attempt to understand ethnic differences in the help seeking process and explore chronological variation in the pathway that different groups take to care.

Review 2: Key Features and Ethnic Variation in the Pathway to Care during FEP

In the second review, it was revealed that there were many important features in the Pathways to care specific to FEP. Although this body of knowledge was mainly dominated by quantitative research, an ever-growing body of qualitative research had also proved insightful. In addition, research had also shown that there were a number of ethnic differences in this process, beyond the variability in rates of detention shown in review 1. From this body of knowledge, the following assumptions about the pathway to care during FEP can now be made.

Firstly, it was clear that self-initiated 'help seeking' for FEP patients was generally quite low (Morgan et al., 2005b). Few patients sought help of their own accord, and relied heavily on family, carers and their social network. The lack of family support in help seeking was also shown to be associated with less desirable pathways to care. It was therefore clear that carers played a significant role in help seeking, with those individuals living in isolation or with weak family ties being at significant disadvantage in their ability to utilise statutory mental health care through optimal means. More generally, help seeking was driven by a series of social processes. Beliefs about the illness (in particular symptom attribution), stigma, shame, dissatisfaction with services and the like, were some of the key elements identified. Such factors have also been shown to mediate and prevent help seeking from statutory services, whilst also promoting help seeking from alternative ones. Morgan et al. (2004) argue that the

severity, nature and frequency of the illness alone does not solely drive help seeking, was therefore supported within this population. It was therefore apparent that the social processes of help seeking, surrounding the patient and carer during FEP, were as important in influencing the route to care, as the clinical illness itself.

Secondly, the literature has highlighted the significance of the General Practitioner (GP). Contact with the GP was the most dominant encounter during the pathway to care, and the encounter most likely to be sought at first contact. In drawing on the Goldberg and Huxley model of service access, Bhui and Bhugra (2002) identified how GP services act as a gateway, as they hold a pivotal role in the care-route of patients from the community to specialised psychiatric treatment. Interestingly, the review demonstrated that Black and Black-Caribbean patients were significantly less likely to have an encounter with a GP in their route to care. The significance of this finding in explaining excessive detention rates amongst Black-Caribbean patients is currently unknown and therefore new research should take into account the role of GP services when attempting to provide new explanatory theories in this area.

Thirdly, the literature has highlighted the role of other clinical and non-clinical encounters. Emergency medical services and criminal Justice agency involvement were both common during FEP, which the literature further suggested was associated with a lack of family involvement and isolated living status. Unwillingness to seek help is likely to increase the necessity of such encounters, especially in instances where patients exhibit self-neglectful and dangerous behaviours. Unlike GP involvement, these pathway encounters involve the 'active' effort of services in their attempt to provide treatment. Resilience, non-compliance and dissatisfaction are therefore understandable responses

in these cases, as the experience of coercive routes to care may feel to some, as a violation of their own liberty.

The review also revealed that Black-Caribbean patients were significantly more likely to have emergency medical contact in their pathways to care. In a systematic review of physical health conditions, Atkinson et al. (2001) also highlighted elevated rates of service use amongst Black-Caribbean patients (e.g. in diabetes and renal care). However, the review did not refer to emergency medical service use for both physical and mental health conditions. It is therefore unclear whether the rates of emergency medical contact are a pattern in help seeking specific to FEP, within the Black-Caribbean community. Nonetheless, it is important that emergency contact be explored in detail when attempting to understanding excessive rates of compulsory admission.

Theorising Ethnic Differences in the Pathway to Care
It is clear that there are ethnic differences in the pathways to care. Ethnic minority patients are significantly more likely to come to psychiatric treatment via emergency medical services and criminal justice agencies, and less likely to access psychiatric services via their General Practitioner (GP). In applying these findings to the adapted Health Care Systems model (Morgan et al., 2004), we are better able to understand how these disparities are likely to occur. As the model suggests, the health care system comprises of three sectors: the popular, folk and professional. Help seeking between these spheres is the product of social processes, such as beliefs about the illness, treatment and choices. From this perspective there appears to be a barrier between the popular and professional sector for Black-Caribbean minority groups in particular. This barrier is likely to be made up of social-cultural processes, which prevent voluntary

medical help seeking, in turn increasing the likelihood of compulsory and adverse routes care. One qualitative study also stated that this barrier may be due to problems in primary care (Johnson and Weich, 2010), which warrants further investigation.

Strengths and Limitations of Literature Reviews

A relative strength of this work was its inclusion of qualitative research. In total, three studies (Johnson and Weich, 2010, Tanskanen et al., 2011, Etheridge et al., 2004) used qualitative methods to explore some aspect of the pathway to care and revealed many important aspects not accounted for by traditional quantitative methodologies. Carers' perspectives were particularly useful here, and highlighted some of the barriers to care and the difficulty in seeking help. It was therefore evident that qualitative work had greatly improved understanding of the pathway to care, through its in depth interrogation of the help seeking process. It would therefore be logical to build upon this idea in the work of this thesis, exploring carers' accounts of the factors leading to detention.

Despite this, this review does have some limitations that should be acknowledged. As argued by Anderson et al. (2010), the existing reviews on the pathway to care during FEP are limited by the lack of standardised assessment tools used within the field. The ability to make like-for-like comparisons between studies is therefore limited, especially in instances where the definition of key variables is not given. Furthermore, the methods used to capture the pathways to care data were not always reported, which also limited the accuracy of the literature review. Studies also failed to describe their method of ethnic categorisation (e.g. self-ascription, research rated, census rated). It is therefore unclear whether the comparisons drawn throughout this work incorporate or conceal

other ethno-cultural variations in help seeking, which may lead to different pathway outcomes. Lastly, the findings of this review may only apply to urban contexts and may not be generalizable to areas where patients live in sparsely populated regions. In particular, the pathway to care may become more complex in places where services are geographically dispersed, less well interconnected and less specialised.

Chapter Conclusion

Black-Caribbean patients are significantly more likely to be detained during their pathway to care in FEP. However, existing research is limited and can only partially explain such disparities. It is therefore likely that other explanation must exist that can better explain ethnic differences in detention rates. The literature on the pathway to care during FEP has revealed many important aspects in the ways services are utilized, and has highlighted where different ethnic groups differ in this process. However, at present, a significant proportion of these insights have yet been applied to understand excessive rates of detention amongst Black-Caribbean patients. Future research should therefore address this issue, and begin to combine key aspects in the pathway to care literature to better understand excessive detention rates during FEP within the Black-Caribbean population.

Potential avenues of interest identified by this chapter are as follows;

1. Illness chronology (i.e. the DUP, DUI and its subcomponents).

2. The type and frequency of encounters made (e.g. GP, A/E, CJ involvement, including those from non-medical sources).

3. The role of ethnic specific social processes which facilitate help seeking, such as beliefs about illness, but also other subjective factors (e.g. help seeking behaviours).

4. The role of cross sectional factors, like clinical, socio and demographic variables.

5. To focus on specific ethnic groups.

Chapter Three:

Methodology; Research Context, Methods and Procedure

Introduction

As revealed in the literature review chapter (Chapter Two), existing research and associated explanations can only partially account for the disproportionate rates of detention amongst Black-Caribbean patients during FEP. Traditional approaches are limited as they fail to account for key social, clinical and help-seeking influences, shown to be of importance from the broader pathways to care literature. It is therefore clear that other factors with additional explanatory power must exist. The present study was designed to overcome these limitations by combining qualitative and quantitative techniques to more comprehensively understand the reasons behind excessive rates of compulsory hospital admission.

Chapter Structure

This chapter outlines the mixed methodology employed in this doctoral work, focusing on the two components employed (qualitative and quantitative). Its structure is split into the following six sections; 1) the thesis objectives; 2) the makeup of the general population and local health care provision; 3) the quantitative methods, including how the core assessment measures were selected, developed and implemented; 4) the

qualitative methodology; 5) how the quantitative and qualitative methodologies were synthesized, which will be followed by a discussion of the overall chapter in part 6.

Thesis Aims

1. To further identify the factors that best explain excessive rates of detention amongst Black-Caribbean patients exclusive to First Episode Psychosis (FEP).

2. To use the findings from aim 1 to develop a theoretical model of the processes which lead to excessive rates of detention amongst Black-Caribbean patients.

Research Objectives

1. To identify ethnic difference in the pathway to care and associated influential factors during First Episode Psychosis (FEP).

2. To identify the determinant of Black-Caribbean excessive rates of detention during FEP using insights derived from objective 1.

3. To understand the process leading to compulsory hospital admission from the subjective viewpoint of carers.

The Research Context

This study was conducted in Birmingham, a city and metropolitan borough in the West Midlands, England (UK). The region has a population of 1,036,878 people (Birmingham City Council, 2011), making it the second largest British city outside of London. The city is extremely diverse, in terms of socioeconomic stratification, ethnic breakup and cultural backgrounds. Since the 1950's the city has seen an influx of various ethnic groups from the islands in the Caribbean and the South Asian subcontinent, and many

other groups since. According to the ethnic breakdown estimate in 2011 (Birmingham City Council, 2011), 53.1% of the city are White-British, 4.8%, White-Other, 6.0% Asian-Indian, 13.5% Asian-Pakistani, 3.0% Asian-Bangladeshi, 4.4% Black-Caribbean, 2.8% Black-African, 2.3% Mixed White/ Black-Caribbean and the remainder of other ethnic categories. With regards to religion, 46.1% of the city defined themselves as Christian, 0.4% Buddhist, 2.1% Hindu, 0.2% Jewish, 21.8% Muslim, 3.0% Sikh, 19.3% no religion and the remainder from other religious categories. Geographically the city is split in to 40 smaller units called wards (see Figure 17), each with its own demographically elected representative of local government.

The Distribution Of Ethnicity And Deprivation In Birmingham – COMPAS report (2008)
Known as an industrial city up until the 1960's Birmingham was considered one of the fastest growing economies in Britain (Cangiano, 2008). With a strong manufacturing community, the city attracted large inflow of settling migrant populations, who were assured jobs in manufacturing. In 1970's and 1980's however, Birmingham suffered a decline due to de-industrialisation, which was not replaced with the creation of new jobs in the service sector. As a result, this economic decline led to increasing levels of deprivation in some wards (Cangiano, 2008). In 2007, a report was commissioned by the Barrow and Cadbury's Trust and specifically aimed at exploring the association between deprivation and ethnicity in Birmingham. The key findings from this report are summarised below; in order to contextualise the analyses conducted in the following chapters.

With regards to the ethnic spread throughout the city, the report revealed a clear trend of ethnic residential concentration. Majority of the White-British population live in the

northern wards of Sutton, Longbridge and the belt of south central and western wards. Ethnic minority groups mainly reside within the inner city areas (middle Ring); in particular, the Asian-Pakistani community is concentrated in the neighbouring wards of Small Heath, Sparkbrook, Sparkhill, and Washwood Heath and to a lesser extent Nechells. Asian-Indians mainly live in the western wards of Sandwell, Handsworth and Soho and the Black-Caribbean population is located mainly in Handsworth and Aston and spread across its neighbouring wards (Figure 16).

Using the index of multiple deprivation (IMD), there was clear pattern of deprivation throughout the city. The areas most affected by deprivation are the south central wards of; Sparkbrook, Sparkhill, Small Heath, Nechells and Washwood Heath; the western wards of Aston, Ladywood, Soho, Handsworth, and other wards such as Kingstanding, Shard End, Kingsbury, Yardley, Stockland Green, Fox Hollies. Conversely, the Sutton wards were least deprived. With relation to ethnicity and deprivation, there is marked polarisation with the least deprived wards having the vast majority of White-British people and more deprived wards containing the most ethnic minority groups (confirmed with a positive correlation coefficient R=0.66). There are some clear exceptions to this, including the wards Sandwell, Shard End and Kingstanding.

Figure 16: Relationship between Index of Multiple Deprivation (IMD) and proportion of ethnic minorities in Birmingham via ward (Map is a replication taken from the COMPAS report (2008))
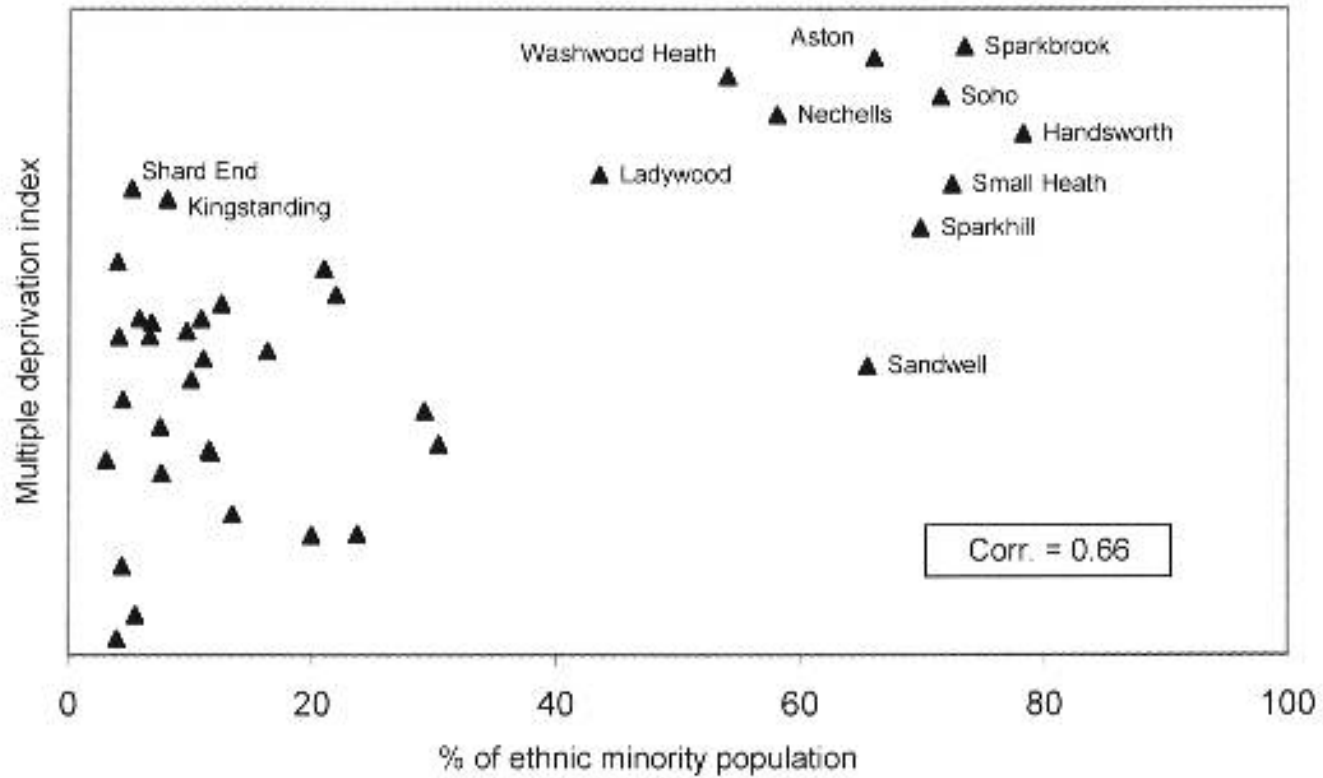
Figure 17: Geographical Representations of Birmingham and Individual Ward Names
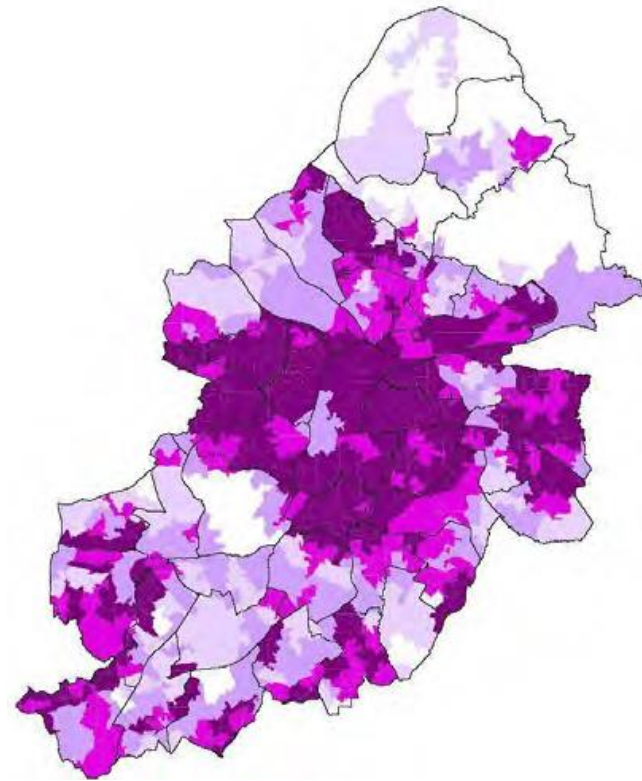
Figure 18: Geographical map of Birmingham and levels deprivation (IMD) - darker colours reflect greater levels of deprivation (Map is a replication taken from the COMPAS report (2008)).

Local Health Service (Professional sector)

The majority of health care provision in Birmingham is part of the National Health Service (NHS). At the point of access, all health care is free with privatised health insurance not necessary to see a medical professional. The region is host to a number of individual NHS organisations, called 'Trusts', that vary in their specific clinical remit and/or geographical catchment provision. These include primary, secondary and tertiary care services, accident and emergency (A&E) treatment facilities, hospitals, rehabilitation facilities and wellness practitioners. Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT) provides all secondary and tertiary mental health care for individuals 16 years old and above. The Trust comprises a variety of services, including psychiatric hospitals, community mental health services, day hospitals and emergency medical facilities.

This study is interested in exploring ethnic variation in the pathway to care during first Episode Psychosis (FEP). In commonality with other cities throughout England and Wales, the region has a dedicated service for this clinical group, called Early Intervention Service (EIS). Birmingham EIS provides comprehensive community-based care for all people experiencing a first episode of psychosis between 16-35 years of age. A specialist Children and Adolescents Mental Health Services (CAMHS) nurse, from Birmingham NHS Children's Hospital, also work within this service, working in collaboration with local CAMHS services for patients under the age of 16. The service also has a specialist Early Detection and Intervention (EDIT) team, who provides assessments, referrals and intervention for those individuals at high risk of developing psychosis.

At the time when the study was conducted, Early Intervention services (EIS) were well established throughout the region, and accepted about 450 new FEP patients annually. The service is based on a recovery model, providing treatment early on in their illness to help patients gain better outcomes in long-term recovery. Referral pathways to early intervention service typically come from other secondary mental health services such as community, crisis and home treatment teams and directly from General Practitioners (GP). At the time of the study, the service consisted of five teams, covering Birmingham East and North (BEN team), South Birmingham (South team), West Central Birmingham, also known as West Heart of Birmingham (west HOB), East Central Birmingham, referred to as East Heart of Birmingham (East HOB) and Solihull. No recruitment took place at the Solihull site, as this region covered a different geographical borough and was only recently established.

A request was made to BSMHFT Information and technology (IT) services for the annual intake of newly accepted patients to Birmingham EIS and their ethnic breakdown over a given year (See table 3). It was clear that different parts of the city served different ethnic populations, however, overall, White-British, Asian-Pakistani and Black Caribbean were the three most dominant ethnic groups found.

Table 3: Ethnic Breakdown of Annual Intake of New Referral into Early Intervention Service (EIS) With Experiencing a First Episode of Psychosis (FEP) - 01/2009-12/2009

Ethnicity	BEN	East HOB	South	West HOB	Total	%
Asian-Bangladeshi	1	3	4	7	15	2.96%
Asian-Indian	5	7	8	15	35	6.90%
Asian- Pakistani	**27**	**29**	**6**	**24**	**86**	**16.96%**
Asian-British Other	2	4	3	3	12	2.37%
Black-African	3	7	3	4	17	3.35%
Black- Caribbean	**20**	**17**	**14**	**39**	**90**	**17.75%**
Black-Other	4	0	1	1	6	1.18%
Mixed White & Black-African	0	0	2	0	2	0.39%
Mixed White & Black-Caribbean	1	5	6	4	16	3.16%
Mixed - Other	3	1	0	0	4	0.79%
Mixed White & Asian	1	1	0	0	2	0.39%
Other Ethnic Group	4	7	4	4	19	3.75%
White - British	**37**	**39**	**44**	**25**	**145**	**28.60%**
White - Irish	0	2	1	7	10	1.97%
White - Other	1	3	3	3	10	1.97%
Not Stated	5	4	7	4	20	3.94%
Not recorded	8	2	6	2	18	3.55%

Rates of Psychosis for Specific Groups

Using the population data obtained from Birmingham City Council data and the yearly intake of EIS patients, a calculation of the annual incidence rates of psychosis was estimated per ethnic group. The results showed that the White-British population in Birmingham were underrepresented in their rates of psychosis in comparison to their population make up, while the Asian-Pakistani patients were slightly over-represented. Black-Caribbean patients had the highest incidence rates of psychosis by just over four times their make up within the general population. It was therefore clear that the ethnic distribution of the incidence of psychosis in the city was not uniform.

Quantitative Methodology

Both the quantitative and qualitative data presented in this chapter were part of a larger research project entitled ENRICH. The ENRICH programme is a National Institute of Health Research (NIHR) funded project aimed to explore various aspects of the interaction between ethnicity, mental health and mental health services. The ENRICH programme consisted of three studies, one of which was similar to the 'pathway to care' stud conducted by Gater et al. (1991).

This thesis aims to answer a unique but associated research question within the 'pathway to care' study from the ENRICH programme. While the overall study aimed to explore the relationship between mental health services and multiple ethnic groups on a number of different domains, this thesis specially focused on three homogenous groups with regards to one outcome (compulsory hospital admission). Black-Caribbean and White-British ethnicities were chosen as the literature review (Chapter Two) revealed that these were the groups frequently used for comparison. In addition, Asian-Pakistani patients were focused upon, as this was the second largest homogenous ethnic minority group within Birmingham EIS services. The methodology presented within this chapter was therefore aimed at complementing the ENRICH study while also remaining unique to its own objectives. Special attention was therefore made to augment the core elements of ENRICH project to better answer the key research questions of the thesis. The author of this thesis was employed as a Research Associate (RA) on the study, and was influential in all stages of the ENRICH design, set-up and data collection procedure. An account of the role played in data collection will also be given in the empirical chapters presented later.

Sampling and Sample Size Calculation

An observational research design was chosen to explore the role of a range of factors in explaining ethnic differences in rates of compulsory hospital admission. The difference in detention rates between Black-Caribbean and White British patients was therefore a primary variable, and thus a sample size calculation was conducted to identify the numbers needed in each groups to detect a significant effect. Estimations were made using the data from AESOP study (Morgan et al., 2005a), which demonstrated a 24% rate of compulsory admission for White-British patients and a 52% rate for Black-Caribbean patients. Using these rates in a sample size calculation set out by Fleiss et al. (2003), it was estimated that 44 patients per group (n= 88) would be needed to detect a 28% difference between the groups, with a significance level of 5% and a 80% power. A prospective cohort of consecutively newly accepted FEP patients within a 2-year time frame (March 2009 - February 2011) was used to obtain this sample size.

As demonstrated in Table 3, the Birmingham cohort of FEP patients has a significant proportion of individuals of Asian-Pakistani origin. In order to determine whether the ethnic variation in detention rates was related specifically to the Black-Caribbean, a sample of Asian-Pakistani participants was also recruited as an additional minority comparative. As no study had explored the rates of detention in the Asian-Pakistani patients in FEP, the convention set out by Bhui et al. (2003) was used as a sample size estimate; which stated that recruiting ethnic groups containing more than 30 participants each is desirable when making comparisons on specific pathway to care outcomes. This sample size estimation is comparable with other peer-reviewed pathway to care research in the area (see Chapter Two).

The clinical lead of Early Intervention Service was then approached about the feasibility of achieving this sample size within the given time frame. Although other doctoral and government funded research projects were being conducted in the service, the number needed for this research was thought achievable, given the yearly intake of newly accepted patients and the successful recruitment rates by previous studies with similar strategies.

Recruitment Strategy

All patients attending Birmingham EIS (within BSMHFT), who were able to give informed consent were invited to participate in the study. Researchers regularly screened all new referral lists for potential participants. Each eligible participant's Community Psychiatric Nurse (CPN) was approached to determine whether the patient was well enough to take part in terms of symptomatology, general wellbeing and individual life circumstances. If the CPN felt that the patient was suitable, information sheet and consent forms were given to the CPN, which in turn was given to the patient – this method follows the procedure for clinical research set out in the Department of Health's research governance framework (Department of Health (DOH), 2005). If the patient indicated to the CPN that they were interested in participation, a researcher contacted the patient to explain the study and answer any questions that they had. The initial contact with the research team took place at a venue suitable for the patient, including patients' homes if requested- where informed consent was taken. Patients were also asked to nominate a carer for a later qualitative study. The definition of a carer for the purpose of this study was someone who had played an important role in the major decisions related to the patient's journey to care and was identified thus by the patient.

Inclusion Criteria

- Experience a First Episode Of Psychosis (FEP), as clinical defined by a diagnosis of F20-29 on the ICD-10 (World Health Organisation WHO, 2007)

- Have never received anti-psychotic medication prior to coming into services.

- To be assessed and accepted into treatment by Early Intervention Service Birmingham by a qualified medical professional.

- *Exclusion Criteria*

- Those patients who have recently returned to service after a period of prolonged disengagement.

Assessments Measures

There are four main components to the quantitative methodology employed in this work; 1) socio-demographic variables, 2) chronological components of FEP, 3) symptom attribution variables and, 3) pathway to care variables. In this next section, each will be detailed including a rationale of how the measures were selected and a description of how they were developed or adapted for this study,

Table 4: All Assessment Measures Used In Quantitative Study with Description

	Assessments	Method	Description
1	Socio-demographics Information sheet	Quantitative, Structured questionnaire	Key patient variables e.g. age, gender, ethnicity, geographical location in the city and Post Code
2	Nottingham Onset Schedule (NOS)	Quantitative, Semi-structured interview schedule & coding framework	Measuring the development and chronological components of a first episode of psychosis: (DUP, Prodrome, DUI)
3	Early Psychosis Attribution Schedule (EPAS)	Quantitative, Semi-structured interview Schedule & coding framework	An approach of recording the attribution of symptoms over the development of psychosis
4	Amended Encounter Form	Quantitative, Semi-structured interview Schedule & coding framework	A systematic method of measuring the pathway to care and help seeking Behaviour during FEP

1. Socio-Demographic Information Sheet

Age, gender, ethnicity, religious affiliation, living and employment status, post-code, occupation, diagnosis and living status were all captured on the socio-demographics information sheet (Appendix 2). Ethnicity was recorded in two ways. Firstly, participants were asked to describe their ethnicity in their own words. This was recorded verbatim. Secondly, a list of census categories was presented to the participant, and they were asked to select the option that best represented their ethnic group. As there was consistency across the sample between these two methods, the standardised census categorisation method was used. Geographical data is also included, such as locality within the city at the time of onset.

Deprivation levels were calculated using post-code data, captured through the socio-demographic information sheet at time of assessment. For each participant, post-code data were converted into Lower Layer Super Output Area (LSOA) boundaries, a system of breaking up England into smaller geographically similar units issued by the Office of National Statistics (ONS). For each LSOA, a numerical score was then obtained, known as Indices of Multiple Deprivation (IMD) - with higher scores reflecting higher levels of deprivation. The English IMD is commonly used within social science's research, and is an aggregate value consisting of the proportionally weighted domains; - Income Deprivation 22.5%, Employment Deprivation 22.5%, Health Deprivation and Disability 13.5%, Education, Skills and Training Deprivation 13.5%, Barriers to Housing and Services 9.3%, Crime 9.3% and living Environment Deprivation 9.3%.

2. Measuring the Development of a First Episode of Psychosis:

The duration of an initial psychotic episode was a key variable in this study. The Duration of Untreated Psychosis (DUP), as this notion is referred to in the literature, was important as it might help explain why detention occurred more frequently in one group in comparison to another. Special attention was therefore made to ensure that it was accurately measured.

Measuring the Duration of Untreated Psychosis (DUP)

The measurement of the Duration of Untreated Psychosis (DUP) is a common practice within the psychiatric literature (Hafner et al., 1992, Perkins et al., 2000, Norman and Malla, 2002), as it has been shown to be important in influencing a patient's recovery trajectory (Marshall et al., 2005). Although there is much consistency about the

significance of DUP on treatment outcomes, less agreement exists on how DUP should be operationalized and measured.

In a recent review, Compton et al. (2007) attempted to highlight the inconsistencies between studies in the definition and operationalization of the DUP construct. While many agreed the DUP should refer to the period between the onset of psychosis and the initiation of adequate treatment; there was less agreement in the ways in which these time points should be measured. It was also clear that many methods failed to take into account the frequency and severity of symptoms when defining the DUP, including the ability to account for periods of brief intermittent psychotic symptoms. Furthermore, there was little agreement as to what should be classified as 'adequate treatment' (e.g. the reduction of psychotic symptoms vs. inclusion of a patient in psychotic care programme vs. the start of anti-psychotic medication). Additionally, the accuracy of the DUP measurement between studies was further questioned, as differences in the information sources used for measurement may lead to varying DUP lengths. Patients may give different accounts of the onset to psychosis to that of family members, colleague and even those of the established health service (Figure 19); giving rise to different approximations of DUP.

The dilemma that arises from the lack of methodological consensus in this area is the inconsistencies that emerge when comparisons are made between studies. Differences in the measurement of the DUP can often lead to variation in the length of the DUP, which can lead to systematic biases between studies and inaccurate clinical inferences to be drawn. In conclusion, Compton et al. (2007) makes a series of recommendations when ensuring the methodological robustness of DUP assessment. These are; 1) the use

of standardised, structured interview assessments, 2) cross validation, using multiple sources and 3) reporting of the inter-rater reliability and test retest measure of the DUP estimate.

Figure 19: A Replication Of A Figure By Compton et al. (2007) Demonstrating How The Duration Of Untreated Psychosis (DUP) May Vary Depending On The Perspectives Of Informants.
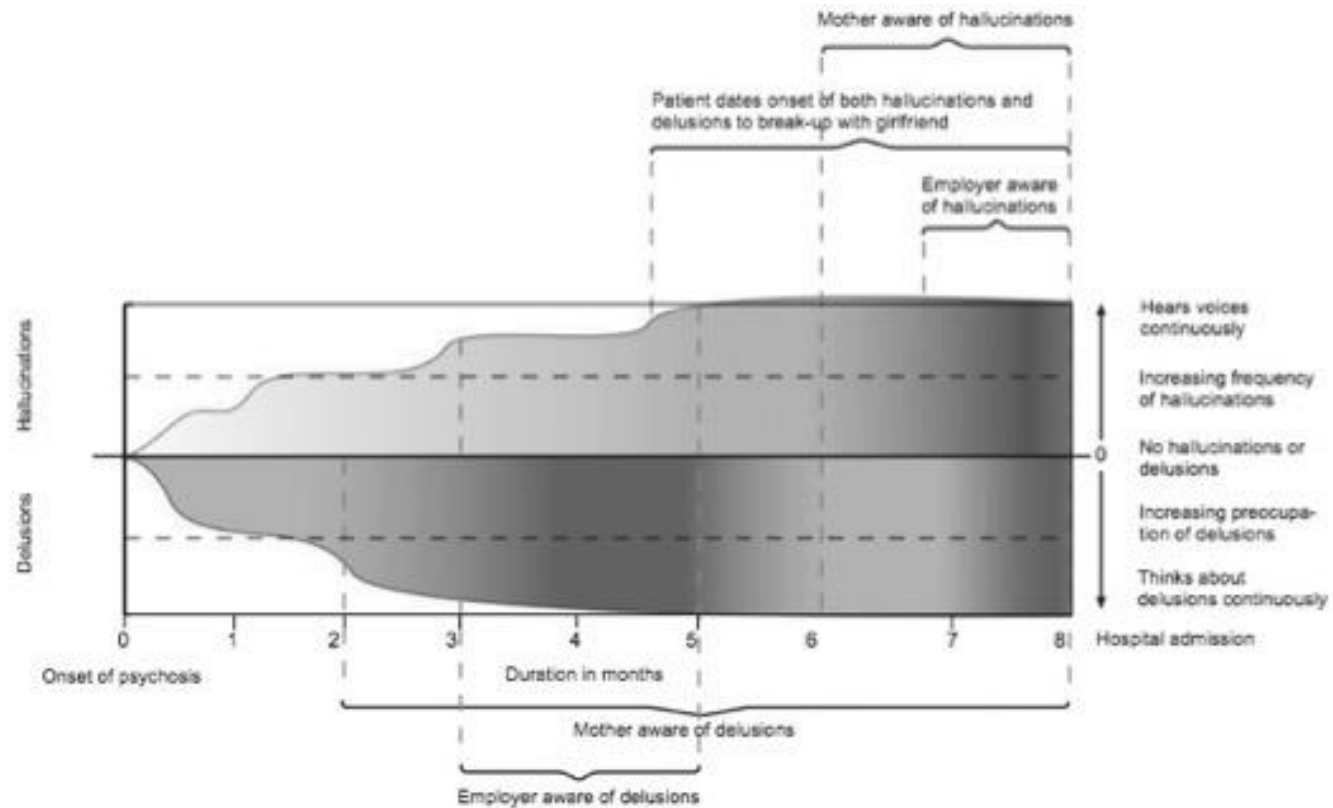
*"Sources of information likely strongly influence the measurement of DUP. In this representation of psychosis, the DUP estimate would range from less than 4–6 months, depending on which informants are interviewed. The actual DUP, using hospital admission as an endpoint, is shown to be 8 months" Compton et al. (2007).

Selecting an Appropriate DUP Measure for This Thesis

There are many different established assessment tools used to measure DUP (Hafner et al., 1992, Perkins et al., 2000, Norman and Malla, 2002, Singh et al., 2005, Andreasen Nc, 1992). After much consideration, *the Nottingham Onset Schedule (NOS)* was finally decided upon for the following reasons: - firstly, the protocol of the NOS followed the recommendations set out by Compton et al. (2007), with a standardised structured interview assessment, cross-validation approach and good inter-rater reliability scores. Secondly, the definitions set out by the NOS matched other studies currently being conducted nationally (Fisher et al., 2008, Ghali et al., 2012). This was felt important, as more accurate comparisons could be made when discussing the results of the work. Finally, as the Ph.D supervisor of this work was an author of the NOS, it made sense for the researcher to draw from this knowledge to maximize the accuracy of the DUP measurement.

Amendments to the NOS

To further improve its methodological rigour of the NOS (Singh et al., 2005), minor amendments were made to its definition criteria. As part of the NOS, investigators are asked to estimate the onset of psychosis from the emergence of 'frank' psychotic symptoms. However, it was felt that this definition was too ambiguous, as a dichotomy between low-level and 'frank' psychotic symptoms could be hard to distinguish in practical terms. To overcome this, the symptom severity criteria from the Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1987) was used to assess the onset of psychosis.

Figure 20: Components in the development of a first episode psychosis, as charted out by the Nottingham onset schedule Onset Schedule (NOS) (Singh et al., 2005).
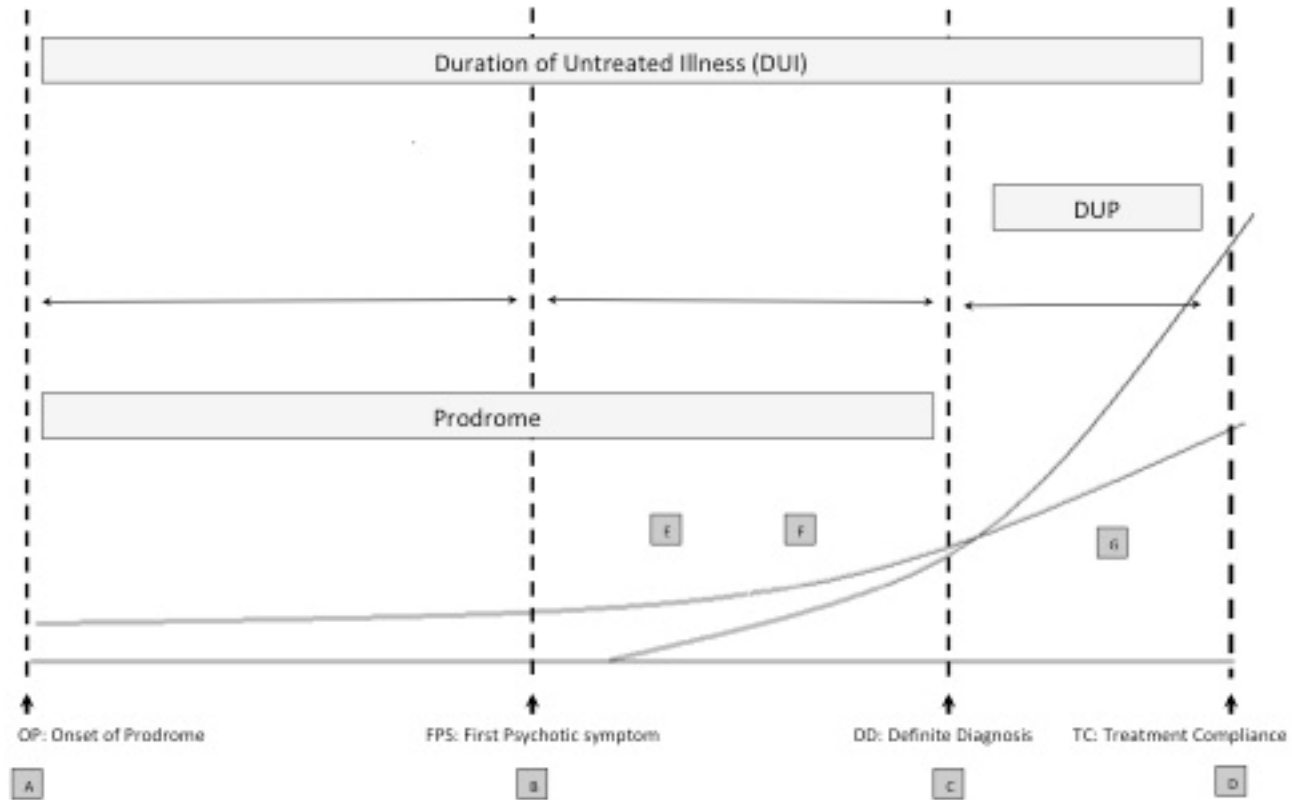
Nottingham Onset Schedule (NOS) (Singh et al., 2005) - Appendix 3

The Nottingham Onset Schedule is a semi-structured interview schedule and rating schedule for establishing the chronology and component of symptom development during a first psychotic episode. Information about the patient's history is collected prior to the interview from medical notes and clinical correspondence to develop a preliminary timeline. This timeline was then used with the patients (and the carer if available) to guide the NOS interview, establishing the dates of when symptoms first emerged and how they developed into the first psychotic episode. Symptom cards and suggested questions are also used to facilitate this. The purpose of these processes is to establish the following four time points in development of psychotic episode;

a) **Onset of Prodrome:** The onset of prodrome is defined as the phase of illness from the emergence of prodromal symptoms to the development of psychotic disorder. Prodromal symptoms usually include non-specific disturbance of mood, thinking, behaviour, perception and functioning. For such symptoms to be considered as part of the psychotic illness there should be no return to premorbid functioning following onset of these symptoms.

b) **First Psychotic Symptom FPS:** Unequivocal presence of one or more positive psychotic symptoms, rating 2 (minimal) or 3 (Mild) on the PANSS, characterised by the definite presence of the symptom which, though is clearly evident occurs only occasionally or intrudes on daily life mildly. In some cases, this phase of illness may not be easily separated from the proceeding phase.

c) **Definite Diagnosis DD:** A rating of 4 or more on any one of the positive symptoms from the PANSS or a group of positive symptoms on the PANSS, with a collective rating of 7 or more, not including those scored as 1 (absent). Symptoms should have occurred for at least one week (transition into psychosis).

d) **Date of start of antipsychotics at adequate dosage**: Adequate dosage is defined as evidence that medication is being taken at 75% or above of the prescribed dosage; and for 75% of the prescribed time, or above. Compliance may be assumed where a patient is on home treatment or is hospitalised, and there is no record of non-compliance. Where a patient has initially been non-compliant, start date of treatment recommencement and is compliant is taken.

Once these time points had been established, three illness-phase variables were created (see figure 20);-

1. **Prodrome** (early phase of illness between points a) and c).

2. **Duration of Untreated Psychosis (DUP)** (period of first episode psychosis, between points c) and d).

3. **Duration of Untreated Illness (DUI)** (between points a) and d)

Secondary Variables Created From the NOS

1. The **mode of onset** referrers to the length of time in which a psychotic episode emerges from the start of first noticeable signs of psychological disturbance. The variable was first operationalized in the Personal and Psychiatric History Schedule (World Health Organization, 1996) and has been used in similar FEP pathway to care

studies (Morgan et al., 2006c, Jablensky et al., 1992). Using this convention, Onset is categorised into three main groups (a) Sudden (psychotic symptoms appeared within days of first noticeable behavioural change); (b) acute (psychotic symptoms appeared within 1 month of first noticeable behavioural change); (c) insidious (psychotic symptoms appeared incrementally over a period of more than 1 month since first noticeable behavioural change). In line with recent research in the area, the three onset categories were amalgamated into two (Morgan et al., 2006c) 'Sudden' and 'Acute' into one category (called acute) and Insidious in the other.

2. **Age at onset** was also calculated by subtracting each patient's data of birth captured through the socio-demographic information sheet, from the date of onset of psychosis from the NOS.

3. During the NOS interview, **reported symptoms** were also captured and categorised **into** 8 symptom clusters; 1) affective and neurotic, 2) hostility and aggression 3) suspiciousness and percussion 4) delusions, 5) social decline 6) hallucinations 7) other 8) none given. These were further grouped into occurring either in the Prodrome or the DUP for each patient.

Reliability: The Nottingham Onset Schedule has high test-retest and inter-rater-reliability (Singh et al., 2005) and is a standard measure of the DUP in several EI services (Fisher, Theodore et al. 2008). All researchers collecting NOS data underwent comprehensive training by the lead developer of the NOS. This involved, shadowing the NOS being conducted by a previously trained researcher (LB), two half days of formal trainings,

listening to two NOS interviews and sending two conducted NOS for inter-rating by the lead research (LB) or principal investigator from the ENRICH programme.

The NOS Procedure

The NOS is conducted with patients and a carer (if possible) as close to the time of illness onset as possible. After a formalised medical assessment has taken place (covering history and mental state,) the NOS is administered through a semi-structured interview, which builds upon a medical assessment to establish the chronology and components of illness before receiving adequate treatment.

There are three main processes in the overall NOS protocol. The first is completing the Preliminary Assessment Sheet (PAS), a document that details any provisional anchor dates and key events around the developing illness. Case notes, and formalised assessment tools are used to develop the PAS, and should be seen as probable timeline of how and when the psychotic illness developed. Key information on this timeline should identify symptoms, life events or significant dates, any diagnoses made, prescriptions given, any mention of compliance or side effects and any signs of recovery. The PAS is then used as an interview schedule during the interview-assessment phase.

The second phase is conducting the semi-structured interview. Participants are firstly informed about the nature of the interview and informed that information about how their psychotic episode started has already be obtained through medical records. They are then told that the purpose of the assessment is to get further details to ensure that the sequence of this accounts is as accurate as possible. An example given in the NOS suggest an introduction like this;

"I am interested in finding out more about how you felt and what happened to you at each stage of your illness. I'm particularly interested in getting a clear idea of how you felt in the early stages, before it became quite obvious to you and your family that there was something definitely wrong with you."

A series of open-ended questions are then used to establish key dates in the unfolding of symptoms, starting with frank psychotic ones. Prompts and symptom flash cards are also used to elicit the presence of symptoms, and once confirmed, are followed up by direct questioning to clarify and established dates. Information elicited is finally repeated back to the participant to ensure accuracy. Finally the date that the patient first started anti-psychotic medication is obtained. Patients are asked what medication they are on, what dosage and when this first commenced. If unclear, participants are presented with information on the PAS as a probe.

All Information is then transferred onto the paper format of the NOS schedule. Hand written notes, taken during the interview is also used during coding the account, and can help where establishing specific dates are ambiguous or unclear.

3. Measuring Symptom Attribution

As established in the literature review (Chapter Two), the ways that patients attribute the cause of symptoms can be important in influencing their route to care. Although many studies have explored this within the wider mental health literature, it has not yet been used to explain ethnic differences in the excessive rates of compulsory detention

during FEP. This thesis hopes to explore this area, and hence special attention was made to ensure the most appropriate methodology was selected.

There are multiple ways to measure a patient's attribution of psychiatric illness, including various vignettes scenarios, questionnaire approaches and semi-structured interview designs. One example of this is the Short Explanatory Model Interview SEMI (Lloyd et al., 1998), which is a semi-structured interview schedule that gets participants to give beliefs about their own illness, including perceived cause, cure and treatment. The Explanatory Model Interview Catalogue (EMIC), (Weiss, 1997) is also another attribution measures, and in commonality with SEMI is loosely based on the explanatory model frame work by Kleinman (1980), which has been shown to be culturally valid. After reviewing and piloting multiple measures, it became apparent that none were specific enough in answering the research objectives set due to the following three reasons;

Firstly, it was clear that many of the existing attribution measures were limited in their cultural sensitivity. Typically, the attribution questionnaires and semi-structured interviews attempt to elicit participant's causal understanding of either their own or a defined psychiatric illness. In doing so, the language used to elicit such a response was often medicalized; using words like 'illness', 'diagnosis' and 'sickness'. Psychosis for many is often a bewildering experience and medical explanations are not always the first ways that symptoms are understood. Cultural understandings, especially for ethnic minority groups, can often be used to make sense of an illness. Typically this falls outside of the medical spectrum of sense-making. To accurately assess the role of symptom attribution in leading to Black-Caribbean excess, cultural sensitivity was

therefore important. Although there are no scales directly designed for the task, in this particular context, it was clear that a relatively flexible tool should be developed; enabling malleability in the recording of patients' responses.

Secondly, it was clear that existing attribution methods were not designed to capture the fluid, malleable and context-dependent nature of attributions. Whittle (1996) found that previously hospitalised patients were significantly more likely to give 'biological' explanations about the nature of their illness than those who were not hospitalised. In addition, carers' attributions changed over time, as carers replaced 'psychosocial' attributions with 'structural' ones (attributions in the social domain) over the course of the study. Williams and Healy (2001) conducted a series of interviews with patients recently referred to psychiatric services. Participants were asked to give unstructured qualitative accounts of factors that they believed brought them into psychiatric care. Very few people reported a single belief about the cause of their illness, and many gave a range of possible and probable causes. The authors argued that the notion of 'explanatory models' of illness (Kleinman, 1980) should be abandoned in favour of 'explanatory maps', as this better conveys the multidimensional and changing nature of attributions. From this body of knowledge, it is clear that the attribution process is complex and multi-faceted, however, it was felt such complexity was not readily captured within existing attribution methodologies.

The final limitation of existing attribution measures is their inability to account for the change over the development of the illness. From the review of measures, it was clear that there are two main approaches to understand the interaction between symptom attribution and the pathways to care during a psychotic episode. The prospective

approach asks participants from the general population to identify the cause of a particular illness/symptom and their probable help seeking behaviour (Zafar et al., 2008). Typically participants are asked to respond to a standardised vignette or illness scenario through either a semi-structured interview or a multiple-response questionnaire. Inferences are then drawn, in which symptom attribution of the general population is applied to a specific clinical population. The retrospective method (Burns et al., 2011, Harrison et al., 1989, Bhugra et al., 2000) is based on clinical samples where patients are asked how they attribute their current symptoms. In both these methods, the reported attributions are taken as approximating attributions involved during the initial help seeking. However, as both these approaches are cross-sectional and do not explore the changes in attributions as symptoms unfold over time; they cannot reliably determine how patients actually behaved when they first became ill.

Collectively, through all three points it became clear that existing attribution measures had limitations for exploring the association between ethnicity and detention. For this reason a new scale was developed, entitled the Emerging Psychosis Attribution Schedule (EPAS) which was developed by the author of this thesis, to answer the research objective sets.

Development and piloting of the Emerging Psychosis Attribution Schedule (EPAS) – (Appendix 4)

The Emerging Psychosis Attribution Schedule (EPAS) is a semi-structured interview, protocol and coding framework used to record how a patient has attributed the presence of symptoms during a first psychotic episode and the emerging phase of psychological dysfunction. The schedule is loosely based on the validated social-

anthropological work of Helman (2007) on lay illness beliefs, whose work has been shown to be cross culturally valid in accounting for the differing ways a patient may understand their illness. This method was taken from the Short Explanatory Model Interview developed by Lloyd et al. (1998) which draws on the previous work of Eisenbruch (1990).

A pilot study was firstly conducted in abridging this approach, which involved conducting the proposed model with six patients and coding them using the framework set out by (Helman, 2007). It was clear that the approach was able to easily capture the majority of the ways patients understood their symptoms, however a new category emerged, where patients reported being aware of their symptoms, but did not hold any causal explanation or give an attribution. A new category was therefore added, '*not attributed*', in addition 'other/no response' was also created.

The EPAS interview was built around an existing clinical assessment, The Nottingham Onset Schedule, NOS (Singh et al., 2005), so that changes in illness development (prodrome and DUP) could be related to changes in attributions recalled. Medical records and the patients' accounts are used to identify symptoms, components (prodrome and definite psychosis) and chronology (duration of untreated psychosis-DUP; and untreated illness-DUI) of a first psychotic episode.

The EPAS semi-structured interview was conducted directly after the administration of the NOS. The EPAS procedure asks participants to recall their attribution of symptoms from phases established during the NOS interview. Special effort is made to ensure that attributions given are the ones occurring at the time when symptoms first appear,

rather than current understandings (e.g. Researcher: "During the NOS interview you reported experiencing auditory hallucinations roughly four months before coming into care, at that time, what *did* you think was causing this experience?"). The EPAS protocol details various methods and procedures to ensure this (e.g. reconfirming with participants throughout, and asking participant to contrast stated attribution with current ones). All information is digitally recorded with consent of the participants and then used for coding.

Attribution statements derived from the interview are then coded into one of the Five EPAS criteria. These are then further grouped into one of two categories; either occurring in the prodrome or in the psychotic phase of illness (DUP).

EPAS Attribution Categories

1. Within-the-individual: those that locate the cause of symptom within, or stemming from within the patient. Here attributions are likely to refer to beliefs surrounding internal psychological, biological or physiological factors.

2. The Natural-world: Cause of symptoms stemming from natural events such as physical illnesses, infections, environmental irritants, reactions to accidents, injury or medicinal and illicit drug use.

3. The Social-world: related to factors in the individual's social world such as relationship problems or adverse life events

4. The Supernatural-world: those emanating from non-natural domains, such as supernatural forces, spiritual possession, divine retribution or punishment.

5. Not attributed: Despite recalling anomalous psychological experiences or unusual behaviour, participant had no theory of causation.

6. Others/No response: Response not categories by other groups, or instances where participants could not recall (i.e. 'I'd rather not say', 'I don't know' or ' I can't remember')

Attribution Type Scoring System

As patients varied in the number of attributions given, a proportional scoring system was developed. For each illness phase (prodrome and the DUP), the number of attributions given for each attribution domain was divided by the total number of attributions in that phase, and then multiplied by 100. The score was interpreted like a percentage and this was therefore calculated for each of the six attribution domains for each participant. When comparisons were made between phases, the mean score of the overall sample was taken (see box 1 for worked example).

Box 1: Attribution Scoring Matrix

- Participant 089 gave 8 attributions in total during her interview, five for prodromal symptoms and three for psychotic ones.
- During the prodromal phase of the illness, one was 'within the individual', three were in the 'social world' and one was in the 'natural world'.
- During the psychotic phase of the illness she gave one 'social world', one 'natural world' attribution and one in the 'not attributed' category.

Attribution scoring matrix

Attribution category	Prodrome score	Psychosis score
Within-the-individual:	$1 / 5 * 100 = 20$	$0/3* 100 = 0$
Social world	$3/ 5 * 100 = 60$	$1/3*100= 33.3$
Natural world	$1/5 * 100 = 20$	$1/3 * 100 = 33.3$
Supernatural world	$0/5 * 100 = 0$	$0/3*100= 0$
Not attributed	$0/5 * 100 = 0$	$1/3*100= 33.3$

- During the prodromal phase of the illness participant 089 gave predominantly social world attributions (60%), followed by 'within the individual' (20%) and 'natural world' (20%) equally.
- During the psychotic phase of the illness, she gave 'social world', 'natural world' and 'not attributed' attribution equally (33.3% each).

Secondary Variables Created From the EPAS

- The **frequency of overall attributions** given was also calculated for each patient. Mean scores were then calculated for both the prodrome and the DUP.

Reliability of Coding

*A*ll researchers conducting the measures were thoroughly trained in both coding and administration of the EPAS. This involved a formalised training session, coding existing interviews from the pilot study phase and reading interview transcripts. A coding manual was also developed to ensure consistence between researcher, giving a description of the codes and potential examples (Appendix 4). Inter-rater agreement was also sought on a selection of cases in categorisation of elicited attribution statements. Two blinded researchers coded attributions from transcripts of EPAS interview conducted by a third researcher. There were an 82.5% agreement in the categorisation of statements, of these 12 were Individual, 18 Social, 12 Natural, 4 Supernatural and 11 not attributed, 7 Other/non-given. The level of agreement between raters was high and statistically significant (kappa 0.766 p<0.001).

4. Measuring the Pathways to Care During First Episode Psychosis (FEP)

Although there is much discussion about the pathways-to-care in the first episode psychosis literature (Morgan et al., 2005a, Compton et al., 2006), there remains little agreement on how it should be methodologically assessed. In a recent systematic review, Singh and Burns (2006) identified a number of different methodologies used and found that many studies developed their own bespoke approaches utilizing narrative methods or adapting other measures. Furthermore, the review highlighted the poor methodological quality in many of these studies, as; many were unsuitable to measure

the multi-layered and complex help seeking strategies with services over a period of time (Lincoln et al., 1998); were unable to provide any psychometric properties for their scales; and failed to use cross validation techniques.

This proves problematic for two reasons. Firstly, a lack of standardisation leads to ambiguities between studies. Spurious results may in truth be the consequence of inconsistencies between measurements, and not the differences in actual outcomes. The consequence of such error can lead to the clouding of clear research paradigms being formed and thus halt scientific agreement in the area. Secondly, poor methodologies can also lead to the generation of invalid and inaccurate assumptions. Many argue that the pathway to care is complex (Anderson et al., 2010, Singh and Grange, 2006), and assessment measures that only capture part of this complexity can often portray a limited view of the real life processes leading to care. Ecological validity, in terms of item construction, is therefore essential, which further becomes complicated in the context of ethnic diversity; when help seeking is likely to occur from multiple sources outside of traditional channels.

Although there are multiple existing methods that can be applied to exploring pathways to care during FEP (Hafner et al., 1992, Sartorius et al., 1986, Cole et al., 1995), the majority fail to address these two important issues. Existing or new scales need to be developed and improved, increasing their methodological quality, whilst also capturing the true complexity of the phenomena.

Theoretical Consideration

Another criticism of the existing pathway-to-care measures is that many are not built on some theoretical model of how individuals utilize health care services. This proves problematic, especially in exploring differences within and between groups, as the entirety of the pathway to care process is not always accounted for. Patients often utilize a range of sources when seeking help for psychiatric services; however, theory is rarely used to develop principles to account for the maximum variation in help seeking behaviour. If accurate and valid pathways to care assessment tools are to be developed, theory must be taken into account in its design, especially in the context of ethnic comparisons.

There are various theoretical models that address the complex and multifaceted nature of the pathway to psychiatric care. In a review of the processes involved, Morgan et al. (2004) identifies a series of structural features important in help seeking. This work suggests that two key features should be accounted for when accurately recording how services are utilized. The first is the role of the social network, including friends and family, resources within the community, support groups and the criminal justice system. Such non-medical agencies are important, as they can often be the first port of call in times of crisis. Family and friends may be asked to provide advice about psychiatric problems, while community organisations, concerned with the wellbeing of an individual, can holistically provide support for those in psychological distress. The other insight from Morgan et al. (2004) work is the availability of alternatives to medical treatment; such as avenues of help from spiritual and religious institutions, referred to as the 'folk sector'.

In Britain, the psychiatric care system is diverse and complex, involving various agencies all working in collaboration. In drawing on the Goldberg and Huxley (1980) model of health care engagement, Bhui and Bhugra (2002) highlight the importance of primary care services as a gateway to specialized mental health care. It is therefore important that any pathway-to-care assessment tool accurately incorporates the role of primary care; as they appear to be pivotal to psychiatric service utilization within the National Health Service (NHS).

Applying Theory to Develop a Pathway to Care During First Episode Psychosis (FEP) – The Encounter Triangle.

Using these theoretical ideas in addition to work of Kleinman (1980) outlined in Chapter Two, a conceptual framework was specifically designed for this doctoral work, to account for all help seeking possibilities during FEP. The encounter triangle (figure 21) illustrates the range of possible contacts an individual is likely to encounter on their journey to psychiatric care. At the base of the triangle are the less formal contacts that an individual may encounter, such as family, and those within the individual's social network (Popular Sector). Above this, lies the non-statutory organisation level, including religious or cultural institutions, schools, youth groups, police services, vocational support workers, social services and other organisations outside of the health care profession (Folk Sector). On the third run, lies medical but non-specialist mental health professionals; mainly those in primary care services, like the general practitioner, A/E services and out of hours clinics (Professional Sector I). Finally, at the top of the pyramid are mental health services, either within the NHS or privately. These included both psychiatric and psychological forms of intervention (Professional Sector II).

The pyramid is also designed to represent the availability of services, with the specialised and less readily available resources at the top and more general and more common resources at the bottom. The layers of the pyramid also demonstrate the referral pathways with the lower levels being influential in directing patients up the pyramid, acting, in some cases as gatekeepers. It is also worth noting that the lines of demarcation between these stages are not absolute, but conceptually represent the breakages between service types.

Figure 21: The Encounter Triangle

4: Mental Health professionals & Organisations

(Professional Sector II)

3: Non-mental health, medical health care

(Professional Sector I)

2: Community, religious voluntary and non-medical organisations

(Folk Sector)

1: Lay contacts, family and friends

(Popular Sector)
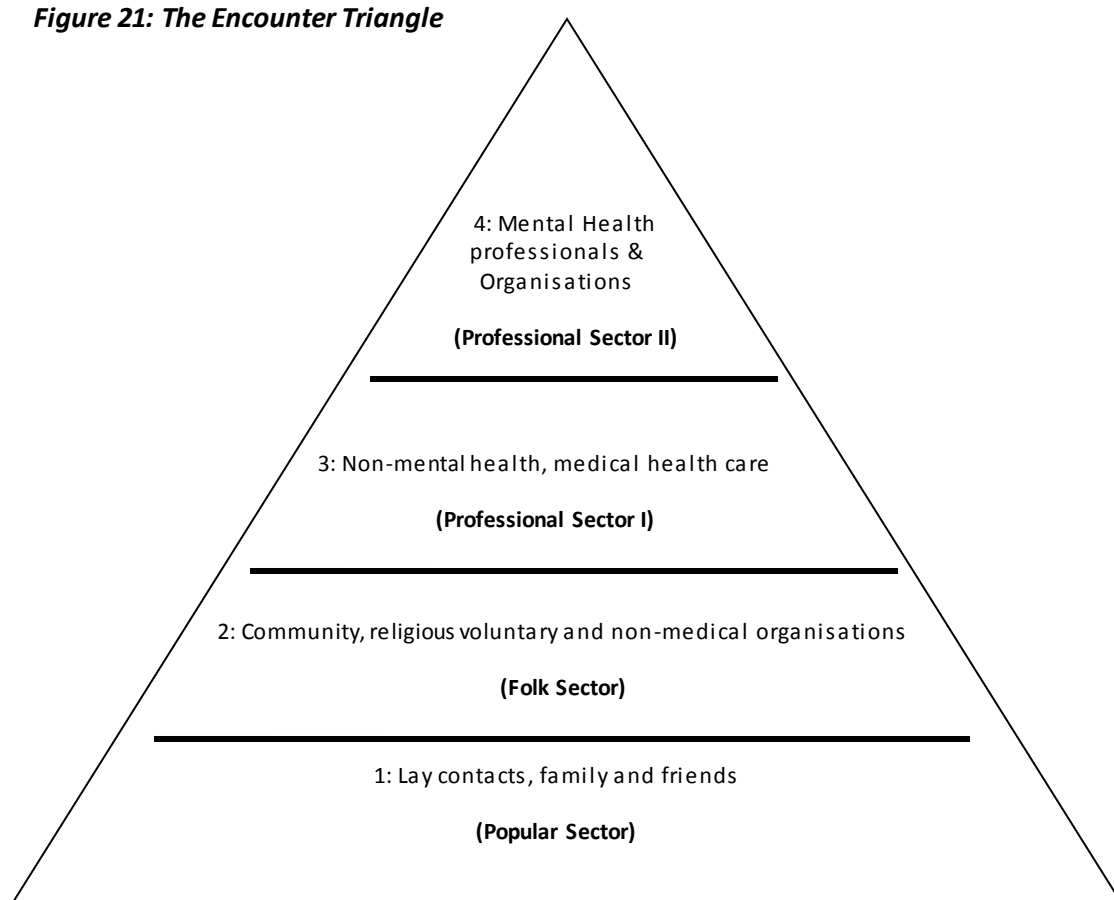
The Significance of Chronology When Measuring the Pathway to Care.
Another conceptual point of importance when developing a pathway to care tool, is its ability to account for the role of *time*. Help seeking and the patient's journey to

psychiatric care is a chronological process, and individuals often seek help at any stage pre, during or after the development of a clinical illness. Existing scales frequently fail to account for this, and do not to clarify/define the start and end points at which the pathway-to-care should be recorded from. In these instances, reliable between-patient comparisons become difficult; as such measures lack of standardisation can frequently lead to systemic biases in measurement, through confounding.

To improve standardisation, capturing the pathway to care alongside the development of a psychotic episode may be of some use. The transition between normal psychopathology and psychosis is an evolving process, where patients often experience low-level psychotic and non-psychotic symptoms well in advance of clear psychosis. Help seeking may commence at any stage in between these points, and is likely to be influenced by the severity of illness and type of clinical presentation within each individual. Problems in the access to services may arise for those patients early on in the illness course, as the seriousness of their condition is underestimated. Likewise, individuals may seek help directly at the level of mental health professionals, where patients' symptoms are severe, unmanageable and persistent. Capturing help seeking attempts that occur alongside a clearly defined chronology of illness development may be important in accounting for such variation in detention rates. Standardising the time window in which the pathway-to-care is measured is therefore important in improving the consistency of recording between patients.

The Selection of A Pathway to Care Tool (Gater et al., 1991)
In their systematic review, Singh and Grange (2006) identify a range of approaches to measure the pathway to care in First Episode Psychosis (FEP). Of these, five studies

developed their own unique approach; five used the pathway-to-care section of the Psychiatric and Personal History Schedule (PPHS) and two used a modified version of this; the 'pathways to care tool' was used in two studies (Perkins et al., 1999, Addington et al., 2002); four approaches developed their own semi-structured interviews (Cole et al., 1995, Cougnard et al., 2004b, Etheridge et al., 2004, Fuchs and Steinert, 2002); one used an amended version of the Interview for the Retrospective Assessment Of Schizophrenia, IRAOS (Hafner et al., 1992, Norman et al., 2004), and three an adapted version of the Encounter form (Gater et al., 1991, Lincoln et al., 1998, Brunet et al., 2007).

The authors also critically appraised the content of each of the scales and demonstrated the many inadequacies within. Only one study made the distinction between prodromal and psychotic help seeking (Addington et al., 2002), three explored the influence of other clinical factors (Larsen et al., 1998, Addington et al., 2002, Cougnard et al., 2004a) nine studies reported the types of contact a patient had in their pathway (Sartorius et al., 1986, Cole et al., 1995, Larsen et al., 1998, Burnett et al., 1999, Chong et al., 2005, Morgan et al., 2005a, Addington et al., 2002, Bhugra et al., 2000); four studies explored some chronological component (e.g. referral delay) (Etheridge et al., 2004, Fuchs and Steinert, 2004, Norman et al., 2004, Lincoln et al., 1998); and two non-statutory help seeking attempts (Sartorius et al., 1986, Chong et al., 2005).

The review demonstrated that although there was much variability between the scales, no single approach was suitable to comprehensively capture all key pathway to care variables during FEP. It was therefore decided that one of the scales should be modified, to incorporate the theoretical consideration previously outlined – In doing so the

Encounter form was selected (Gater et al., 1991). The first recorded use of the Encounter form was published in an international study in 1991 (Gater et al., 1991), looking at the referral pathway taken by 1554 patients newly accepted into mental health services. The article is also regularly cited within the broader psychiatric literature and has been used in other FEP studies (Lincoln et al., 1998). The authors state that the encounter form was used to gather systematic information about the sources of care used by patients before coming into services, chronological components in referral route, source of referral, presenting problems and treatment options. At the start of this project, the Encounter form was currently being used in a national evaluation of early intervention, which also influenced its selection for this work. After piloting the scale and receiving training, the Encounter form was finally selected due to its ease of use, suitability in answering the research objectives (ENRICH project's and Thesis's) and comparability to national research in the area.

Modification of the Encounter Form (Gater et al., 1991) - Appendix 5

In measuring the pathways of how patients came to psychiatric services, and amended version of the Encounter Form (Gater et al., 1991) was used. The Encounter form is a structured assessment tool used to capture all help seeking attempts and contact that a patient made in the journey to psychiatric treatment, referred to as 'Encounters'. The version was amended in its application to the first episode psychosis population, which involved developing a coding manual to ensure consistency between researchers and the development of new categories (e.g. was medication prescribed? what was the nature of the intervention? and who attended the appointment?). In addition the Encounter Form was built around the Nottingham Onset Schedule (NOS) as a guide to

ensure that all encounters were capture during a first psychotic episode and the pre-occurring prodromal phase (Encounters were also coded with this regard).

Adapted Encounter Form Assessment Procedure

The Encounter form assessment consists of two phases. The first involves a medical note screening exercise; in which the researcher meticulously mapped out all the contacts that an individual had with services in their route to care. This normally involves reading medical notes, finding all medical correspondents from referring agencies and talking to the patient's clinical team. This process is a retrospective one, and patients were recruited once they had entered an appropriate psychiatric service (e.g. Early Intervention Service, Psychiatric hospital, Community mental health service – depending on local service provision). Once all information is gathered a provisional pathway to care timeline is created; where key features; such as the date, nature of contact, the referral route to contact, core intervention and attendance are recorded.

In the second phase, the NOS assessment is conducted with the patient in the form of a semi structured interview, assessing all help seeking around; 1) onset of patients' prodromal phase of illness, 2) the onset of psychosis and 3) the start of anti-psychotic medication. The provisional timeline is also validated during this time special emphasis is made on eliciting other help seeking attempts; those unlikely to be captured by medical records, such a community and lay help seeking (popular and folk sectors). Once all information has been collected, both the timeline and patients account are consolidated to form an accurate timeline. Once the final timeline has been created, a completed version is recorded on the amended Encounter Form (Gater et al., 1991) in sequential order.

Reliability of the Encounter Form

Researchers were trained in both measures and were provided with the adapted Encounter Form coding manual and operational procedure. Pilot study interviews were also conducted and each coded individually by the two raters. The kappa coefficient and inter-class correlation was calculated to assess the level of agreement between the two raters on 8 domains commonly used within the pathway to care literature. Categorical data used in the kappa analysis were dichotomised into two categories (yes/no), while continuous data was kept in its original format. The results of the reliability exercise demonstrated that the scale had 'moderate' to 'good' levels of agreement (Table 5), using the benchmarking conventions set out by Altman (1991)

Table 5: Inter-Rater Reliability Scores on the Amended Encounter Form

Domain	Test	Test score
1st encounter in pathway	Kappa	0.489
Number of contacts in prodrome	Intra Class Correlation (ICC)	0.529
Number of contacts in FEP	Intra Class Correlation (ICC)	0.527
Police involvement	Kappa	0.648
GP involvement	Kappa	0.585
Hospitalisation	Kappa	0.659
Home treatment	Kappa	0.598
Religious institutions	Kappa	0.474

The following variables were created using information obtained from the information gathered from the Encounter Form and the NOS: -

Box 2: Definition of key pathway to care variables collected in study

	Variables	Description
1	**Compulsory hospital admission:**	When a patient is sectioned under the mental health act and involuntarily hospitalised at any point during the Duration of untreated illness (DUI)
2	**Emergency medical encounter/ Services involvement**	An encounter with Accident and emergency departments or out of hours and emergency primary care services (e.g. badger clinic) at any point during DUI
3	**General Practitioner encounter:**	An encounter with a General Practitioner during the DUI
4	**Criminal justice agency encounter:**	An encounter with the police services under section 135/136 of mental health act or place of safety referrals during the DUI
5	**Encounter type at first contact:**	The first type of encounter type made during the DUP as defined by the NOS.
6	**Encounter type at second and third contact:**	The second and third type of encounter made during DUP
7	**Frequency of encounters:**	The number of encounters made during prodrome and DUP
8	**Cluster of encounter type made overall:**	The frequency of folk sector, professional sector and popular sector help seeking made
9	**Help seeking initiation:**	The person(s) responsible for the initiation of the encounter (patient own choice, joint decision with family/friends or family choice alone).
10	**Help seeking support:**	People who attended each encounter (patient on their own, with family and friends, or family/ friends on their own).
11	**Health Service Help Seeking Delay:**	Referring to the length of time between the onset of psychosis to the first contact with health services,
12	**Referral Delay to mental health service:**	The length of time between the 'first contact' and first referral to mental health service and
13	**Treatment Delay:**	The length between the first referral received by mental health services to the start of anti-psychotic medication
14	**Unsuccessful help seeking attempts:**	Encounters made that did lead to a referral in the pathway to care
15	**Help seeking direct from criminal justice services**	The person/organization who initiated criminal justice agency involvement.
16	**Pathway to care initiation:**	The person (s) responsible for the first encounter made
17	**Social support:**	The number of encounters made in which a close other was also present
18	**Referral making:**	The persons initiating the encounters made (self, social network members or services).

Overall Quantitative Study Data Collection Procedure

Recruitment: In January 2009, a presentation about this study and the ENRICH project

was made to all four of the EIS teams. Staff members agreed to the study, and suggested

ways to facilitate the successful recruitment of new patients to services. The teams were

then divided amongst the study team, of which two were allocated to the author of this

thesis (LB). Monthly, a list of newly accepted patients were obtained by from the Trust Information and Technology (IT) department, which was cross-referenced with a list of new referrals provided by the clinical team secretary. Key workers were then approached and requested to pass on information about the nature of the research to the patient within the first three months of service acceptance. If the participant agreed to be contacted by a researcher, an agreeable date was made where the information sheet, consent sheet and assessment could be conducted. In some instance the patients' poor engagement with services or clinical recovery was a barrier to being approached. In these cases, care co-ordinators were asked for periodical updates when there were changes with regards to these recruitment barriers. They were subsequently re-approached later.

Assessment: Assessments were conducted at a location suitable to the patient. Normally, these were at the patients' current home address, community mental health centre or the assessment room at the BSMHFT research and development unit. The information sheet and consent form were first presented (Appendix 6), and the patient was given an opportunity to ask as many questions as they felt necessary before agree to participate. Prior to meeting, the note screening exercises needed from the Nottingham Onset Schedule (NOS) (Preliminary assessment sheet - PAS) and Encounter form assessments were conducted. This was brought to the assessment, which detailed a brief description of the history of their first psychotic episode and pathway to the early intervention service.

The socio-demographic sheet was completed, asking key information about age, ethnicity, educational history and diagnosis. This was then followed by conducting the

NOS assessment. If agreeable the whole interview process was then recorded via a digital voice recorder, important for coding at a later stage. Shortly after the NOS, the Early Psychosis Attribution Schedule (EPAS) was conducted, where patients were asked to recall their attribution of symptoms at the time when they first appeared. Key symptoms mentioned during the NOS were written down by the researcher and represented during this phase as a prompt. Attributions were then captured on a sheet for later coding. Finally, the pathways-to-care interview was conducted, based on the Encounter Form. Here all contacts that patients' had with services during the development of their psychosis were established. Again, help seeking was structured around the information derived from the NOS. Key information was reordered and later quantified and coded.

Participants were then debriefed about the purpose of the research and asked to nominate a carer to be interviewed, someone who they thought had a good understanding of how their illness developed and their pathway to care. Contact details were then taken down securely and contact later made via phone or letters for the subsequent qualitative study.

Data handling and coding: Once returning to the office, researchers anonymised all information giving each participant a unique identifying number. A password-protected spread-sheet was created in which the patient's names, age, researcher and unique identifier was given. Audio recordings were uploaded onto a central drive, securely held on the NHS trust server- accessible only to the research team.

For each patient, the appropriate coding of the NOS, EPAS and Encounter form was conducted. Audio files were used as a reliability tool to augment the written notes taken during the interview. The lead researcher (author of this work) frequently checked a random selection of cases for consistency and amended coding accordingly. A coding manual and protocol was also used (see appendix). Where ambiguities or inconsistencies in coding were found, case discussion was brought up at team meetings for finalized coding. Once the coding was complete for each case, all data was entered into a cloud-based database, hosted by the Mental Health Research Network. The database has its advantages over using a single file approach for the following reasons; 1) it allows for simulations entry by multiple researcher 2) it alerts researchers to missing data and errors in imputing increasing the consistency in data entry.

Ethics: Full NHS Research Ethics Committee was sought and for this study and others within the ENRICH programme. The Warwickshire Research Ethics Committee (WREC) gave ethical approval on the 10th of December 2008, subject to minor amendments. Amended documents were submitted and were finally approved in February 2009. The study was approved by the Birmingham and Solihull Mental Health Foundation (BSMHFT) Trust's Research and Development Department on the 11th March 2009.

Qualitative Methodology

Introduction

Qualitative methodologies have been useful in understanding subtle and nuanced processes involved in help seeking and the factors leading patients to care, specifically during to FEP (see Chapter Two). However, such methods are rarely used to explore ethnic disparities in detention rates. Carers' perspectives are particularly excluded from existing literature, which may be of concern, as carers often have an important role in facilitating help seeking and have more objective recollections of how symptoms develop and how services are utilised. In addressing this, a qualitative study was designed to gain a complementary insight into the processes leading to ethnic differences in detention rates. In doing so, this study draws on carers' narrative accounts of the events leading to compulsory hospitalisation and drawing out unique trends in the data as they apply to specific ethnic groups. This section hopes to detail the methodology employed in the designing, recruiting and analysing of the qualitative work later presented (Chapter Six).

Specific Qualitative Research Objectives and Questions

Objective: To understand the process leading to compulsory hospital admission from the subjective account of carers.

Aim 1: To identify the emergent themes around the processes leading to compulsory hospital admission during FEP.

Aim 2: To identify factors ethnic variation in the previous objective.

Study Design

The purpose of this qualitative component to this work is to explore some of the factors leading to compulsory hospitalisation with specific interest in the subjective accounts of Black-Caribbean carers. Rather than attempting to capture carers' opinion, this study focused on obtaining, comparing and contrasting ethnic differences in actual experiences. The approach therefore used attempted to elicit narrative accounts of how the patient's symptoms developed, help seeking behaviour/choices and the pathway to care, and how symptoms were understood. In a similar way to the quantitative methodology, a topic guide schedule was developed which closely followed the line of questioning derived from the NOS, Encounter form and EPAS. This was structured around a narrative guide in which each carer was asked to give a history of how the patient's symptoms developed, recalled early signs of psychological dysfunction, how they attributed the problem and the processes leading to them coming into service through adverse routes. Key socio-demographic information was also captured, such as age gender and ethnicity.

Piloting

As this study was connected to a broader project recruiting from a similar cohort, ample time was given to pilot different qualitative method in attempting to obtain the richest narrative account possible. It was found that using a topic guide was more suitable than a semi-structured interview schedule, as each carers had a different entry point into to their loved ones journey to psychiatric care. Rather than attempting to force a structure upon these accounts, a topic guide was chosen, that allowed important subject matter to be covered whilst also allowing for flexibility in approach used.

Sampling

All patients were recruited into the qualitative arm of the study were asked to nominate a carer, someone who they believed had seen or observed their route into care. Names and contact details were obtain from willing patients at the end of the quantitative interview and later contacted. Although all carers identified from the previous method were approached for the wider study, special attention was made for those who had experienced compulsory hospital admission. Ethnicity was also an important consideration when recruiting, to ensure that sufficient numbers in the ethnic groups could be recruited for meaning comparison. Recruitment was therefore purposeful with regards to this.

Definition of Carer

For the purpose of the qualitative study, a carer was defined as someone who had a close relationship with the patient during the development of his or her first psychotic episode and had witnessed the unfolding of associated events. In addition they were also required to be involved in, or have witnessed, the route that the patient took into psychiatric care.

Inclusion Criteria

1. Carers of a patients recruited in the quantitative arm of this research study
2. To have first-hand experience of a the pathway to care during FEP and to have experienced how symptoms developed
3. To be formally nominated by a patient recruited in the quantitate phase of the study

Exclusion criteria

1. Carers with limited recollections of the event

2. Those with poor conversational English

Qualitative Analytical Approach - Thematic Analysis

There are multiple approaches used to conduct and analyse qualitative information in health care research. Lyons and Coyle (2006) outline a series of different approaches used in psychological research, including Interpretive Phenomenological Analysis, Grounded Theory and Discourse Analysis; each with its own theoretical and epistemological assumption of how qualitative data should be treated. In selecting an appropriate method for the purpose of this thesis, much thought was given into both the unique strengths and weaknesses of each of these methods. As the aim of the qualitative study was explorative in nature, it was felt that using a more generalised methodology was more suitable at this stage, as using a particular qualitative approach may overlook some forms of information being generated. A thematic analysis approach was therefore selected, specifically due to its flexibility.

Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data. It not only organises information in a minimal form, but also attempts to interpret it. The approach is a widely used qualitative analytical method; however, is poorly defined and rarely acknowledged as its own method within the literature (Braun and Clarke, 2006). Due to its frequent oversight and abuse, Braun and Clarke (2006) clearly emphasise that researcher using the approach should make explicit the particular steps taken when applying this method to their study. Using the processes outlined by the authors, the following thematic approach was decided upon;

- *Method of theme creation:* As the purpose of this work was to explore the factors that can best account for the excessive rates of detention amongst Black-Caribbean patients, a 'dominance' strategy was chosen whereby themes were created based on the frequency at which they were found within the transcripts. While it was possible that generating themes through its 'uniqueness', it was felt that this method would give voice to idiosyncratic points amongst the sample interviewed and not that of the actual groups on a whole.

- *Detailed description of one aspect of the data vs. rich description of the data set overall:* There are likely to be many factors which influence patients journey to care, and account for ethnic disparities in detention rates. The interview schedule was designed to guides carers through a narrative account of the patient's journey to care, focusing on symptoms, beliefs, and help seeking behaviour. In addition, other themes of importance may arise naturally through discussion, which was not thought of beforehand. The process of analysis for this study aims at developing a rich description of the dataset, rather than attempting to focus on particular item (i.e. only help seeking behaviours).

- *Deductive vs. inductive approach:* Closely linked to the previous notion is the dichotomy between inductive and deductive approach. A deductive approach was taken, in which the theoretical model of help seeking described in chapter two (Morgan et al., 2004) was used to help identify associated themes emerging from the data. Ethnic comparisons were also made with regards to this

- Explicit vs. semantic analysis: In this study analysis was taken at the explicit level. With themes generating from the items explicitly mentioned in the literature rather than lose semantic interpretations.

Data Collection Procedure

Recruitment: Patients recruited in the quantitative phase of the study were asked to nominate a carer/informant; someone who they felt witnessed the development of their first psychotic episode and was important in their journey to care. Names and contact details were obtained at the end of the participant interview and the patient was asked to inform the individual that they would be contacted. Information sheet and consent form were sent to the carers (Appendix 7) and were given enough time to think about the study before deciding to take part. Contact was made, and if agreeable a face-to-face or telephone interview was arranged.

Interviews: Firstly, the researcher went through the information sheet and consent form with carer before obtaining consent. Socio-demographic information was then obtained and the nature of the interview explained. A topic guide was developed based loosely around the quantitative measures conducted (Appendix 8). The guide was designed to be flexible, allowing carers to give narrative account of events leading to care, with limited prompts by the researcher to confirm dates and timing of events. Interviews were also used as a validation tool for the quantitative phase of the study, and carers also conducted other questionnaires related to the broader ENRICH project. This information is not included in the thesis. Participants were asked to confirm that they were comfortable with the audio-recording before starting the interview. After the

interviews, participants were debriefed about the nature of the ENRICH project and specific objectives of this doctoral research.

Data handling: Audio files were transcribed via verbatim, and all unique identifiers and identifiable information were anonymised. Audio files were securely uploaded onto a NHS encrypted server, only available to the researcher and other members of study team. The original audio-files on the Dictaphone were then deleted.

Process of Analysis: Firstly, transcripts were read and reread in order for the research to familiarise himself with the data. In the left hand margin of each transcript, notes and annotations were used to identify significant excerpts that were of interests and that were closely linked to the purpose of the study. These were then collated within each transcript based on similarity and then compared and contrasted to others transcripts. Through this process super ordinate themes emerged.

Ethnic comparison was then made by comparing the frequency of each theme between the two main ethnic groups. Prominent themes that only emerged in one ethnic group were also captured.

Reliability of coding: Two independent sources were used to ensure that the codes generated were reliable and objectively created. Firstly, a fellow ENRICH researcher read a sample of the transcripts in each of the two ethnic groups. Independently she generated themes of importance and these were then compared against the themes that had been generated by the author of this work. Where differences emerged, both coders integrated the themes from the separate analyses until a compromise could be

met. A first draft of the final themes was then sent to a qualitative researcher with the medical school, who help finalise the themes.

Quotes: For illustrative purposes quotes were used to give content to the themes in order to provide practical examples for the reader. Quotes were selected on the basis of reflecting the theme most accurately whist also providing some context to the nature in which the theme emerged.

Synthesizing Qualitative and Quantitative Methodology

Rationale for a mix method design

Existing approaches used to explore ethnic differences in detention rates have mainly been conducted using quantitative epidemiological methods (Morgan et al., 2005a, Birchwood et al., 1992, Burnett et al., 1999). Such procedures have uncovered the importance of many factors in explaining ethnic disparities in detention rates; such as age, gender, diagnosis and criminal justice agency encounters. However as demonstrated in chapter Two, there are a range of other variables known to be important in influencing the pathway to care more generally, which have not yet been used to understand excessive detention rates amongst Black-Caribbean patients. A quantitative epidemiological approach was therefore decided upon as the primary methodology in this thesis, in order to build upon existing research.

Morgan et al. (2004) highlights the potential advantages of qualitative methodologies in revealing the factors that lead to ethnic disparities in the pathway-to-care. In doing so, their work has drawn on various examples of how qualitative methodologies have been used to uncover cultural, social and interpersonal influences in health behaviours. In the literature review chapter, qualitative approaches have successfully uncovered some new insights to health care utilization during FEP, and revealed the many factors that impede, delay and facilitate the utilization of psychiatric service (Etheridge et al., 2004, Johnson and Weich, 2010, Tanskanen et al., 2011). Despite such insights, little published qualitative work has attempted to explain Black-Caribbean excessive rates of detention during FEP.

The primary aim of this project is to uncover the factors that lead to the excessive detention rates amongst Black-Caribbean patients, during FEP. A combination of both quantitative-epidemiological methods mixed with qualitative ones was therefore chosen; to not only add breath to the list of significant determinants, but also add depth in understanding. It is through this that the presented work attempts to uncover which factors lead to excess and explain why these factors are important.

Mixed Method Approach: The Convergent Parallel Design (figure 22)

There are various ways in which to conduct a mixed method study design (Tashakkori and Teddie, 2003, Creswell and Plano Clark, 2007), which differ in the way they combine qualitative and quantitative methods. Creswell and Plano Clark (2007), identify six common methods, whereby a quantitative method is followed by or preceded by a qualitative one, conducted simultaneously with, or independently from one another. From this perspective, the sequence or assembly of the contrasting components are key in answering the research question. Will the qualitative approach build upon or inform the qualitative design? Will both be conducted with equal weighting and the findings compared and contrasted? It is these questions that the mixed methods researcher must ask themselves before the appropriate methodologies are selected.

For the purposes of this work, the 'Convergent Parallel Design' strategy was decided upon. Here, both the quantitative and qualitative data analysis are conducted independently and then compared and related at a later stage. As this work hopes to build upon the existing epistemological research, the convergent parallel design was thought suitable. This is because it enables the independent development of existing quantitative approaches whilst also enabling new insights from a previously unexplored

qualitative perspective. Through this combination, it is intended that a richer and fuller account of the factors leading to excessive rates of detention would be achieved (Figure 22)

Figure 22 the Convergent Parallel Design
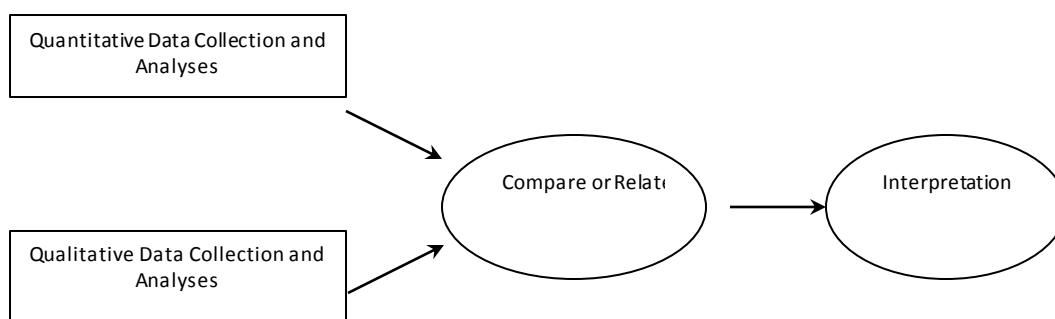
The application of the convergent parallel design in this work (figure 23)

The empirical components of this work will be split into two discrete phases. The first phase of this study attempts to build on existing epidemiological work, exploring the influence of new, uncharted variables quantitatively. In the second phase, a qualitative study will investigate the factors leading to excessive rates in detention amongst BME groups from the accounts of carers. Both phases will be analysed interdependently from one another and then brought together in a later stage to be compared and interrelated. This will then lead to a final level of interpretation where both parts will be brought together to better understand ethnic differences in the rates of detention during FEP.

Figure 23: The Application Of The Convergent Parallel Design Applied In This Thesis.

Phase 1.1:

Exploring ethnic differences in the pathway to care during FEP and associated factors

Phase 1.2: Determinants of the excessive rates of detention for Black-Caribbean patients during FEP.

Phase 2:

Exploration of factors leading to compulsory detention for Black Caribbean patients from the subjective accounts of carers

Compare & Relate

Interpretation
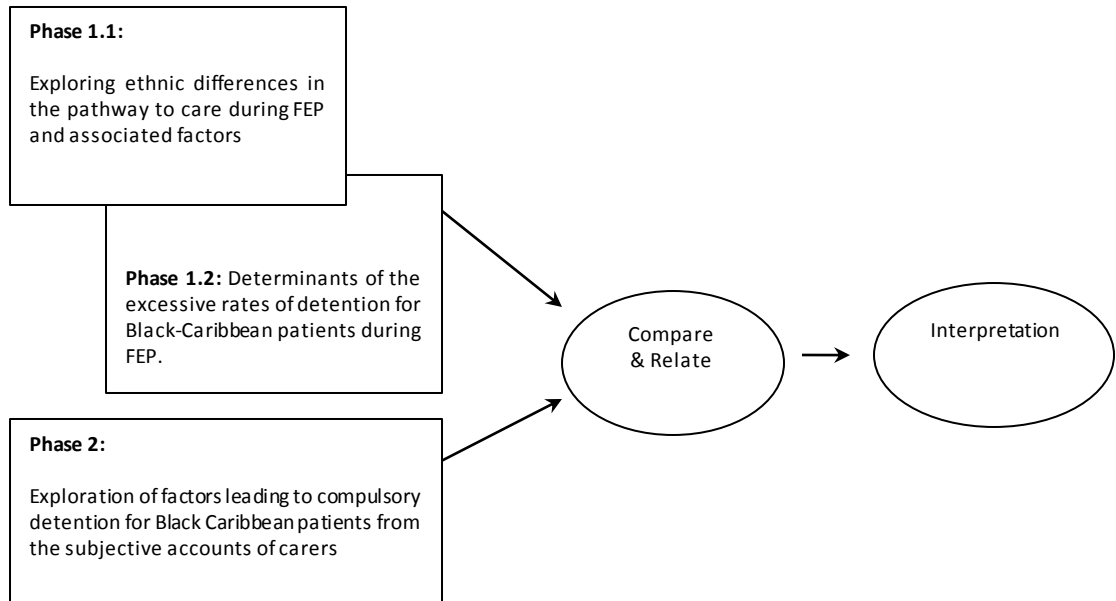
Chapter Discussion

Existing research attempting to explain Black-Caribbean's excessive detention rates during FEP is limited. Quantitative research in this area has begun to uncover some of the proximal factors of this, however, even the more complex and well-designed studies cannot fully account for Black Caribbean's association with significantly higher detention rates. It is therefore likely that other factors with better explanatory power must account for this relationship. Within the scientific community, there is much congruency in the types of methodology used to explain the excess in detention rates, which are often quantitative and cross-sectional. Described by some as 'contingency' based research (Morgan et al., 2004, Pescosolido, 1991), these approaches have been criticised for their lack of ability to account for the dynamic and context important processes involved.

The quantitative methodology of this study aims to overcome this limitation and builds on the existing approaches used within the literature, to explore the roles of unexplored factors, such as symptom attribution, clinical factors and specific help seeking behaviours. Although qualitative research has revealed many important processes during the pathway-to-care in first episode psychosis, the approach is rarely used explain known ethnic differences. Furthermore, Carers are thought to play a key role how patients seek help, however, their perspectives are also missing from our existing understanding. A qualitative study was therefore decided upon in respect to these two important points, with aim to further enhance understating of the phenomena.

In essence, this study is both exploratory and explanatory; exploring the role of new uncharted variables and then using them to better explain ethnic differences in adverse pathways to care. Both levels of investigation will be combined at a further stage of analyses, using a convergent parallel design strategy. It is through this intermixing of approaches and methodologies that a more comprehensive understanding of the reason for disparities in adverse routes to care for ethnic minority patients will be gained.

Chapter Four:

Quantitative Results I; Sample Characteristics, and Ethnic Comparisons of the Pathway to Care During First Episode Psychosis (FEP)

Introduction

As demonstrated in the literature review chapter, ethnic disparities in compulsory hospital admission can partially be explained by differences in the encounters made during the pathway to care, employment status, diagnosis, help seeking behaviour and clinical presentation (Morgan et al., 2005a, Harrison et al., 1989). Despite this, much of the variance that explains excessive rates of detention is yet to be accounted for, which suggests that other unknown factors of importance may also be at play. This chapter has two purposes; firstly, to identify ethnic differences in the rates of hospital admission in this sample; and secondly to identify ethnic differences in the ways FEP patients come to care. In the next chapter (chapter five) significant findings from this chapter will be used in an **explanatory way** to account for the relationship between Black-Caribbean ethnicity and elevated rates of detention statistically.

Chapter Objective

1. To identify ethnic differences in the rates of compulsory hospital admission during FEP.
2. To identify ethnic differences in the factors and influential processes during the pathway to care.

Analytic Strategy

Firstly, socio-demographical information was explored using descriptive statistics. Comparisons between samples were made using chi-squared on categorical data and T-test on continuous data. Secondly the chi-squared test and unadjusted odd ratio (via a logistic regression function) were used to explore ethnic differences and the magnitude of such differences on key pathway to care outcomes (e.g. Detention, GP involvement). A one-way ANOVA was applied to make comparisons on the deprivation data. In making comparisons on all other categorical variables, such as encounters made during the pathway to care and help seeking behaviours, odd ratio and chi-squared tests were applied where suitable. With regards to comparison of continuous data, the distribution of data was firstly explored to see if they were normal. As much of the data was skewed, non-parametric statistics were selected dependent on the number of comparison made (i.e. Kruskal-Wallis or Mann-Whitney). Bonfernoi corrections were applied for post hoc test analyses where necessary.

Results

Recruitment

Over the study period, 148 consecutive FEP cases were recruited from Early Intervention Services in Birmingham. For the purposes of the ENRICH project, a sample size of 120

participants were required, with no specification on ethnic grouping. Once this number was achieved, sampling became purposeful for this doctoral work; specifically targeting the ethnic groups needed for the research objectives stated. Primarily, this involved re-approaching those patients who were not engaging with services or were too unwell to take part in the study when first approached. In addition, newer referrals were also recruited where necessary.

In total, 122 participants were recruited; of these, 46 were White-British (37.7%), 44 Black-Caribbean (36.06%) and 32 Asian-Pakistani (26.22%). The remaining 26 participants recruited for ENRICH project were from various other ethnicities – 7 were Asian-Bangladeshi, 5 Mixed White and Black-Caribbean, 4 Black-African, 4 Asian-Indian, 2 White-Irish, 1 Mixed- Black-African, 1 Mixed-Other and 2 other. Rather than attempting to include these into another group, these patients were excluded from the study. Of the final 122 participant recruited into this study, data on 53.7% of the cases were solely collected by the author of this thesis; 14.6% jointly by the author and another researcher; and 31.7% by solely by another researcher.

With regards to the clinical population, 499 newly accepted FEP patients entered Early Intervention Services over the study period. Of these, 142 were White-British, 76 Black-Caribbean, 102 Asian-Pakistani, 20 Asian-Bangladeshi, 27 Asian-Indian, 21 Mixed White Black-Caribbean, 14 Black-African, 11 Other Black, 8 White Other, 7 White-Eastern European and the remainder were of other ethnic backgrounds. A 38.45% recruitment rates for three main ethnic groups was therefore achieved. Comparisons were made between the recruited sample and the clinical population using and independent T-test (F scores) and Chi-Squared (χ^2) on key demographics. There were very few ethnic

differences, however, the Black-Caribbean patients were significantly older than their relative clinical population and the White-British sample had more males (Table 6). Comparisons were not made on other domains like education or employment status as these were routinely collected on a service level.

Table 6: Comparisons between Recruited Sample and Overall EIS Intake over the Study Period

		Asian-Pakistani	Black-Caribbean	White-British
Age (Mean)	Recruited sample	25.66	22.66	23.391
	Clinical Population	23.5	25.947	24.782
	F	0.437	1.123	0.001
	p	0.42	0.00	0.087
Gender (% males)	Recruited Sample	22(68.8%)	33(75.0%)	52(36.6%)
	Clinical Population	74(72.5%)	53(69.7%)	90(63.4%)
	χ^2	1.73	0.094	4.611
	P	0.418	0.464	0.032

Sample Characteristics (Table 7)

The thesis sample had mean age of 23.16 (*SD* = 4.293), 75.4 % were male and 89.3% were single. The majority reported no religious affiliation (36.9 %), and 58.2% reported not engaging in any religious practices. 84.4% of the sample was born in the United Kingdom (UK), and the majority spoke English as their first language (98.4%). In terms of living arrangements and educational attainment, 73.8% of the sample lived with family members, 26.2% reported no qualification and 37.7% educated to school level with the remainder beyond school level (36.15). Roughly half of the sample was unemployed at the time of the assessment (55.7%) and 59% reported being in work or education at the time of the onset of psychosis. Finally, the majority of patients stated that a family member was their primary care giver (75 %).

In relation to ethnicity and socio-demographics, clear differences emerged between the samples. In relation to 'relationship status', the majority of Black-Caribbean and White-British patients were single, in contrast to the Asian-Pakistani group who, primarily, were married (75%). With regards to religion, the majority of the White-British sample reported having no affiliation with any religious group (65.2%). This was in stark contacts with the Asian-Pakistani sample, which predominantly identified with 'Islam' (90.6%) and the Black-Caribbean sample to 'Christianity' (65.95). 51% of Asian-Pakistani sample stated that they practice their religion, in comparison to 43.2% of the Black-Caribbean group and 13% of the White-British sample. In relation to 'migrant generation', the majority of the Asian-Pakistani and Black-Caribbean sample were 2nd generation and above, and thus most likely the children and grandchildren of those immigrating from outside the UK. In terms of living status, the majority of patients lived with their 'Others', which mainly consisted of family. However, this was not the case in Black-Caribbean patients, who lived 'alone' (65.6%). Chi-Squared analyses revealed that the Black-Caribbean samples were significantly more likely to live 'Alone' in comparison to the White-British ($\chi^2 = 9.48$, *df* = 1, *P* = .002), and Asian-Pakistani patients ($\chi^2 = 12.61$, *df* = 1, *p* = .000). There were also a trend suggesting educational differences between the groups, with the White-British group (82.6%) having greater level of education attainment in comparison to the Black-Caribbean (68.2%) and Asian-Pakistani (68.8%) sample.

Patients' Conceptualisation of Ethnicity

Prior to obtaining patients ethnicity using the UK census categories, patients were asked to describe their ethnicity in their own words (verbatim), which was used as an additional method to assess the accuracy of ethnic categorisation. With regards to the

Black-Caribbean group, patients most readily identified with being 'Black-British' (36.7%), followed by 'British-Caribbean' (32.7%), 'Black' (6.1%), 'Afro-Caribbean' (4.1%), 'Caribbean' (4.1%) and Other- using a mixture of the words, Black, Caribbean, British and Jamaican (12.2%). For the White-British group, 63.0% of the sample defined themselves as 'White-British', 8.7 % as 'White', 8.7% as 'British', 2.2% as 'English', 2.2% as 'European' and the remainder of other designations (13%). Finally, the Asian-Pakistani sample predominantly described themselves as 'Pakistani' (50%), followed by 'British-Pakistani' (15.6%), 'Asian-Pakistani' (12.5%), 'British-Asian' (6.3%), 'Asian' (6.3%) and the remainder from other designation, such as Kashmiri or Muslim (9.2%). As these categories mirrored the census rating, census categories were used throughout when making ethnic comparison in this work.

Deprivation Data

Overall the sample had a mean IMD score of 44.50 (SD, 17.25), which was higher than the mean IMD score for the entire city of Birmingham (37.54) (Birmingham City Council, 2013) – it was therefore clear that on average the sample came from the more deprived areas of the city. According to the data from Birmingham city council, the areas of Washwood Heath, Sparkbrook, Lozells and East Handsworth, Bordesley Green, Aston, Shard End, Nechells, Kingstanding, Soho, Tyburn and Ladywood were in ranked in the bottom 10% of most deprived areas in all of Birmingham. With regards to the recruited participant, 37.7% of the Ph.D sample came from these areas. A one way ANOVA used to make comparisons between the sample revealed a significant difference between the three groups in relation to their IMD scores (F= 7.18, df = 2, p =.001). Bonferroni corrected post-hoc analyses revealed significantly higher deprivation score for both the Black-Caribbean (p=.034) and Asian-Pakistani (p=.001) sample in comparison to the

White-British sample, suggesting these groups were more severely deprived. Although the Asian-Pakistani sample had the lowest IMD scores of the entire sample, no difference was found between them and the Black-Caribbean group (p=0. 648).

Table 7: Ethnic Comparison of Sample Characteristics

		Asian -Pakistani (n=32)	Black - Caribbean (n=44)	White- British (n=46)	P
Gender	Male	22(68.8%)	33(75%)	37 (80.4%)	
Age at assessment	16-23	18 (56.3%)	30 (68.2%)	24 (52.2%)	0.284
	24+	14 (43.8%)	14 (31.8%)	22 (47.8%)	
Relationship status	Stable	8 (25%)	1 (2.3%)	4 (8.7%)	0.006
	Single	24 (75%)	43 (97.7%)	42 (91.3%)	
Religious Affiliation	Christianity	0 (0%)	29 (65.9%)	14 (30.4%)	0.000
	Islam	29 (90.6%)	1 (2.3%)	1 (2.2%)	
	Non	3 (9.4%)	12 (27.3%)	30 (65.2%)	
	Other	0 (0%)	2 (4.5%)	1 (2.2%)	
Religious practice	N	6 (18.8%)	25 (56.8%)	40 (87%)	0.000
	Y	26 (81.3%)	19 (43.2%)	6 (13%)	
Country Birth	Other	9 (28.10%)	10 (22.7%)	0 (0%)	0.001
	UK	23 (71.9%)	34 (77.3%)	46 (100%)	
Migrant Generation	Not Applicable	0 (0%)	0 (0%)	44 (95.7%)	0.000
	2nd & 3rd	23 (71.9%)	35 (79.5%)	1 (2.2%)	
	1st	9 (28.1%)	9 (20.5%)	1 (2.2%)	
Living Status	Alone	3 (9.4%)	21 (47.7%)	8 (17.4%)	0.009
	With Others	29 (90.6%)	23 (52.3%)	38 (82.6%)	
Employment Status	Unemployed	17 (53.1%)	27 (61.4%)	24 (52.2%)	0.641
	Other	15 (46.9%)	17 (38.6%)	22 (47.8%)	
Work or education during FEP	No	12 (37.5%)	20 (45.5%)	18 (39.1%)	0.754
	Yes	20 (62.5%)	24 (54.5%)	28 (60.9%)	
Carer	Non	0(0%)	8 (18.2%)	4 (8.7%)	0.904
	Family	29 (90.6%)	29 (65.9%)	34 (73.9%)	
	Other	3 (9.4%)	7(15.9%)	8 (17.4%)	
Deprivation	Mean IMD, (SD)	51.43 (14.37)	46.66(15.93)	37.30 (18.14)	0.001
Education attainment	No Qualifications	10(31.3%)	14(31.8%)	8(17.4%)	0.225
	Qualifications	22(68.8%)	30(68.2%)	38(82.6%)	

Descriptive Statistics and Ethnic Comparison of Pathway to Care Variables

In total, five groups of analyses were conducted, covering the themes 1) Encounters made, 2) Clinical and symptomatology related factors, 3) Symptom attribution, 4) Help Seeking Behaviours and 5) Social Network Involvement. In this next section each of these themes will be taken in turn, exploring descriptives and then by making ethnic comparisons.

1. Encounters during the Pathway to Care

Ethnic Differences in Compulsory Hospital Admission (Primary variable)

Overall a significant difference between the three groups was found in the rates of compulsory detention (χ^2 = 15.30, *df* =2, p = .000). The results suggested that Black-Caribbean patients were roughly 5 times more likely (OR= 5.05, *p<0*001, 95% CI = 2.035-12.5) to experience compulsory hospital admission in their pathway to care during FEP than White-British patients. The results also showed that Black-Caribbean Patients were roughly 4 times more likely to experiences compulsory hospital admission in comparison to Asian-Pakistani patients (OR = 4.06, p=0. 005 95% CI 1.522 -10.824). Conversely, the same was not found for Asian-Pakistani Patient in comparison to White-British Patients (OR = .219, *p* =.068, 95% CI = 0.45-3.47).

Ethnic Differences in Other Pathway to Care Outcomes

In relation to criminal justice agency involvement (Section 135/136 of the mental health act or police contact/place of safety referrals), the Chi-Squared analysis did not reveal any difference between the three groups (χ^2 = 0.79, *df* = 2, *p* = 0.67), and hence no further analyses were conducted.

In relation to GP involvement, White-British (84.8%) and Asian-Pakistani (87.5%) patients had a similar level of GP contact in their pathway to care; this was in contrast to Black-Caribbean sample (65.9%). Chi-squared analyses revealed that this difference was significant (χ^2 = 6.79, *df* =2, *p* = .032). Odd ratios were then used for further analyses, which revealed that Black-Caribbean patients were significantly less likely to experience GP involvement in their pathway to care than White British patients (OR = .347, *p*=. 042 95% CI = .125-.960). No difference was found between Asian-Pakistani and White British Patients (OR = 1.26, *p*= .735, 95% CI= .335-4.71).

Finally, comparisons were made between the three ethnic groups in relation to emergency medical contact. The chi-squared analyses revealed a significant difference between the three groups (χ^2 (2), N = 122 = 7.722, p = .021), with those of Asian-Pakistani ethnicity having the least amount of emergency medical contact (25%) and the Black Caribbean patients' having the greatest (56.8%). Odds ratios were then used to explore this finding further, which revealed that Black-Caribbean patients were almost four times more likely to have emergency medical contact in their pathways to care (OR = 3.95, *p* =007, 95% CI=. 1.455-10.71) in comparison to Asian-Pakistani patients, however, no difference was found between White-British patient and Asian-Pakistani patients (OR = 2.11, *p* = .140, 95% CI= .783-5.70). There was also no differences between Black-Caribbean and White-British patients (OR =1.87, *p*= .143, 95% CI =. 810-4.317)

Table 8: Odds Ratio of Pathways to Care Outcomes during FEP via Ethnicity

	Yes	No	OR*	P	CI*
Compulsory hospital admission					
Asian Pakistani (%)	9(28.1)	23(71.9)	1.25	.675	0.446-3.47
Black Caribbean	27(61.4)	17(38.6%)	5.05	.000	2.035-12.55
White-British	22(23.9)	35(76.1)	1		
Emergency Medical Contact					
Black Caribbean	25(56.8)	19(43.2)	3.95	.007	1.455-10.71
White-British	19(41.3)	27(58.7)	2.11	.140	.783-5.70
Asian Pakistani	8(25.0)	24(75.0)	1		
GP Involvement					
Asian Pakistani	28(87.5)	4(12.5)	1.256	.735	.335-4.71
Black Caribbean	29(65.9)	15(34.1)	0.35	.042	.125-.96
White-British	39(84.8)	7(15.2)	1		
Criminal Justice Involvement					
Asian Pakistani	10 (31.3)	22(68.8)	1.039	0.42	.601-3.45
Black Caribbean	17(38.6)	27(61.4)	1.439	0.94	.391-2.76
White-British	14(30.4)	32(69.6)	1		

*OR = Odd ratios, CI = Confidence intervals

First Contact

The majority of patients had their first encounter with services during the psychotic phase of illness (53.3%), with the remainder during the Prodrome – there were no ethnic differences with regards to this (χ^2= 3.762, *df* = 2, *p* = . 152). At first contact, patients were most likely to encounter the General Practitioner (GP) (44.3 %); followed by Lay Persons' (family, Friends, colleagues etc.) and Emergency medical Service (11.5%); Criminal Justice Services (10.7%); Faith based organisations (8.2); School Employees (6.6%), Mental Health Service (5.7%) and Others (1.6%). Although GP contact was the most common 'first contact' made between three groups (see table 9), the ethnic differences began to emerge after this point – namely, Asian-Pakistani patients were more likely to make first contact with 'Faith Base Organisations' (21.9%), and Black-Caribbean with 'Criminal Justice contact' (18.2%) and 'Lay persons' (18.2%). A first contact analysis was also conducted, dichotomising all encounters into medical vs. non-

medical contact. No significant differences were found between the three ethnic groups with regards to this.

Table 9: Ethnic Comparisons of Phase of Illness When Fist Contact Was Made and Types of Encounter at First Contact

		Asian - Pakistani (n=32) (%)	Black – Caribbean (n=44)	White- British (n=46)	P
Phase of illness when First Contact was made	During the Prodrome	11(34.4)	20(45.5)	26(56.5)	.152
	During FEP	21(65.6)	24(54.5)	20(43.5)	
Encounter type a first contact	Faith Based Organisations	7 (21.9)	2(4.5)	1(2.2)	
	Emergency Medical Services	4(12.5)	5(11.4)	5(10.9)	
	Mental Health Services	1(3.1)	2(4.5)	4(8.7)	
	Criminal Justice service	1(3.1)	8(18.2)	4(8.7)	
	General Practitioner	15(46.9)	17(48.6)	22(47.8)	
	Lay Persons	1(3.1)	8(18.2)	5(10.9)	
	School Employees	3(9.4)	2(4.5)	5(10.9)	

Second and Third Contact

At 'Second Contact' differences began to emerge in comparison to 'First Contact'. Here, 'Mental Health Services' became the most dominant encounter, accounting for 36.1% of all encounters made, which was closely followed by contact with the 'General Practitioner' (29.5%). At 'Third Contact', this difference further increased, with Mental Health Services accounting for 54.9% of all encounters made and GP contact 16.4%. Ethnic comparisons were then made at both 'Second' and 'Third Contact' however no significant differences were found (Second Contact: Black-Caribbean – Mental Health service = 36.4% and GP =27.3%; Asian-Pakistani - Mental Health = 34.4% and GP = 28.1%; White British Mental Health = 37% and GP=32.6%) and 'Third Contact' (Black

Caribbean – Mental Health =63.6, GP = 11.4%; Asian-Pakistani - Mental Health = 38.7%, GP = 19.4%, and White British - Mental Health = 58.6 and GP=19.6).

Frequency of Encounters

Using the protocol developed from the NOS, the pathway to care was conceptualized as the sequence of Encounters that a patient has in their route to psychiatric care from the onset of non-specific symptom, through the onset of psychosis to the start of Anti-Psychotic medication. The entire sample had multiple encounters during the entire pathways to care (M= 6.73, SD 2.36), with a minimum of 2 encounters and a maximum of 15. 68% of the sample had 7 or less encounters with a mode of 5. There was a slight variation in the mean frequency between the three ethnic groups, however the difference was not significant.

Figure 24: Sample Distribution of Encounter Made During the Pathway to Care
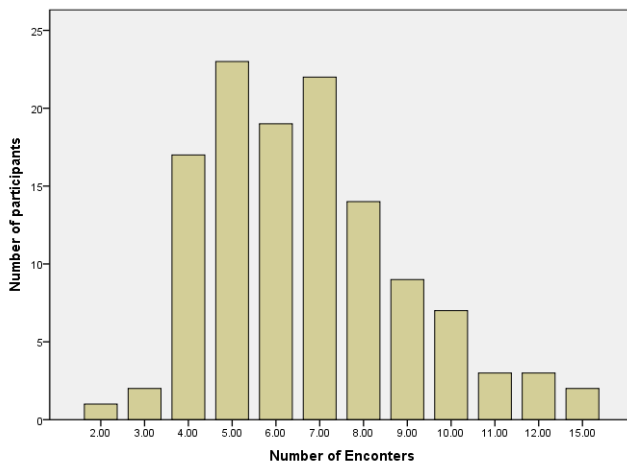
Comparison of Types of Encounters Made Over the Entire Pathway

Comparisons were then made to explore the types of encounters made during the entire pathway. All encounter types were coded into seven main groups, 1) Faith

Encounter (religious, spiritual and cultural help seeking contacts) 2; Emergency medical (Accident and emergency services, out of hours primary care services 3; Mental Health Services (All psychiatric and Psychological interventions) 4; Criminal Justice agencies (police and judicial services) 5; Primary Care (General Practitioners), 6: Non-medical services, 3rd sector, school employees and Voluntary groups 7) Lay persons (family, Friends, Colleagues and social networks). Using the framework set out by Morgan et al. (2004), these were further developed into three main categories with;

1. Professional Sector – medical encounters, allied health professional and statutory associated services (2, 3, 4 and 5).

2. Popular Sector – all help freely available within one's own social network and community, without the consultation of medical doctors or folk healers (6, 7).

3. Folk sector – non-medical professionals, who provide treatment often using the values of the community, which they serve (1).

Rather than making comparison based on the frequency of each of the encounter types, a proportional scoring system was devised, as all patients had multiple contacts with each of the different encounter categories. The number of contacts with each encounter types were then divided by the total number of encounter and then multiplied by 100. For each encounter type, a score similar to a percentage was created. Each encounter types score was then dichotomised via the mean sample scores into 1) below average and 2) above average scores, comparisons were then made based on this distinction.

The results demonstrated a significant difference in proportion of 'Professional Sector' and 'Folk Sector' encounters during the pathway to care between the three groups, but not in 'Popular Sector' encounters (Table 10). Odds ratios were conducted to explore this trend further, and revealed that Asian- Pakistani patients were 28 times more likely to have 'Folk Sector' encounter in their pathway to care than the White- British patient (OR= 28.28, p=. 000, 95% CI 5.83-137.30). The same was true but to a lesser extent for the Black-Caribbean sample, as this group were roughly 7 times more likely to have 'Folk Sector' encounter during their pathway to care than White-British patient (OR 7.33, 95% CI = 1.521-35.347). In a similar way odd ratios were calculated to make comparisons in the proportion of professional sectors involvement in the pathway to care. The result demonstrated that Asian-Pakistani patients were significantly less likely to have professional sectors involvement in their pathway to care then White-British patients (OR= .299, p =. 003, 95% CI =.088-.600). No difference was found between Black-Caribbean and White-British patients.

Table 10: Ethnic Comparison on the Proportions of Professional, Folk and Popular Sector Encounter in the Pathway to Care during FEP.

	Proportions	Asian –Pakistani (n=32) (%)	Black - Caribbean (n=44)	White-British (n=46)	OR	P
Popular Sector	Low	20(62.5)	29(65.9)	32(69.6)	0.43	0.807
	High	12(37.5)	15(34.1)	14(30.4)		
Folk Sector	Low	14(43.8)	33(75.0)	44(95.7)	26.83	0.000
	High	18(56.3)	11(25.0)	2(4.3)		
Professional sector	Low	21(65.6)	18(40.9)	14(30.49)	9.69	0.008
	High	11(34.4)	26(59.1)	32(69.6)		

2. Clinical and Symptomatology Related Variables

Clinical Variables - DUI, DUP & Prodome

Descriptive analyses revealed that DUP, DUI and Prodrome scores were all positively skewed and non-normally distributed, and hence using the mean as a measure of central tendency was inappropriate in describing and analysing the data (Figures 24-27). Instead, median values were used for each. Overall, the median DUP for the entire sample was 349 day (M =668.95, SD=880). For the Prodrome, a median number of 365 days was found (M=720.38, SD =1037). This equated to approximately 12 months. For the DUI, a median score of 1056 was found (M=1372.20, SD=13.97), this equates to 2.89 years.

Ethnic comparisons were then conducted on the DUP, DUI, and Prodrome values. In similarity with prior research conducted in the area (Morgan et al., 2003, Morgan et al., 2005a, Skeate et al., 2002) median scores were uses to dichotomise each variable into long and short categories (i.e, Long DUP, short DUP). In relation to the DUI and DUP, the statistical analyses did not find any difference between the three groups (See table 4). Conversely, in relation to the Prodrome, a significant difference was found between the three groups (χ^2 = 6.46, *df* =2, *p* = .040) Post-Hoc analyses revealed that both the Asian-Pakistani (χ^2 = 4.94, *df* = 1, *p* = .026); and Black-Caribbean sample (χ^2 = 4.42, *df* =2, *p* = .036) had significantly shorter prodromes in comparison to the White-British sample. No difference was found between Black-Caribbean and Asian-Pakistani patients (χ^2 = .090, *df* = 1, *p* = .764).

Figure 25: Distribution of Prodrome Scores

Mean = 720.38
Std. Dev. = 1037.559
N = 122
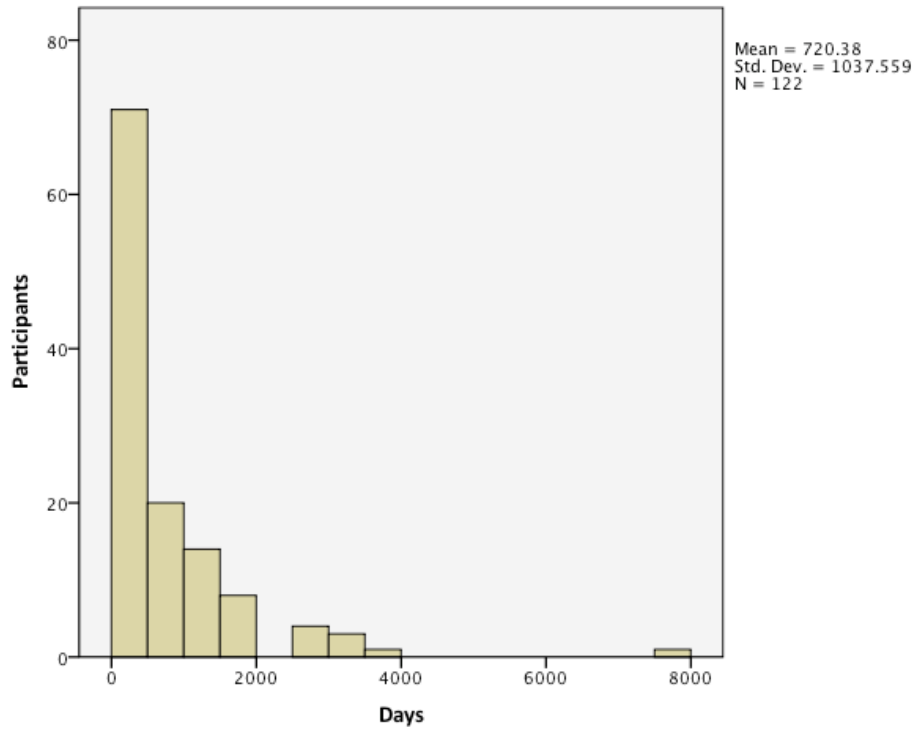
Figure 26: Distribution of DUP scores

Mean = 668.95
Std. Dev. = 880.695
N = 122
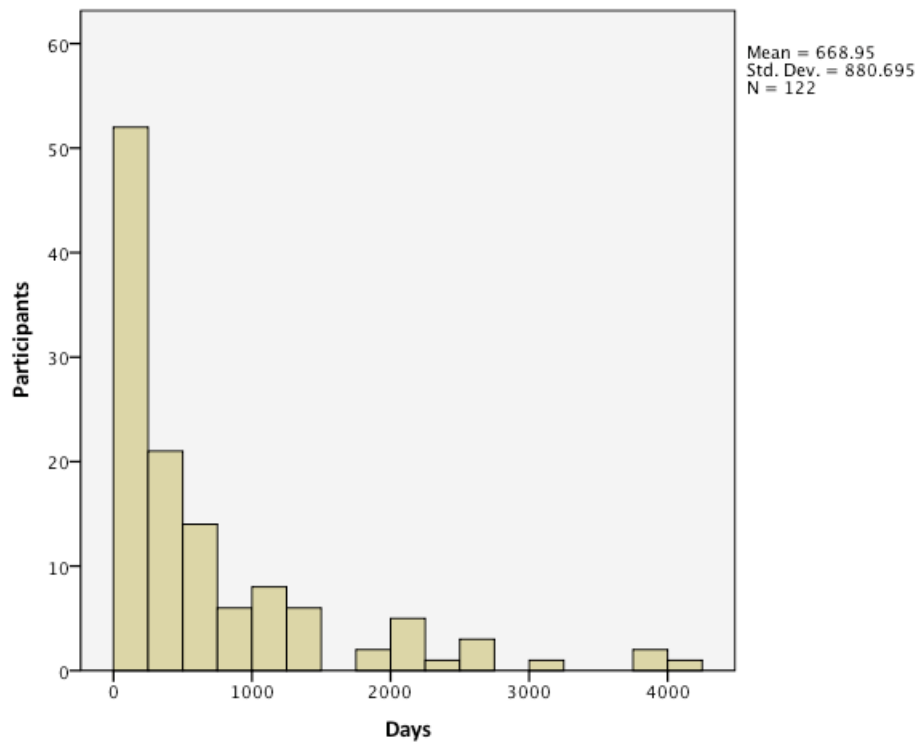
Figure 27: Distribution of DUI Scores
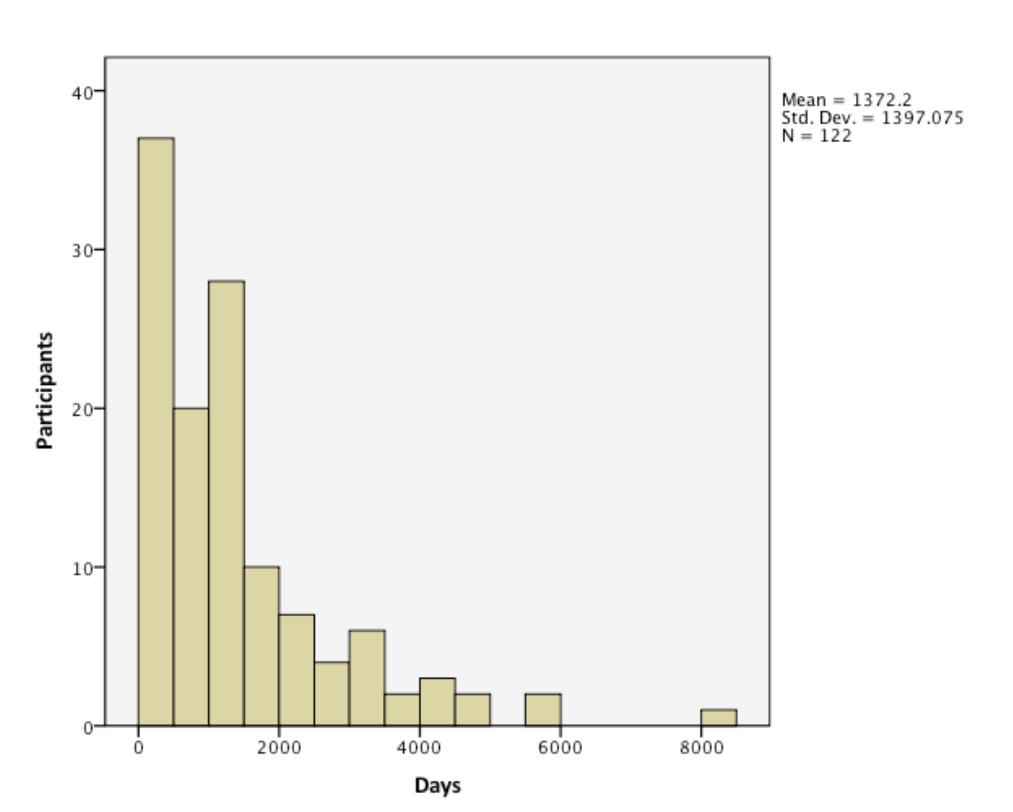
Components of DUP

The DUP is an aggregate variable, which comprises of three subcomponents, including; 1) a help seeking delays, 2) a mental health referral delay and 3) a delay in administering treatment. For each patient, these three variables were calculated. 'Help seeking delays' were measured from the onset of Psychosis to the date that first medical contact was made – and is the number of days between the emergence of a psychotic episode and the involvement of medical professionals. The analysis revealed a median help seeking delay value of 105.5 day (M=386.90, SD = 708.61), which equates to roughly 3.5 months (30.41 days per month). However, the statistical analyses revealed no significant differences between the three ethnic groups when a Kruskal-Wallis test was applied (χ^2= .475, *df* =2, *p* = .788).

The second variable calculated was mental health service delay. This is the number of days between the first medical contact and the first contact with a mental health service. Although mental health service contact may occur before the emergence of psychosis (i.e. during the Prodrome), this variable only accounts for contact with service during the DUP. The results found a median service delay of 2 days (M=127, SD=457.34). Again, there was much variability between the three ethnic groups, with Asian-Pakistani having a median service delay of 8.5 day, the Black-Caribbean sample a median of 0 days, and the White-British sample having 2.50 days. Statistical comparisons were then made using Kruskal-Wallis test and revealed a significant difference between the three groups (χ^2= 7.42, *df* = 2, *p* = .024). Bonferroni corrected (at the .01 level) post-hoc analyses were subsequently conducted, comparing each of the three groups to one another. The Mann-Whitney test revealed a significant difference between the Asian-Pakistani sample and the Black-Caribbean sample (U= 474, *p* = .010, *z* = -2.57), but not the White-British and Asian-Pakistani sample (U = 628, *p* = .262, *z* = -1.121) or the White-British and Black-Caribbean sample (U = 791, *p* = .058, *z* = -1.90) at the adjusted for level.

Finally, comparisons were made on treatment delays and the length of time (in days) between the first mental health service contact during FEP and start of anti-psychotic medication at the therapeutic dosage (see NOS methodology in chapter 4 for detail of criteria). In some instance the General Practitioners may prescribe anti-psychotic medication, and hence treatment occurs before mental health service involvement. In these cases, treatment delay is captured as negative value. The results demonstrated median treatment delays of 13 days (M= 154, SD= 219.052). In relation to ethnicity, the Asian-Pakistani sample had a median treatment delay of 3.5 days, Black Caribbean 15 days and White British 19.5 days (see table 2). The Kruskal-Wallis test revealed that the

difference between the three groups was not significant (χ^2= 1.02, *df* =2, *p* = .602) and hence no post hoc analyses were conducted. Figure 28 shows a graphical representation of each of the components of DUP using the median scores generated from this study.

Figure 28: Graphical Representation of Median DUI, DUP and Prodrome Scores with Components of DUP
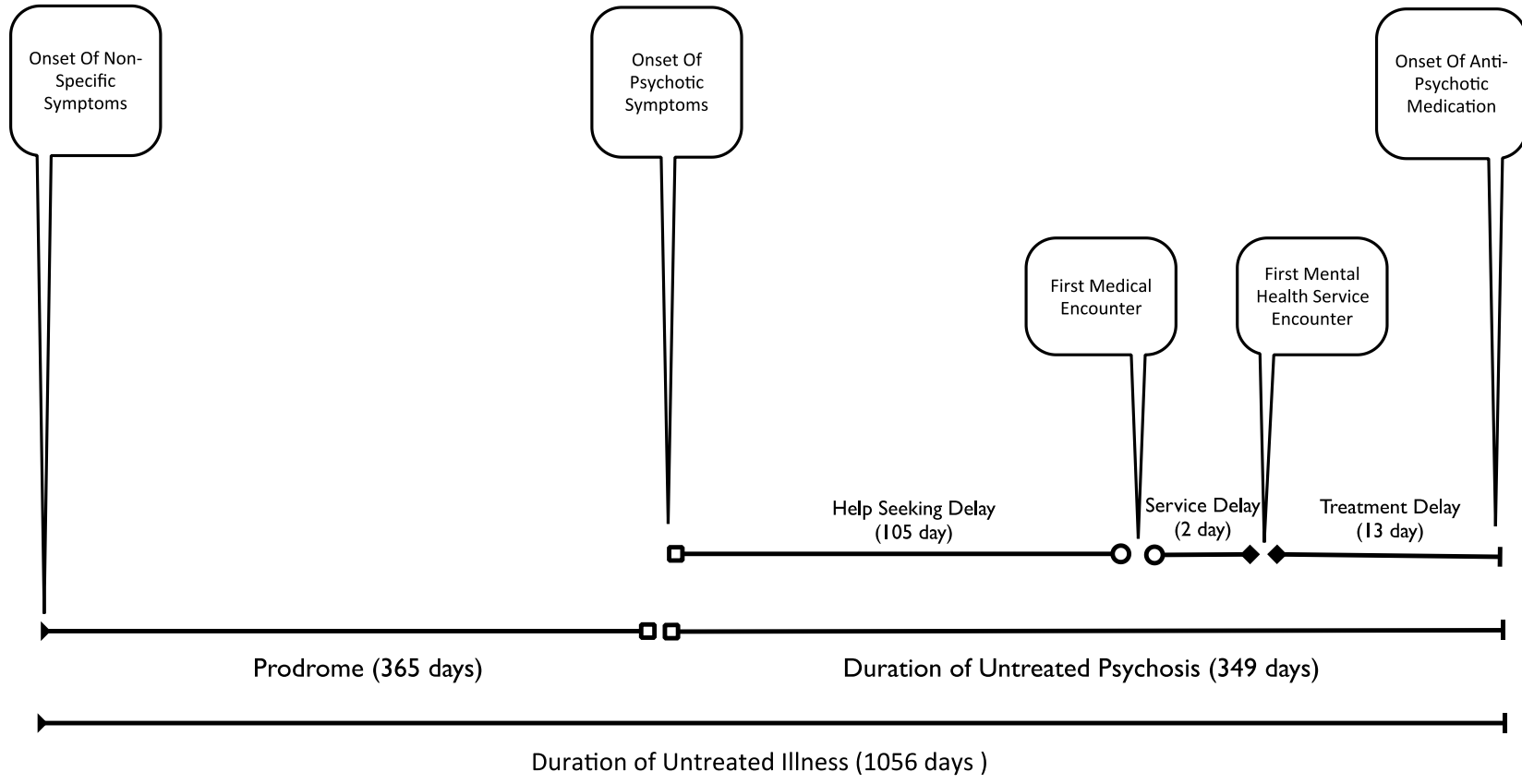
- *Figure's not to scale, values reflect median number of day for overall group*

Mode of Onset

The mode of onset is a categorical variable that describe the length of time in which a psychotic episode emerges. The results revealed that the majority of the sample had an insidious mode of onset (74.6%) - there was no significant difference in onset type between the three ethnic groups (χ^2 = 1.981, *df*=2, *p* = .271).

Diagnosis and Age of Onset

In relation to diagnosis, 77% of the sample had a diagnosis of 'broad' Schizophrenia, 18% a depressive psychosis and only 5% a manic psychotic episode. In relation to ethnicity, there was a trend suggesting that Black-Caribbean patients were less likely to have depressive psychoses than the other groups, however, this difference was not significant. For each patient, age at onset of psychosis was also calculated; using a calculation involving the date of birth and the onset date of psychosis from the NOS and socio-demographic information sheet. The entire sample had a mean age of onset was 18.89 (Mdn= 18.00, SD= 5.61). There was no difference between the groups with regards to this (*p*=. 359)

Table 11: Ethnic Comparison on Clinical Variables

		Asian - Pakistani (n=32)	Black - Caribbean (n=44)	White-British (n=46)	P
DUP, n (%)	Short	12 (37.5)	25(46.8)	24 (52.2)	0.234
	Long	20 (62.5)	19(43.2)	22 (47.8)	
DUI, n (%)	Short	17(53.1)	26 (59.1)	17(37)	0.096
	Long	15(46.9)	18 (40.9)	29 (63)	
Prodrome, n (%)	Short	20 (62.5)	26(59.1)	17(37.0)	0.040
	Long	12(37.5)	18(40.9)	29(63.0)	
Treatment Delays, Median (mean, SD)		3.5 (157.92. 392.5)	15 (134.41, 248.2)	19.5 (172.15, 328.61)	0.602
Help-seeking Delay, Median (mean, SD)		122 (316, 527.47)	143 (427.75, 824.3)	77.50 (396.89, 709.9)	0.788
Service Delay, Median (mean, SD)		8.50 (188.25, 421.3)	0 (49.68, 181.05)	2.50 (159.24, 631.94)	0.024
Mode of onset, n (%)	Short	11(34.4)	9(20.5)	11(23.9)	0.371
	Long	21(65.6)	35(79.5)	35(76.1)	
Diagnosis, n (%)	Broad Schizophrenia	24(75)	38(86.4)	32(69.6)	.354
	Depressive Psychosis	7(21.9)	4(9.1)	11(23.9)	
	Manic Psychosis	1(3.1)	2(4.5)	3(6.5)	
Age at onset, Mean (SD)		20.09 (6.586)	18.04(5.490)	18.30(4.944)	.359

Reported Symptoms

During the Nottingham Onset Schedule (NOS) assessments patients were ask to recall the types of symptoms they had experienced during both the prodrome and psychotic phase. Once a compressive list had be achieved, reported symptoms were then grouped into 8 symptom clusters; 1) affective and neurotic, 2) hostility and aggression 3) suspiciousness and persecution 4) delusions, 5) social decline 6) hallucinations 7) other 8) none given. During both phases of the illness patients reported experiencing multiple symptoms, with a mean of 3.6 symptoms in the Prodrome and 4.01 during the psychotic phase of illness. As patients gave multiple symptoms, a standardised score for each category was developed, estimating the proportion of symptoms experienced overall. During the prodromal phase of the illness, the most common symptom cluster was 'Affective and Neurotic' symptoms; accounting for 42.96% of all reported symptoms.

However during the psychotic phase of the illness, the most common symptom cluster was hallucination (26.44) followed by delusions (20%). Ethnic comparisons were then made in both phases of illness, however, no significant differences were found–this was also true in relation to the frequency of symptoms reported (Table 12 & 13).

Table 12: Ethnic Comparison of Frequency of Symptoms Reported Phase Wise.

Frequency of symptoms	Asian –Pakistani (n=32)	Black – Caribbean (n=44)	White-British (n=46)	P
Prodrome (SD)	4.5313 (2.89)	3.8182 (1.84)	4.9348(2.37)	0.081
DUP (SD)	3.5625 (1.81)	4.0909 (1.802)	4.2609(1.94)	0.253

Table 13: Ethnic Comparison in Proportion or Symptoms in Each Symptom Cluster

	Frequency of symptoms	Asian –Pakistani (n=32)	Black – Caribbean (n=44)	White-British (n=46)	P
Prodrome	Affective and Neurotic	38.12	53.93	41.35	0.106
	Hostility and aggression	4.2	0.71	3.26	0.224
	Suspiciousness and percussion	5.68	4.35	7.90	0.613
	Delusions	7.21	4.03	7.96	0.232
	Decline in social Functioning	7.24	6.27	6.72	0.910
	Hallucinations	7.53	6.61	10.73	0.299
	Other	17.53	6.11	17.73	0.006
	Non-reported	12.5	18.18	4.35	0.120
DUP	Affective and Neurotic	11.14	11.47	12.53	0.165
	Hostility and aggression	8.42	6.65	4.15	0.228
	Suspiciousness and Percussion	11.90	18.56	14.89	0.148
	Delusions	14.00	23.18	20.06	0.278
	Decline in social Functioning	0.63	1.23	2.67	0.907
	Hallucinations	30.38	22.81	27.18	0.588
	Other	10.95	9.29	12.00	0.610
	Non-reported	12.50	6.82	6.52	0.978

3. Symptom Attribution Variables

Frequency of Reported Attributions

The results demonstrated that the entire sample had multiple and simultaneously held attributions; with a median number of 2 attributions (M=1.62, SD= 1.45) and range of 0-8 during the Prodromal phase of illness. This was also true during the DUP with a median score of 2 (M= 1.66, SD= 1.03) and a range of 0-4. Comparisons were then made between the two illness phases, however, no significant difference was found (Z = 0.327, p=0. 743). Comparisons were also made via ethnicity. A significant difference was found between the three ethnic groups during the Prodromal phase of the illness (p= 0.057), suggesting that White-British patients gave more prodromal attribution in comparison to the other two groups. Conversely the same was not true during the DUP (Table 10).

Comparison of Attribution Types

Analyses were then conducted on the types of attributions given (see Chapter Three for attribution coding methodology). The results demonstrated that during the Prodrome, patients were most likely to hold attribution in the social domain (32.26%), followed by not attributing symptoms (24.83%). Conversely, during the psychotic phase of the illness (DUP), patients were most likely to not attribute symptoms (46.40%), followed by giving supernatural world attributions (19.60%). As the data was non-normally distributed, non-parametric statics were used for ethnic comparison. Kruskal-Wallis test found no significant differences in attribution score on any of the attribution category domains during the Prodrome (Table 14). However, during the DUP, a significant difference was found on both the supernatural category (H = 14.182, df = 2, p = 001) and 'not attributed' category (H =11.24, df=2, *p*=004). Mann-Whitney tests were used to follow up this finding. A Bonferroni correction was applied so comparison could be

made between the samples in supernatural attribution scores - effects were reported at 0.02 level. The results revealed a significant difference between Asian-Pakistani patients and Black-Caribbean (U = 513, r=021) and Asian-Pakistani and White-British patients (U =435, r=000) in 'supernatural' attributions. In relation to 'not attributed' scores, a Bonferroni correction was also applied at a higher significance level (0.01). Results revealed that a significant difference between Asian-Pakistani patients and White-British patient (U=472, r= 0.004) and Asian Pakistani and Black-Caribbean (U =425 r=0.002). No difference was found between Black-Caribbean and White-British patients.

Table 14: Ethnic Comparison of the Frequency of Attribution and Types of Attributions Given During the Prodrome

		Asian –Pakistani (n=32)	Black – Caribbean (n=44)	White-British (n=46)	P
Attribution Frequency Median (Mean, SD)	Prodrome	1 (1.54, 1.00)	1 (1.47, 1.00)	2.00 (1.97, 1.35)	0.057
	DUP	2 (1.59, 1.10)	2 (1.795. 1.00)	1 (1.58,1.02)	0.687
Prodrome	Individual	16.54	6	14.82	0.214
	Natural	4.54	1.7	10.33	0.211
	Social	35.42	31.44	30.84	0.938
	Supernatural	1.56	1.52	3.16	0.546
	Not Attributed	20.05	27.46	25.64	0.708
	No response/Other	21.87	31.81	15.21	0.173
DUP	Individual	9.38	9.85	16.3	0.392
	Natural	5.73	4.73	5.62	0.993
	Social	2.6	7.01	5.8	0.586
	Supernatural	39.06	18.37	7.25	0.001
	Not Attributed	24.48	55.49	51.91	0.004
	No response/Other	18.7	4.54	13.0435	0.148

*Definition of attribution codes can be found on page 117-118 in the method section

Figure 29: Phase Wise Comparisons of Symptom Attributions by Asian-Pakistani Patients
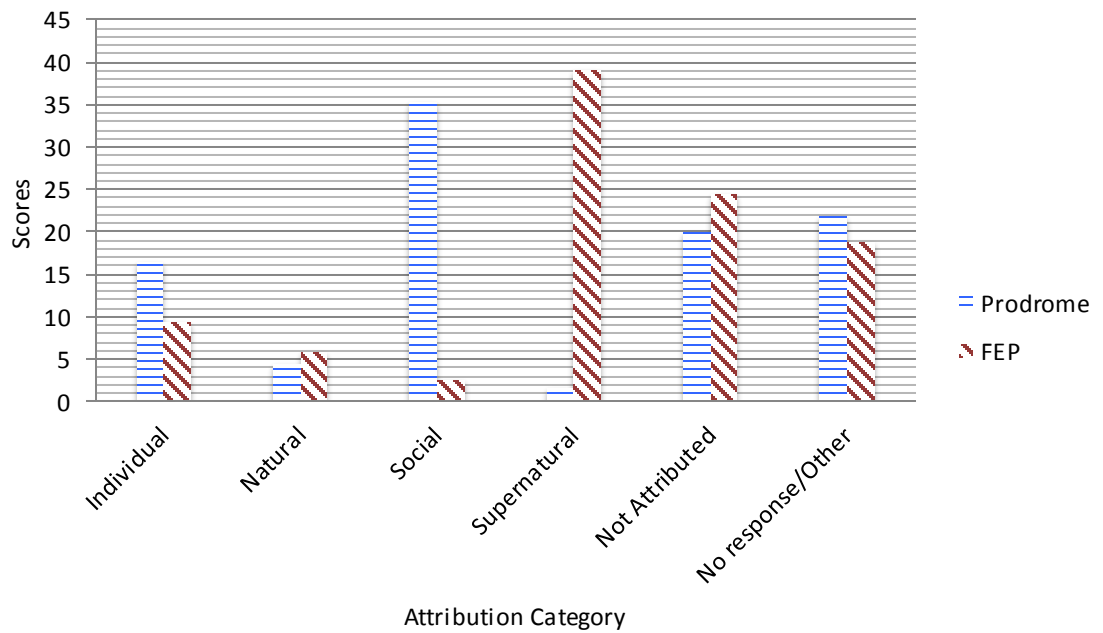
Figure 30: Phase Wise Comparisons of Symptom Attributions by Black-Caribbean Patients
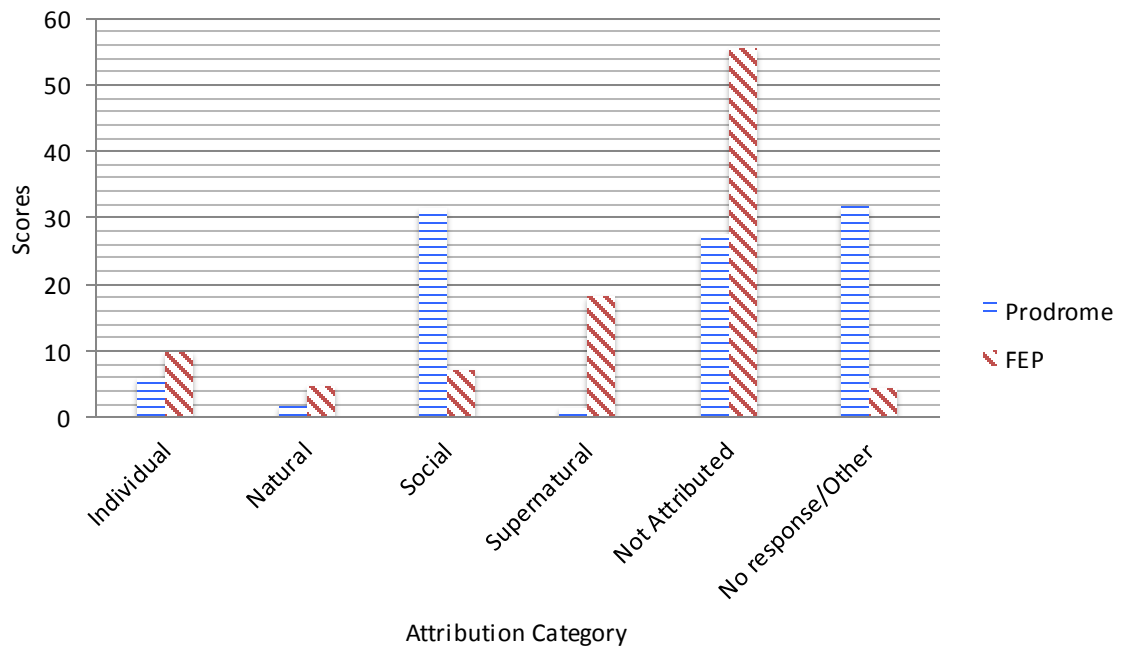
Figure 31: Phase Wise Comparisons of Symptom Attributions by White-British Patients
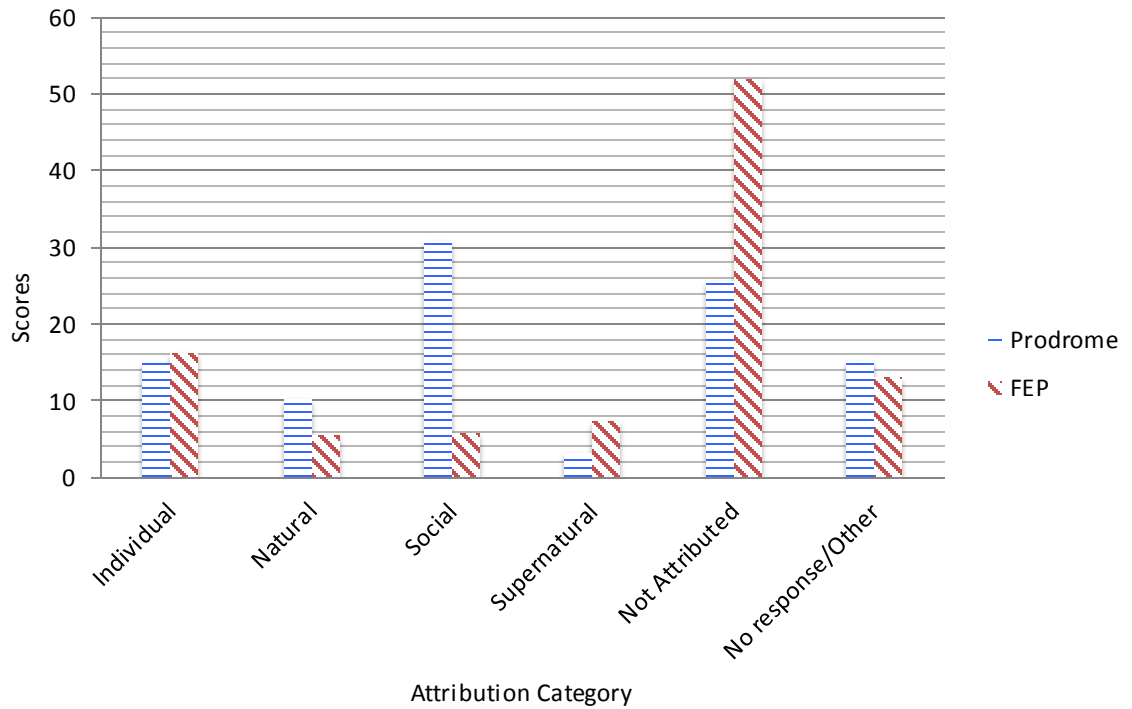
4. Help Seeking Behaviours and Social Network Involvement

Social Support

Firstly, comparisons were made on the social support available of each patient at each encounter. As patients made multiple help seeking attempts a proportional scoring system was devised, giving the percentage of overall encounters attended by the patients social support – lower score reflected lower levels of social support, while higher score reflected higher levels. The mean score for the entire sample was 44.57%, however, In relation to ethnicity, it was clear that there were significant differences, with Black-Caribbean (35.78%) patients having the lowest social support, followed by the White-British patients (41.2%) and then the Asian-Pakistani (60.01%). As data was not normally distributed, a Kruskal-Wallis test was applied, which suggested that this difference was significant (H = 11.27, *df* = 2, *p*= .004). Post hoc analyses were conducted

and a Bonferroni correction applied at the .01 level. A significant difference was found between Asian-Pakistani and White British patient (U=495, *p* =014), Asian Pakistani and Black Caribbean (U=395.50 *p*=001), but not Black-Caribbean and White-British (U =888 p .314). With regards to gender, there appeared to be no difference between males (37.55%) and female (30.47%) in their social support during their pathway to care.

Referral Making

Secondly, comparisons were made on the persons likely to make the referral. Again as multiple referrals occurred along the pathway to care, a scoring system was derived, giving the proportions of referral made by the 1) Self-referral, 2) Social network referral and 3) Service referral (higher scores reflected a greater proportion of the individual in referral process). Overall, the result demonstrated that referrals mainly came from service (55.52%), followed by the social network (27.37%), the patient (13.16%) and finally 'not known' (2.95%). Non-parametric analyses were then conducted on each of these domains between the three ethnic groups, however, no significant difference were observed (Table 15)

Table 15: Ethnic Comparison On The Types Of Referrals Made Using proportional scores

Proportional Referral scores	Asian – Pakistani (n=32)	Black – Caribbean (n=44)	White-British (n=46)	H	P
Self-referral,	13.68	14.21	11.79	0.123	0.94
Social network suggested	32.46	23	28	4.435	0.109
Services suggested	51.78	60.53	53.34	3.616	0.164

Unsuccessful Help Seeking Attempts

Finally, analyses were conducted on the number of unsuccessful encounters made during the pathway to care (successful vs. Non successful). Unsuccessful encounters

were those services that did not propagate the patients through the pathway to psychiatric care. Overall, the results show that the groups had a mean number of 2.37 unsuccessful encounters with a median score of 2. There was slight ethnic variation in the mean number of unsuccessful attempts, Asian-Pakistani = 2.50, Black-Caribbean = 2.80 and White-British 2.65. Odds ratios were calculated to make comparisons between the three ethnic groups in relation to unsuccessful help seeking, with scores greater than 2 in one category and scores less than or equal to 2 in another. The result demonstrated that Black Caribbean patients were roughly 2.5 times more likely to have greater amount of unsuccessful help seeking attempts then White-British patients. No difference was found between South-Asian and White British patients.

Help-seeking Direct from Criminal Justice Services

In the Black-Caribbean sample, 50% of the 'first criminal justice agency involvement contact' was initiated by services (e.g. Section 135, 136 of the MHA other medical services), followed by 'self-initiation' (37.5%) and 12.5% by the 'social network members'. This contrasted criminal justice help seeking in the White-British sample, where 'social network members' initiated the all criminal justice agency help seeking. In a similar way, comparisons were made exploring ethnic variation in overall criminal justice contact. The results showed that all three groups contact was predominantly initiated by services (Black-Caribbean, 78%, White-British 73%, Asian-Pakistani 69.2%), followed by the 'social network' in the Asian-Pakistani (23.1%) and White British (20%) groups, and the 'client' themselves (self-referral) in the Black-Caribbean group (13%). This difference was not significant ($\chi^2 = 1.90$, *df* = 4, *p* =.755).

Pathway to Care Initiation

Finally, an exploration of the person responsible for initiation of overall help seeking was conducted. The result showed that Black-Caribbean patients had the greatest proportion of self-initiated help seeking, however this did not differ significantly from the other two groups (χ^2 = .745, df = 2, p =.689).

Table 16: Ethnic Differences In Help Seeking Initiation Self Vs. Other

		Asian -Pakistani (n=32)	Black - Caribbean (n=44)	White-British (n=46)	P
Help seeking initiated	Self	8(25%)	15(34.1)	13(31.7)	0.689
	Other	24(75.0)	29(65.9)	28(68.3)	

Box 3: Key Findings from Chapter

- Black-Caribbean patients were roughly 5 and 4 times more likely to experience compulsory hospital admission in their pathway to care than White-British and Asian-Pakistani patients respectively.
- Black-Caribbean patients were less likely to have GP contact in their pathway to care.
- Black-Caribbean patients were four times more likely to emergency medical contact in their pathway to care.
- Asian- Pakistani patients and Black-Caribbean sample were roughly 7 times more likely to have 'Folk Sector' encounter during their pathway to care than White-British patient.
- Asian-Pakistani and Black-Caribbean sample had significantly shorter prodromes in comparison to the White-British sample.
- Black-Caribbean sample had the shortest service delay.
- Asian-Pakistani patients and Black-Caribbean held more 'supernatural' attributions scores.
- Black-Caribbean patients had the lowest level of social support in the help seeking process of all the three groups
- Black Caribbean patients were roughly 2.5 times more likely to have greater amount of unsuccessful help seeking attempts than White-British patients.

Chapter Five:

Quantitative Results II; Explaining Excessive Rates of Compulsory Hospital Admission amongst Black-Caribbean Patients

Introduction

As identified in the previous chapter, Black-Caribbean patients are between four and five times more likely to experience compulsory hospital admission in their routes to care, in comparison to White-British (OR= 5.05, p≤. 001, 95% CI = 2.04-12.50) and Asian-Pakistani Patients (OR = 4.06, p≤. 005, 95%, CI 1.52 -10.82). In the process of beginning to explain such disproportionate detention rates, the previous chapter also identified how a multi-ethnic sample of FEP patients came to utilize psychiatric services. The results showed a range of differences, including ethnic variation in encounters made during the pathway to care, clinical factors, help seeking behaviour, symptom attributions and the involvement of the patients' social network. It was therefore apparent that excessive rates of detention were only one area in which Black-Caribbean patients diverged in their routes to care. The insights derived from this initial exploratory stage were therefore advantageous in contextualising the route taken to treatment for specific groups, and helped illuminate avenues for further explanatory investigation. The purpose of this chapter is to add to this initial stage of analyses, and

identify the specific factors that account for the relationship between detention rates and Black-Caribbean ethnicity statistically.

Chapter Objectives

1. To identify variables from the data set that hold crude associations with compulsory hospital admission.

2. To use the insights from the previous objective to explain excessive rates of detention amongst Black-Caribbean patients.

Analytic Strategy

Firstly, the unadjusted odds ratios were calculated on all socio-demographic and pathway to care variables, to identify crude associations with compulsory hospital admission (Dependent Variable). In addition, the unadjusted odds of compulsory hospital admission were also calculated for age and gender (young vs. old, and male vs. female) controlling for ethnicity, as the previous literature was unclear if excessive detention rates only occurred amongst young Black-Caribbean males (Harrison et al., 1989, Morgan et al., 2005a).

Secondly, significant variables in the unadjusted odd analyses were carried forward into the moderator and mediator analyses using a pre-established criteria (Baron and Kenny, 1986, MacKinnon, 2008). The notion of a moderating and mediating variable is widely used in the social science and the psychiatric literature (Bebbington et al., 2011, Fisher et al., 2012), when attempting to explain the known relationship between two variables. Although the concept of a moderating and mediating variable are often confused, Baron

and Kenny (1986) state that a moderator is a factor that *effects* the direction or strength (positively or negatively) between an independent variable (IV) and a dependent variable (DV). On the other hand, a mediator is a variable that *accounts* for the relationship between the IV and DV. In applying these notions in a practical sense, Baron and Kenny (1986) outline two methodological frameworks to assess if a factor of interest meets the assumption of these variable. As the primary purpose of this chapter was to explain the relationship between ethnicity (IV) and compulsory detention (DV), the framework set out Baron and Kenny (1986) was applied. According to their work, mediation would require; - firstly, a relationship between (a) the IV (ethnicity) and the proposed mediating variable; secondly, (c) a relationship between the IV (ethnicity) and the DV (detention); and thirdly, the relationship between the IV (ethnicity) and mediating variable together, on the DV (detention) – see figure 32. For a mediating variable to be confirmed, both (a) and (c) must be statistically significant, in addition, the relationship between the IV and DV must be greatest in the second association outlined above in comparison to the third. Total mediation occurs, when the relationship between the IV and DV become non-significant in the third statistical equation (essentially being accounted for by mediator variable).

Figure 32: Applied Mediatory Hypothesis
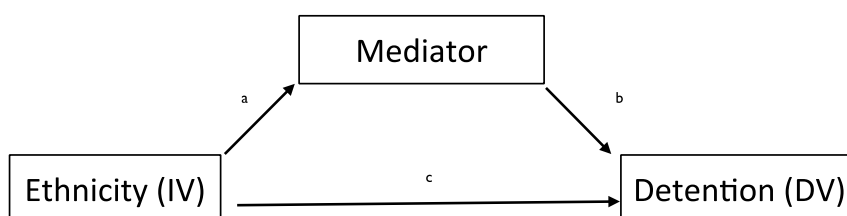
Similarly, moderation (see figure 34) would require; (a) a significant relationship between the IV (ethnicity) and DV (detention); (b) a relationship between the proposed

moderating variable and DV (detention); and thirdly (c) a significant relationship between the IV (ethnicity) combined with the moderating variable, through interaction effects terms, on the DV (detention). The moderator hypothesis is supported if path c is significant. Directionality can be assessed by comparing path c to path a; with a greater relationship observed in path c suggesting positive moderation and a reduced relationship in paths c suggesting negative moderation. Both moderator and mediator analyses were conducted using a logistic regression model created using SPSS version 21 (IBM, 2012).

Figure 33: Applied Moderator Hypothesis
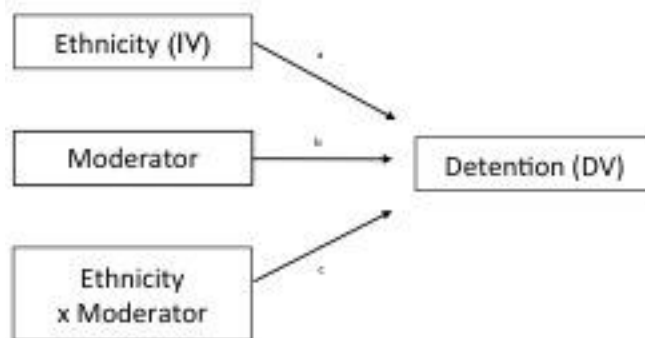
Significant moderating and mediating variables established in the previous stage were then carried forward into multivariate analyses (logistic regression model) with detention as the DV. This was used to see how much these variables collectively diminished ethnicity's relationship with detention, if at all, essentially controlling for these factors together.

Finally, the association between ethnicity and detention was explored in an alternative way, using decision tree analyses. Decision tree analysis is a form of machine learning that uses data already obtained to classify a specific outcome. The approach is relatively

new to the area of clinical investigation (Tuebbicke et al., 2012), but has shown its application in some mental health care research (Bonner, 2001, Batterham et al., 2009). Essentially, the analysis uses a pre-determined algorithm to develop a model that best represents the relationship between inputted data and a binary outcome. This is then presented in the form of a graphical representation with a hierarchal structure, depicting mutually exclusive routes that lead to specified outcomes. Multiple variables can be entered simultaneously and the algorithm used will calculate which ones best classify (maps out) the data. At the top of the tree is the root, the variable most important in classifying the outcome. From this variable, branches emerge which depict the attributes of the routes leading to new nodes (new variables). This process is repeated until the data set can most accurately classify the end outcome (referred to as the leaf or a decision). An example is shown in figure 34. The method used in decision tree analysis is set out by work of Quinlan (1986) in which the ID3 algorithm, an automatic process to decision tree creation, was outlined. Although Quinlan (1986) was not the original inventor of the decision tree processes (p. 84), his work pioneered the notion of building the tree using some form of information measure – in turn improving on the previous methodology used. Decision tree analysis was conducted using the WEKA data mining tool software (Hall, 2009).

In applying the decision tree analysis to this work, a decision tree was created with detention selected as the outcome variable and ethnicity as one of the predictors. Other variables that also had an association with detention were also included in the model, and the tree was then used to see if ethnicity emerged as the main predictor (root), or as a node to model important factors.

Figure 34: Example of a simple decision tree by Quinlan (1986) in predicting weather on a particular day, P and N are the outcomes (Leaf)
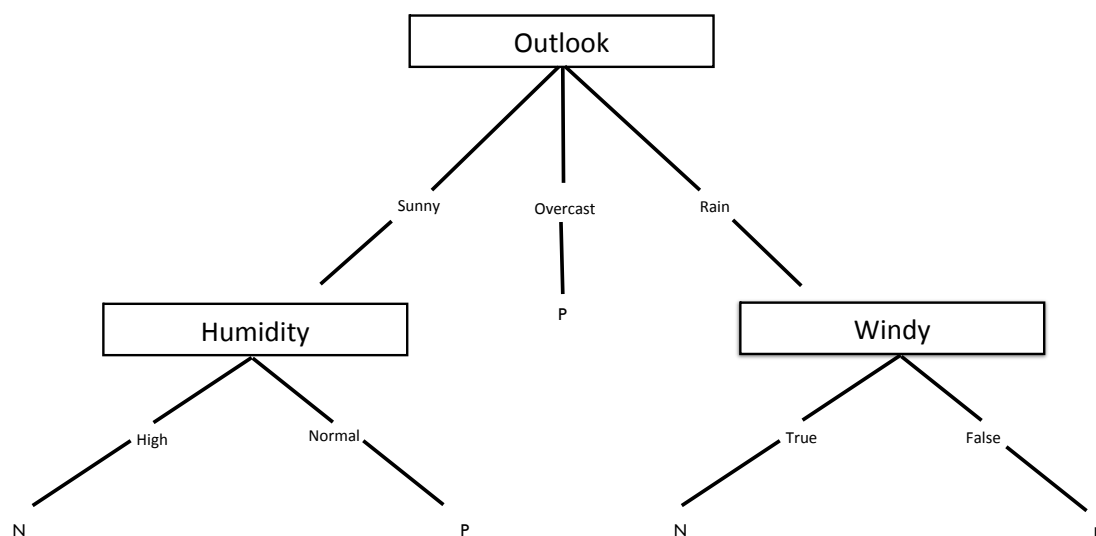
Results

Characteristics of the Detained Sample

In total, 47 of the 122 patients (39%) experienced compulsory hospital admission during their pathway to care. Of these 47, 57.4% were Black-Caribbean, 23.4% White-British and 19.1% Asian-Pakistani. The majority of the detained patients had a broad Schizophrenia-like first psychotic episode (83.0%), with 10.6% diagnosed with a depressive psychosis and 6.4 % manic psychosis. With regards to age, the majority of the sample were between 16-23 years (59.6%). 63.8% of the sample was unemployed and 74.5% were male. Carers were most commonly reported as a family member (68.1%), followed by not having a carer (17.0%), and 'other' (14.9%). The group had a higher proportion of religious believers, with 80.9% identifying with a faith group (e.g. Islam, Christianity), however, only 42% reported that they practiced their religion. 76.6%

of the sample were born in the UK, and 46.8% were 2nd generation migrants.

Unadjusted Odds for Compulsory Hospital Admission

The unadjusted odds of compulsory detention were calculated on key variables from the broader data set; ones identified through the literature to have an impact on the pathway to care. Firstly, the results demonstrated that criminal justice agency referral and emergency medical contact were independently associated with compulsory detention (table 17). No relationship was found between compulsory detention and either GP or 'Folk Sector' involvement. The analyses on demographic variables revealed that 'Living Status' was positively related to detention. In particular those living alone were at greater risk of detention in comparison to those living with others. This finding No other socio-demographic variables differences were found (table 17). As demonstrated in table 20, the following clinical factors were significantly associated with compulsory detention; a shorter prodrome; a shorter service delay; a decline in social functioning during the Prodrome and hallucinations during the Prodrome. No relationship was found between the help seeking behaviours and social network involvement (table 19) and the majority of the attribution variables, however, those patients who did not hold 'within the individual' attributions during the prodrome were significantly more likely to be detained (table 18).

Table 17: Unadjusted Odds Ratios of Encounters and Socio-Demographics via Compulsory Hospitalisation (% are in rows)

	Compulsory	Non-Compulsory	OR	P	CI
Criminal Justice Agency					
Yes	27(65.9)	14(34.10)	5.88	≤0.001	2.592-13.350
No	20(24.70)	61(75.30)	1.00		
Folk Sector					
Yes	9(29.0)	22(71.0)	0.57	0.212	.237- 1.376
No	38(41.8)	53(58.2)	1.00		
Emergency Medical Service					
Yes	22(42.30)	30(57.7)	4.25	0.000	1.958- 9.231
No	17(24.3)	53(75.70)	1.00		
Overall GP Involvement					
No	14(53.80)	12(46.20)	2.23	0.074	.925- 5.362
Yes	33(34.4)	63(65.6)	1		
GP contact in prodrome					
No	33(40.7)	48(59.3)	1.326	.480	.606-2.901
Yes	27(65.9)	14(34.1)	1		
GP contact in DUP					
No	23(37.1)	39(62.9)	0.88	.742	.426-1.835
Yes	24(40.0)	36(60.0)	1		
Deprivation scores (IMD)					
Above mean	26(41.3)	37(58.7)	1.27	0.520	.612-2.643
Below mean	21 (35.6)	38(64.4)	1.00		
Gender					
Males	35(38.0)	57(62)	0.92	0.848	.396-2.140
Females	12(38.0)	18(62)	1.00		
Employment					
Unemployed	38(55.9)	30(44.10)	1.72	0.156	0.814-3.629
Other	17(31.5)	37(68.5)	1.00		
Living Status					
Alone	18(56.3)	14(43.8)	2.70	0.018	1.183-6.181
With Others	61(67.8)	29(32.2)	1.00		
Country of Birth					
Other	11(57.9)	8(41.1)	2.56	0.065	.945-6.933
UK	36(35.0)	67(64.0)	1.00		
Age					
16-23	28(38.9)	44(61.1)	0.96	0.921	.459-2.02
24+	19(38.0)	31(62.0)	1.00		
Religious practice					
Yes	20(39.2)	31(60.8)	1.05	0.894	.502-2.201
No	44(62.0)	27(38.0)	1.00		
Relationship Status					
Single	43(39.40)	66(60.6)	1.47	0.545	.425-5.060
Stable	4(30.8)	9(69.20)	1.00		
Religious affiliation					
Religious	33(42.9)	44(57.10)	1.05	.894	502-2.201
Non-Religious	31(68.9)	14(31.10)	1.00		

Table 18: Unadjusted Odds Attribution Types via Compulsory Hospitalisation (% are in Columns)

		Compulsory	Non-Compulsory	OR	P	CI
prodrome						
Within the Individual						
	Yes	5(10.60)	54(72)	0.267	0.028	.107-.880
	No	42(89.40)	21(28)	1		
In the natural world						
	yes	4(8.5)	67(89.3)	0.70	0.779	.221-2.746
	No	43(91.5)	8(10.70)	1		
In the Social world						
	yes	16(34.0)	35(46.70)	0.59	0.170	.277-1.255
	No	31(66)	40(53.3)	1		
In the supernatural world						
	yes	46(97.90)	6(8)	4.00	0.206	.466-34.327
	No	1(2.10)	69(92.0)	1		
Not Attributed						
	Yes	14(29.80)	27(36)	0.75	0.480	.345-1.650
	No	33(70.2)	48(64)	1		
DUP						
Within the Individual						
	Yes	8(17)	19(25)	1.654	0.285	.685-4.157
	No	39(83)	56(74)	1		
In the natural world						
	yes	6(12.8)	41(87.20)	2.6	0.260	.588-7.136
	No	70(93.30)	5(6.70)	1		
In the Social world						
	yes	13(27.7)	24(32)	0.997	0.996	.306-3.251
	No	34(72.30)	51(68.0)	1		
In the supernatural world						
	yes	31(66)	43(57.30)	0.364	0.612	.364-1.813
	No	16(34)	32(42.70)	1		
Not Attributed						
	Yes	31(66)	43(57.3)	1.44	0.334	.676-3.075
	No	16(34)	32(42.70)	1		

Table 19: Unadjusted Odds Ratios of Help Seeking Behaviours and social network involvement Via Detention (% are in Columns)

	Compulsory	Non-Compulsory	OR	P	CI
Unsuccessful Help Seeking					
Above Mdn	21(44.70)	24(32.0)	0.96	0.920	.464-1.998
Below Mdn	26(53.3)	51(68.0)	1.00		
Help seeking support scores					
Above Mdn	24(51.60)	39(52.0)	1.04	0.920	.501-2.153
Below mdn	23(48.9)	36(48.0)	1.00		
Client Suggested Help seeking					
Above	23(48.9)	40(53.3)	1.20	0.633	.569-2.526
Below	24(51.1%)	35(46.7)	1.00		
Family Suggested Help seeking					
Above	18(38.3)	32(42.7)	0.84	0.636	.404-1.740
Below	29(61.7)	43(57.3)	1.00		
Help seeking initiation					
Self	14(29.8)	22(29.3)	1.022	.975	.460-2.272
Others	33(70.2)	53(70.7)	1		
First contact					
Medical	27(36.0)	20(42.6)	.759	.470	.360-1.601
Non-Medical	48(64.0)	27(57.4)	1		

Table 20: Unadjusted Odds Ratios of Symptoms via Compulsory Hospitalisation (n, % are in Columns)

		Compulsory	Non Compulsory	OR	P	CI
Prodrome						
Affective and Neurotic						
	Yes	33(70.2)	60(80)	0.589	0.219	0.254-1.369
	No	14(28.80)	15(20)	1		
Aggression & Hostility						
	Yes	2(4.3)	11(14.70)	0.259	0.088	0.055-1.223
	No	45(95.7)	64.30)	1		
Suspiciousness & persecution						
	Yes	11(23.4)	17(22.7)	1.042	0.925	0.439-2.476
	No	36(76.6)	58(77.3)	1		
Delusional thinking						
	Yes	9(19.10)	69(80)	0.947	0.908	0.377-2.379
	No	38(80.9)	15(20)	1		
Decline in Social Functioning						
	Yes	8(17)	49(65.3)	0.387	0.038	0.158-0.948
	No	39(83.0)	26(34.7)	1		
Hallucinations						
	Yes	8(17)	29(38.7)	0.325	0.014	0.133-0.793
	No	39(83.0)	46(61.3)	1		
DUP						
Affective and Neurotic						
	No	31(60)	40(53.3)	0.59	0.17	0.277-1.255
	Yes	16(34)	35(46.7)	1		
Aggression & Hostility						
	No	32(68.10)	59(78.7)	1.729	0.194	0.757-3.946
	Yes	15(31.9)	16(21.3)	1		
Suspiciousness & persecution						
	No	20(42.6)	31(41.3)	0.951	0.894	0.454-1.991
	Yes	27(57.4)	44(58.7)	1		
Delusional thinking						
	No	18(38.0)	31(41.30)	1.135	0.739	0.538-2.394
	Yes	29(61.7)	44(58.7)	1		
Decline in Social Functioning						
	No	45(95.7)	67(89.3)	0.372	0.225	0.076-1.834
	Yes	2(4.3)	(8(10.7)	1		
Hallucinations						
	No	13(27)	61(81.3)	0.6	0.247	0.253-1.424
	Yes	34(72.3)	14(18.7)	1		

Table 21: Unadjusted Odds Ratios of Clinical Variables Via Detention (n, % are in Columns)

	Compulsory	Non-Compulsory	OR	P	CI
Prodrome					
Short	30(63,8)	33(44.0)	2.25	0.034	1.061-4.753
Long	17(36.2)	42(56.0)	1		
DUP					
Long	30(42.6)	41(54.7)	0.61	0.194	294-1.282
Short	27(57.4)	34(45.3)	1		
Help seeking Delay					
Long	38(80.9)	64(85.3)	1.38	0.516	.523-3.628
Short	9(19.1)	11(14.7)	1		
Service Delay					
Short	30(63.8)	34(45.3)	2.13	0.048	1.006-4.500
Long	17(36.2)	41(54.7)	1		
Treatment Delay					
Long	32(68.10)	42(56)	1.68	0.185	781-3.599
Short	15(31.9)	33(44)	1		
Diagnosis					
Depressive Psychosis	5(22.7)	17(77.3)	0.11	0.638	.270-7.358
Manic Psychosis	3(50.0)	3(50)	1.41	0.683	.141-1319
Broad Schizophrenia	39(41.5)	55(58.5)	1		
Mode of Onset					
Acute	13(41.9)	18(58.1)	1.211	0.652	.528-2.777
Other	34(37.4)	57(62.6)	1		

Gender and Age via Ethnicity on Detention

In relation to gender, the results demonstrated that Black-Caribbean males were 2.5 times more likely to be detained in comparison to White-British males (OR = 2.455, p = .039, 95% CI =1.045-5.766), and Black-Caribbean females roughly 8 times more likely to be detain than White-British females. In terms of age, both younger (16-23) and older (>23 years) Black-Caribbean patients were significantly more likely to be detained in comparison to White-British patients, however the difference was greatest in the elder sample.

Table 22: Unadjusted Odds for Age, Gender via Compulsory Hospitalisation (n,% are in rows)

	Compulsory	Non Compulsory	OR	P	CI
Gender - Males					
Black Caribbean	18(54)	15(45)	2.455	0.039	1.045-5.766
Asian Pakistani	7(31.8)	15(68.2)	0.955	0.93	0.34-2.679
White-British	10(27)	27(73)	1		
Females					
Black Caribbean	9(81.8)	2(18.2)	8.125	0.01	1.665-39.658
Asian Pakistani	2(20)	8(80.0)	0.451	0.331	0.091-2.24
White-British	1(11.1)	8(88.9)	1		
Age - 16-23 years					
Black Caribbean	17(56.7)	13(43.3)	2.724	0.024	1.14-6.508
Asian Pakistani	6(33.30)	12(66.7)	1.042	0.942	0.349-3.111
White-British	5(20.8)	19(79)	1		
>23					
Black Caribbean	4(28.6)	10(71.4)	4.412	0.018	1.285-15.147
Asian Pakistani	3(21.4)	11(78.6)	0.481	0.286	0.126-1.846
White-British	6(27)	16(72.7)	1		

Mediator and Moderator Analyses

From the unadjusted odds analyses conducted, emergency medical contact; living status; service delay; prodrome length; criminal justice agency involvement; 'within the individual' world attribution during the prodrome; decline in social function during the prodrome and hallucinations during the prodrome showed crude associations with compulsory hospital admission. Moderator and mediator analyses were therefore conducted on these variables to see if they could be used to explain the relationship between ethnicity and the rates of detention observed. Variables were chosen as they met the initial requirements for the moderator and mediator criteria set out in the work of Baron and Kenny (1986).

The results showed that Black-Caribbean ethnicity's association with detention was partially mediated by the variables; Emergency Medical Agency Contact; Living alone; Short Prodrome; and Short Service Delay (Table 23). Moderator analyses were then conducted on the variables not meeting the criteria for the mediation and found that; Criminal Justice Agency involvement; hallucinations during the Prodrome; and decline in social function during the Prodrome, all met the criteria for moderation (Table 24). In specific criminal justice agency involvement significantly increased Black-Caribbean ethnicity's relationship with detention, whilst the decline in social functioning and hallucination during the prodrome significantly reduced ethnicity's relationship with detention.

Figure 35 graphically depicts the significant variables from mediation analysis that account for Black-Caribbean ethnicity's relationship with detention, whilst figure 5 displays similar information from the moderation analysis.

Table 23: Logistic regression for mediator analyses of detention on ethnicity (yes vs. no). See Figure 32 for details of paths

Mediator			P	OR	95% C.I	
Emergency Medical Contact (Yes v. No)						
	Path a	Emergency medical Contact vs. non	0.02	2.49	1.17	5.3
	Path b	Black-Caribbean vs. Other	<0.01	4.61	2.09	10.16
	Path c	Black-Caribbean vs. Other [AND]	<0.01	3.94	1.72	9.03
		Emergency medical Contact vs. Non	<0.01	3.63	1.61	8.19
Criminal justice Involvement (Yes v. No)						
	Path a	Criminal justice involvement vs. non	<0.01	5.882	2.592	13.35
	Path b	Black-Caribbean vs. Other	<0.01	4.606	2.087	10.164
	Path c	Black-Caribbean vs. Other [AND]	<0.01	5.342	2.197	12.992
		Criminal justice agency Involvement vs. non	<0.01	6.735	2.734	16.593
Living status *(Yes v. No)*						
	Path a	Living status vs. Alone	0.02	2.704	1.183	6.181
	Path b	Black-Caribbean vs. Other	<0.01	4.606	2.087	10.164
	Path c	Black-Caribbean vs. Other [AND]	<0.01	3.941	1.708	9.093
		Living status vs. Alone	0.03	0.602	0.242	1.501
"Individual attribution' in prodrome *(Yes v. No)*						
	Path a	"Individual attribution' in prodrome vs. non	0.03	3.267	1.137	9.385
	Path b	Black-Caribbean vs. Other	<0.01	4.606	2.087	10.164
	Path c	Black-Caribbean vs. Other [AND]	<0.01	4.535	2.05	10.034
		"Individual attribution' in prodrome vs. non	0.39	0.652	0.245	1.735
Short prodrome (Present v. Non present)						
	Path a	Short prodrome vs. Long prodrome	0.03	2.246	1.061	4.753
	Path b	Black-Caribbean vs. Other	<0.01	4.606	2.087	10.164
	Path c	Black-Caribbean vs. Other [AND]	<0.01	4.429	1.984	9.888
		Short prodrome vs. Long prodrome	0.07	0.479	0.216	1.062
Service Delay *(Short v. Long)*						
	Path a	Short Service Delay vs. Long Service Delay	0.05	2.128	1.006	4.5
	Path b	Black-Caribbean vs. Other	<0.01	4.606	2.087	10.164
	Path c	Black-Caribbean vs. Other [AND]	<0.01	4.17	1.859	9.352
		Short Service Delay vs. Long Service Delay	0.24	0.618	0.277	1.378
Hallucination in prodrome (Present v. Non present)						
	Path a	Hallucination in prodrome vs. non	<0.01	3.073	1.26	7.495
	Path b	Black-Caribbean vs. Other [AND]	<0.01	4.606	2.087	10.164
	Path c	Black-Caribbean vs. Other [AND]	<0.01	4.795	2.108	10.904
		Hallucination in prodrome vs. non	0.015	3.272	1.263	8.475
Decline in Social Functioning during prodrome (Present v. Non present)						
	Path a	Social Decline in prodrome vs. long	0.04	2.587	1.055	6.344
	Path b	Black-Caribbean vs. Other	<0.01	4.606	2.087	10.164
	Path c	Black-Caribbean vs. Other [AND]	<0.01	4.701	2.089	10.577
		Social Decline in prodrome vs. long	0.04	2.69	1.035	6.993

Table 24: Logistic regression for moderator analyses of detention and ethnicity (yes vs. no).
See Figure 33 for details of paths

Mediator			P	OR	95% C.I	
Criminal justice Involvement (Yes v. No)						
	Path a	Black-Caribbean vs. Other	<0.01	4.606	2.087	10.164
	Path b	Criminal justice Involvement vs. Non	<0.01	5.882	2.592	13.35
	Path c	Criminal justice Involvement vs. Non [X] Black-Caribbean Ethnicity vs. Other	<0.01	6.787	2.059	22.373
Decline in Social Functioning during prodrome (Present v. Non present)						
	Path a	Black-Caribbean Ethnicity vs. Other	<0.01	4.606	2.087	10.164
	Path b	Decline in social function vs. Non	0.04	2.587	1.055	6.344
	Path c	Decline in social function vs. Non [X] Black-Caribbean Ethnicity vs. Other	<0.01	2.458	1.429	4.229
Hallucination in prodrome (Present v. Non present)						
	Path a	Black-Caribbean Ethnicity vs. Other	<0.01	4.606	2.087	10.164
	Path b	Hallucination vs. Non	0.01	3.073	1.26	7.495
	Path c	Hallucination vs. Non [X] Black-Caribbean Ethnicity vs. Other	<0.01	2.896	1.665	5.037

Figure 35: Variables Shown to Mediate Black-Caribbean's Relationship with Detention
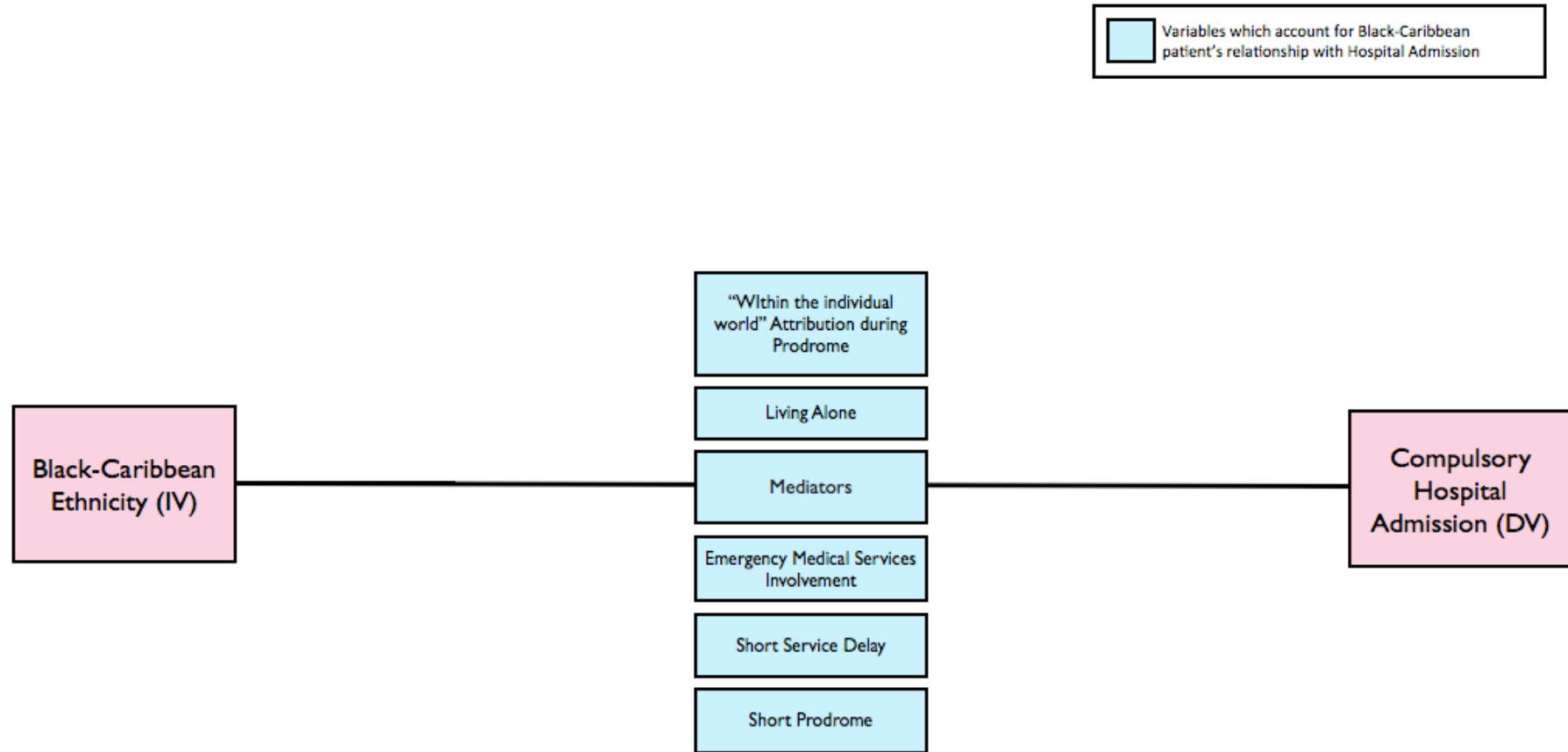
Figure 36: Variables Shown to Moderate Black-Caribbean's Relationship with Detention
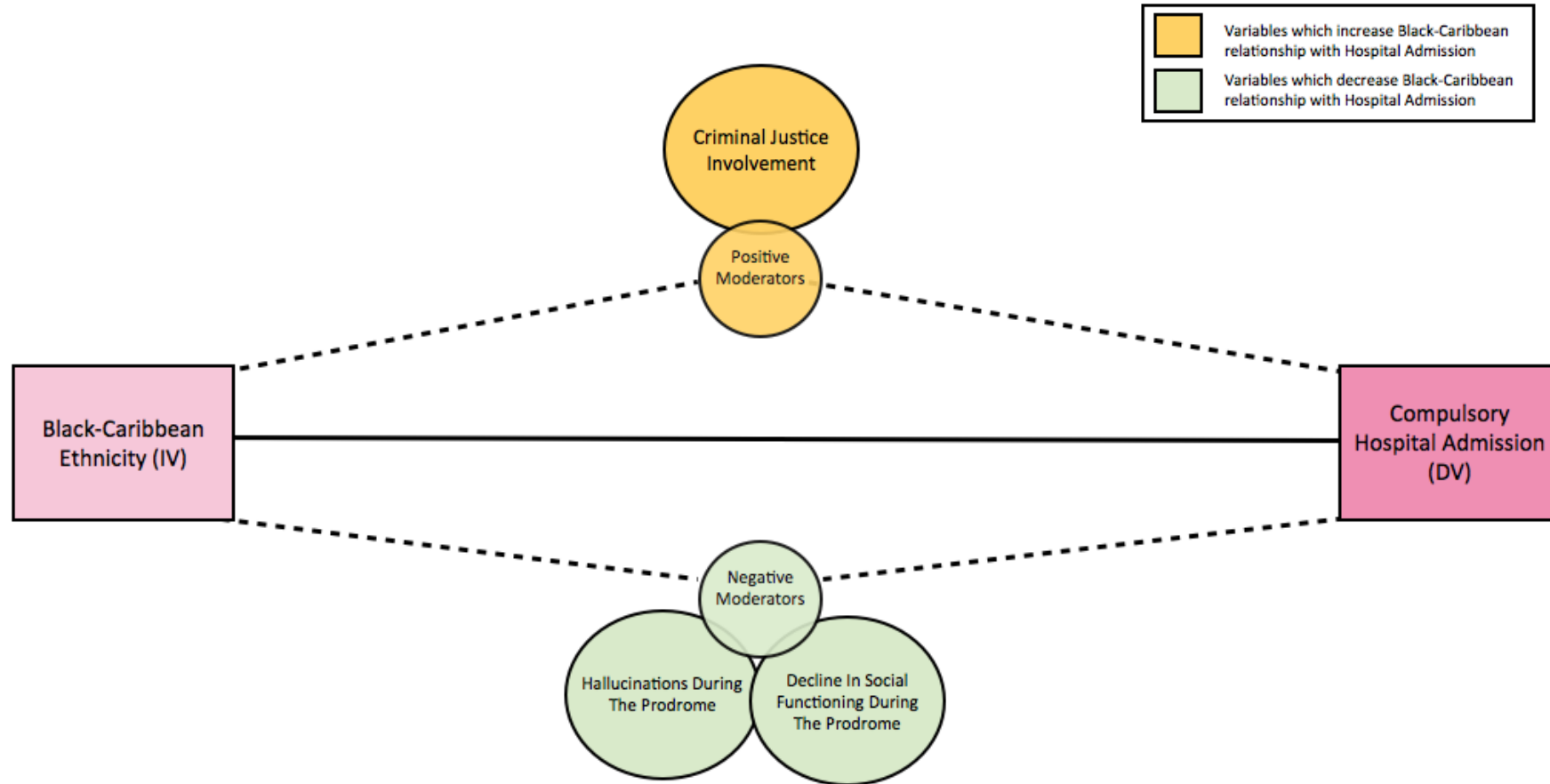
Adjusted odds analyses (Multivariate analyses)

Using the inferences from the previous three stages, a final logic regression model was developed using the forced entry method on SPSS (IBM, 2012). In addition to ethnicity, not having 'within the individual world attribution' during the Prodrome; living alone; emergency medical service involvement; short service delay; and short Prodrome length were included in the model as they were shown to mediate ethnicity's relationship with detention. Likewise, not reporting hallucinations during the Prodrome; and not experiencing social decline during the prodrome were included, as these negatively moderated ethnicity's relationship with detention.

The results of the model showed that the relationship between ethnicity and detention diminished (p=0.052), only slightly exceeding the p=>0.05 significant probability value. In addition, the model also showed a reduction in the odds of detention for Black-Caribbean patients, by almost half of its unadjusted level. It was therefore apparent that the other significant variables in the model were important in explaining excessive rates of detention for Black-Caribbean patients.

Table 25: Final Logistic regression analyses of predictor of the detention (yes vs. no)

	B	S.E.	Wald	df	p	OR	95% C.I. Lower	Upper
Black-Caribbean v. Other	*.962*	*.497*	*3.752*	*1*	*.053*	*2.618*	*.989*	*6.932*
Emergency Medical Contact v. Non	1.539	.469	10.756	1	.001	4.659	1.857	11.688
Short prodrome v Long.	.921	.471	3.835	1	.050	2.513	.999	6.319
Living Alone v. With others	1.017	.555	3.354	1	.067	2.765	.931	8.211
Decline in social function vs. Non	-.614	.550	1.246	1	.264	.541	.184	1.591
Short Service delay v. Long	.295	.477	.383	1	.536	1.343	.528	3.419
Short prodrome v Long.	.788	.644	1.497	1	.221	2.200	.622	7.777
Hallucination vs. Non	-1.183	.579	4.175	1	.041	.306	.099	.953

Decision Tree Analyses

Firstly, a tree was built using the ID3 algorithm on the 18 significant variables shown in the previous stages of analyses (Chapter Four and Five) to be associated with either ethnicity or detention, age and gender were also included due to previous research suggesting their explanatory importance. The results of the analysis showed the ID3 tree held a 63.93% accuracy rate in predicting the outcome detention using a selection of these variables. In an attempt to improve the accuracy of prediction, the j48 model was used, an alternative algorithm to decision tree creation. This tree structure showed improved accuracy rate of 70.49% using the variables; criminal justice agency involvement, Ethnicity, prodrome length, GP contact during prodrome, Service delay, deprivation level (IMD), Folk sector contact, emergency medical Involvement contact and not 'attributing symptom' during psychosis (Figure 37). Put slightly differently the change in decision tree algorithm from ID3 to j48, improved the amount of the outcome variable (compulsory hospital admission) that could be explained by the entered data.

Figure 37: J48 Decision Tree of Compulsory Hospital Admission
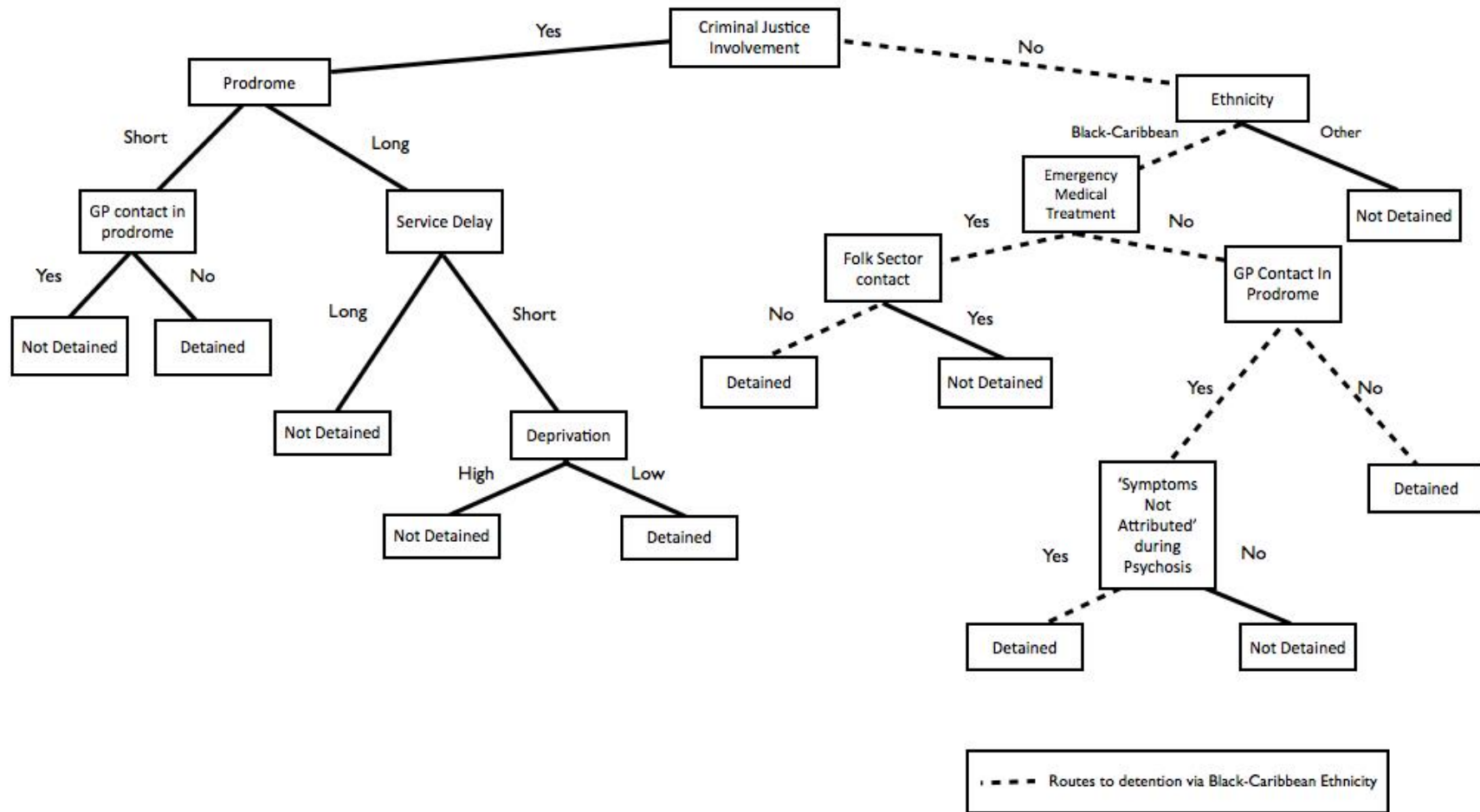
Decision Tree Analyses Results (figure 37)

The results of the decision tree demonstrated the complexity in routes to detention using the 8 variables. Five of these variables were used to predict detention, and six variables were used to predict non-detention. The model chose Criminal justice involvement as a root note, suggesting that this variable had the greatest role in predicting whether a patient was detained or not.

For those patients without criminal justice involvement, Ethnicity became the second variable of importance, predicting that those of 'non Black-Caribbean' ethnicity would not be detained. For those patients of Black-Caribbean ethnicity, prediction to detention became more complex, involving several routes. The first involved emergency medical contact, predicting Black-patients with emergency medical treatment but without folk sector involvement would be detained. The second and third involved not having GP contact during the prodrome and 'not attributing symptoms' during the prodrome.

Conversely, for those patients who did have criminal justice system involvement in their pathway to care, the tree generates an entirely different route to detention. Surprisingly ethnicity did not feature in this arm of the tree, which confirmed the result found in the moderator analysis that ethnicities association with detention could not be exclusively explained by criminal justice involvement.

Chapter Six:

Qualitative Results; Carers' Account of the Processes Leading To Compulsory Hospital Admission, With Specific Focus on Black-Caribbean Ethnicity

Introduction

Research exploring ethnic variation in compulsory hospital admission during FEP has mainly been conducted using quantitative-epidemiological approaches. Qualitative research can provide useful insights into the process of mental health service usage, but no studies have used it to understand the excessive rates of detention for Black-Caribbean patients, specific to FEP. As described in the literature review (Chapter Two), three studies conducted in England and Wales have used qualitative methodology to examine the pathway to care during FEP, and revealed many barriers to the access of psychiatric care, the role of symptom attribution and experiences of services (Tanskanen et al., 2011, Etheridge et al., 2004, Johnson and Weich, 2010). Furthermore, these studies demonstrated the usefulness in exploring the perspective of those individuals within the patients' social network, such as family members and carers, as this group often have enhanced insight into how psychiatric treatment was finally obtained.

Chapter Objectives

1. To explore carers' experiences of the processes that lead to compulsory hospital admission

2. To examine similarities and differences in the experience of detention between carers from different ethnic groups.

Recruitment and Sample Characteristics

In total, 23 compulsory hospitalised FEP patients consented to have a carer or family member included in the study – which equated to roughly 50% of all detained patients recruited in the quantitative sample. Before the interviews, carers were asked to confirm that they had good knowledge of the processes leading to detention, and had adequate understanding into how the patients' illness had developed. They were also asked if they would be willing to talk at length about these two themes, as it was thought that discussing these could be distressing. Two carers declined participation due to prior work and life commitments, and a further two were unable to be contacted via the details provided by the patient. In addition, two other carers were excluded due to lack of English language proficiency.

In total 17 interviews were conducted, of which 8 were carers of Black-Caribbean patients, 7 to White-British patients and 2 to Asian-Pakistani patients. For the purpose of analysis, these groups were further categorized into Black-Caribbean and Non Black-Caribbean groups. In terms of the characteristics of the carers, 58.8% were mothers of the patient, 17.6% fathers, 11.8% brothers and the remainder from other groups (Table 26). The mean age of the group was 45 years old (S.D = 10.87yrs).

Table 26: Participant Numbers And Characteristics Of Carers Recruited Into The Study.

Comparative Groups	Transcript ID	Patients' Ethnicity	Carer's Ethnicity	Carers' Age	Carer	Patient
Black-Caribbean	CARER 01	Black - Caribbean	Black - Caribbean	51	Father	Son
	CARER 02	Black - Caribbean	Black - Caribbean	53	Mother	Son
	CARER 03	Black - Caribbean	Black - Caribbean	29	Sister	Sister
	CARER 04	Black - Caribbean	Black - Caribbean	44	Mother	Daughter
	CARER 05	Black - Caribbean	Black - Caribbean	47	Mother	Son
	CARER 06	Black - Caribbean	Black - Caribbean	53	Mother	Son
	CARER 07	Black - Caribbean	Black - Caribbean	49	Mother	Daughter
	CARER 08	Black - Caribbean	Black - Caribbean	42	Mother	Daughter
Non-Black-Caribbean	CARER 09	White British	White British	62	Father	Son
	CARER 10	White British	White British	54	Father	Son
	CARER 11	White British	Black - Caribbean	27	Husband	Wife
	CARER 12	White British	White British	51	Mother	Son
	CARER 13	White British	White British	54	Mother	Son
	CARER 14	White British	White British	51	Mother	Son
	CARER 15	White British	White British	42	Mother	Son
	CARER 16	Asian-Pakistani	Asian-Pakistani	30	Brother	Son
	CARER 17	Asian-Pakistani	Asian-Pakistani	26	Brother	Son

Results

Emergent Themes

The results of the analysis revealed that the processes leading to compulsory hospital admission during FEP were complex, and involved a multitude of different factors on a range of levels. In total, the following five superordinate themes emerged, including: The appraisal of the early signs of psychosis; Psychosis as a crisis event; A variety of help seeking behaviours; The role of statutory services; and Other.

Theme 1: The Appraisal of Early Signs of Psychosis

A recurrent theme throughout the transcripts was the significance of the early signs of psychosis and its function in the process of help seeking. It was clear that carers emphasised the importance of the early signs of psychosis, as it was thought to be a key step in help seeking. In most cases however, these early signs were commonly missed, misconstrued or misunderstood by carers, which prevented early help seeking

behaviours. This was particularly true in the help seeking attempts through less adverse clinical encounters (i.e. general practitioner, community mental health team). In total, the following four sub-themes contributed to the category, 1) misattribution, uncertainty and confusion 2) Not noticing the early signs of psychosis 3) Barriers to appraising the early signs and 4) appraising the early signs as not significant.

Misattribution, Uncertainty and Confusion.

In total there were 20 references across 9 different interviews where carers' reported misattributing or being uncertain about the early signs of psychosis. Although carers often noticed a change in the patient, they failed to accurately label or attribute it. There were a number of reasons for this, which ranged from confusing symptoms with fluctuations in the patients' emotions, to misattributing symptoms to heightened states of spirituality, drug usage and teenage rebellion:

> *"I did think it was because of the cannabis, but like, because of the behaviour thing, I was thinking to myself, was it something that was already there and the cannabis has just made it/covered it up. You know and it was just waiting to come out. I did really think it was the cannabis at that time, you know. It was just his behaviour, you know, he was just doing things, over repeating, repetitive things and that, over and over.*

> (Carer 14)

There was little ethnic variation in the misattribution, labelling or attribution of symptoms, as four of the eight Black-Caribbean transcripts displayed this theme in comparison to five of the nine non Black-Caribbean cases.

Failing To Notice the Early Signs of Psychosis.

The second most common subtheme in this category was the idea that carers often failed to notice any early signs. Right up until the time when frank psychotic symptoms emerged, carers and their families perceived the patient as being 'normal' and hence had no reason to seek help:

> *"I didn't see a sign or nothing for how long. The only thing she used to say to me was 'I need to leave that school, I want you to change the school,' and I'm saying 'Why do you want to change the school?' But she didn't say anything. Every September and every holiday of the September she'd say 'I need to change my school.'*

(Carer 08)

An indirect reference to this suggested that in some cases frank psychotic symptoms appeared out of nowhere, commonly described as 'coming out of the blue' with no prior warning or indication. This theme occurred in seven transcripts, of which four were Black-Caribbean and 3 were from the other group.

Barriers to Appraisal

From the carers' perceptive there were many barriers to the appraisal of early signs of psychosis. Firstly, carers reported that the patient often expressed psychological distress during the early stages of the illness, in terms of life difficulties, such as personal relationship problems, troubles at work or school and lack of vocational attainment. As a result, it was difficult for carers to pick up on psychological ill-health of the patient and hence did not seek help:

"No, no, nothing. The only thing he said to me is, he did not have a job, and he always use to say he would like to have a job, and things like that and so I didn't really notice things (referring to symptoms) like that, to the extent that I would say, he was going off his head. When I really noticed something, that I knew there was a problem was when he was sectioned and they released him. It was from then"

<div align="right">(Carer 01)</div>

The quote from the previous subtheme also illustrates this notion. It was clear that this theme was most dominant amongst the Black-Caribbean sample, as it was found in 5 cases in comparison to only 1 of the non Black-Caribbean group.

Carers also thought that their loved ones often concealed their symptoms, which prevented their appraisal of early signs. In 5 transcripts, carers reported that patients would often deliberately hide or be reluctant to talk about their mental health (stress, anxiety, mood and low level psychotic symptoms), which prevented the carers from truly assessing what was going on. One mother recalled her difficulty in trying to get her son to talk about her problems:

"He was just quiet. He was just within himself. You couldn't get much... '[Name] how are things?' or 'How are you?' You know, 'I'm alright' but that's it. You'd see the depression, but he wouldn't say. He wouldn't let us know or give us any inkling what might have been going on.

<div align="right">(Carer 02)</div>

There was less variation between the two ethnic groups in this subtheme, occurring in 2 Black Caribbean transcripts and 3 from the other group.

Appraising Early Signs as Non-Significant

Another factor that prevented action to early help seeking was the belief that early signs of psychosis were 'not important' or 'temporary'. There were many reasons for this, including viewing symptoms as transitory, fleeting or related to the changes of adolescence:

> *" Carer: So yea, at the end of 2007 was when we first really noticed.*
>
> *Interviewer: Ok, so the end of 2007, and so what were you thinking at the time?*
>
> *Carer: When he started speaking to himself, we thought it was temporary. He didn't use to/ it was nothing major, he just to laugh a bit, that was it"*
>
> (Carer 17)

One carer stated that the family were waiting to see what would happen before seeking help, hoping the symptoms would just go away in time (Carer 16). Another carer suggested that although they acknowledge the early signs of psychosis, they felt that it did not require any external attention, as she thought the symptoms would just pass:

> *"Well I suppose I used to think to myself that one day, he's gonna wake up and get himself together, and get himself a job and he's gonna be ok, but it never happened, you just hoped that he would…"*
>
> (Carer 14)

Another reason for not viewing symptoms as significant was the fact they were often in constant fluctuation, from being really intense at one point in time to non-existent at another:

"More or less, it was just an up or down kind of a thing. It wasn't like a constant, like feeling depressed, it was not like that"

(Carer 04)

Finally one Black-Caribbean carer admitted to underestimating the seriousness of depression, as he did not realise that depression could lead to 'real' mental health problems:

"I use to think that depression was something that you were like fed up, and you aint got no energy to do anything and blah blah blah, and things aren't going your way. And I thought that was depression, but there is more to depression than that, but depression is something that you can't control, when it's something that's taking you over, and you feel…(Exaggerated exhale)"

(Carer 01)

Theme 2: Psychosis as a Crisis Event

Closely linked to the importance of appraisal of the early symptoms, is the ways in which frank psychotic symptoms emerge. It was evident from the majority of the transcripts that psychosis presented itself in the form of a *crisis event,* with a sudden change in the psychopathology of the patients, resulting in bewilderment and distress within the family. In most cases this crisis event triggered help seeking and was the start of the

process which lead to compulsory hospital admission. There were 14 references of this theme across 10 interviews.

From the carers' perspective, there were several forms to the emergence of psychosis as a 'crisis'. The first was described as threatening displays of psychological disturbance, most commonly expressed through attempts and acts of irrational verbal and non-verbal aggression:

> *"Worse, yea, he became very violent, when I would not give him money, cigarettes. He was ok, if i was giving him what he wanted, and I must admit, I did give him to make him go away. I know it's stupid. You know I realise now, because I have other children to look after and it was just one of them. Here you are, have 10 fags and leave me alone. Just get off my case, so to speak".*
>
> (Carer 15)

The second involved other random behaviours, such as overly religious actions (e.g. elaborate praying), unusual repetitive and dramatic gesturing, loud crying, discussing and rapid articulation of delusional beliefs, pacing, drastic neglect in personal hygiene and appearance and disturbances to sleep patterns.

> *"But when he came home he was... I think he'd probably been awake all night and he was still...you know, talking nonstop and again, still with these bizarre ideas and it just carried on like that and we were just...we were monitoring him. I forget at which... To me as well, it's a blur that weekend because it's a blur of*

not having any sleep whatsoever and ending up calling 999 and events just kind

of got totally out of hand because [patient's name] got worse....."

The term 'having a breakdown' was frequently used to describe this type of behaviour throughout transcripts.

"*...Yes. I knew then and I'd said to the paramedics that...you know, 'He needs a*

psychiatrist.' You know, he was having a breakdown. I thought it was a

breakdown of some sort, the same as what I'd had, but to my horror they

couldn't do anything. The doctor wouldn't come out. I was told we'd have to

wait to speak to the GP."

In general, there was a clear ethnic trend in this theme, with seven of the eight Black-Caribbean patients reporting this theme in comparison to four from the other ethnic groups.

For the family, the event of the crisis was extremely distressing and alarming and resulted in a variety of related behaviours and help seeking strategies – a point that will be discussed further in the next theme. There was a clear ethnic trend in this, with seven of the eight Black-Caribbean patients reporting this theme in comparison to four from the other ethnic groups.

Theme 3: A Variety of Help Seeking Behaviours

In most instances carers and families attempted to actively address the psychotic symptoms displayed. Typically, carers' help seeking behaviours took the form of help seeking from external sources. However, this process was very diverse and influenced by a number of factors. In total there were three sub-themes across this category, including 1) Help seeking from external sources, 2) Barriers To Help Seeking From External Sources, and 3) Dealing With Psychosis Within The Family Unit

Help Seeking From External Sources

By far the most common help seeking behaviours displayed by the carer and the family network were seeking help from external sources. There were 13 references to this across 9 transcripts, suggesting that families were essential in the help seeking process. Active help seeking from external sources occurred in many forms, including carers' suggesting that the patient should go to their GP (Carer 07) and actively making contact with medical (Carers 04, 07, 05) and non-medical services (carer 15):

> *"Before [Patient's daughter's name] birth, before any of the babies, I went to take her to the doctors' and I said to the doctor, 'I need her to get some kind of check because she's not behaving normally,' because of course yes, I know teenagers don't listen to you all the time and they don't want to do their duties all the time but this was something more"*
>
> (Carer 17)

Active help seeking from the wider social/family network was also common (Carers, 05, 04, 07, 02 and 14), as carers often sought advice from friends, colleagues and the extended family network;

> *'It was my mum's sister. My mum contacted her sister. Well, we were out and we were like visiting her sister and she was asking for any good doctors that she knows and she recommended her own GP and so mum referred [Name] through my auntie's GP'*　　　　　　　　　　　　　　　　　　　　　(Carers 14)

There was however, one example where the wider family inhibited medical help seeking, as one carers' family stated that her daughter was craving attention and not really ill. There was slight ethnic variation in these forms of behaviours, with six of the eight Black-Caribbean patients' carers reporting this in comparison to two of the nine from the other group. Another prominent form of external help seeking that occurred was from that of police. There were six references across 4 transcripts, which suggested that family members active sought help from the police. This was usually during a crisis period or where symptoms lead to risky behaviours during routine home life:

> *'Yea, he walked off, but [patient's brother] did not know where he had gone. So, I was going to go down to [specific named] police station and you could tell he was bloodied after [Patient's Brother] had hit him like, sort of a thing. And the next thing I got at 2pm in the afternoon was a telephone call from [specific named] hospital, to tell me he was in there sort of a thing. 2pm on a Saturday. So then I shot up there sort of a thing"*

(Carer 10)

In most cases police services accompanied paramedic services when the family requested a medical emergency through calling 999. This form of help seeking was least common among Black-Caribbean carers.

Spirituality was another theme that influenced help seeking from external sources. There were ten references of this across five transcripts; however there was little ethnic variation in this between the two groups. During the help seeking process some carers suggested that drawing on religion aided in the help seeking process from external source. Praying to god, drawing on religious organisational structures and seeking religious counsel were often cited as great help seeking supports (Carers 03, 05, 16);

> *"The church at the time, after the incident, they were praying, obviously they prayed for us, they prayed for me and all the family and everything. But I did not seek the church, because they knew about it. But me personally, I do pray, and that's what kept me, I was able to pray and deal with him in prayer and I was able to take what I was going through in prayer, and I was able to ask the holy spirit to direct me as for the right place to get the right help for him"*
>
> (Carer 05)

Carers also discussed direct help seeking from faith based agencies, such as religious leaders, cultural healers and prayer groups (Carer 16, 17, 03). There was also one instance where a cultural healer, suggested that the family seek help from medical services (carer 17), as demon possession was only one possibility of what could be going on:

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"Carer: Yea, he, started, started talking to himself in 2008 like. It was becoming

daily. Something about the food "this food aint right", something's in the food.

The one day I heard him say to himself "leave me alone", see we thought there

was something wrong with him. And so, we took him our religious scholar like.

Interviewer: Was he an Imam?

Carer: Yes, he was an Imam. We took him there and said this is what was wrong

with him like. And he was like, there's nothing wrong with him like. There is no

demon or anything like that. And he goes 'you need to take him to the doctors'

like"

(Carer 17)

Barriers to Help Seeking from External Sources

The analysis revealed a number of barriers to seeking help from external sources, which appeared in 5 of the 16 transcripts. The first barrier was a lack of knowledge of where to go for help. Carers often described how they were unknowledgeable about types of services that could alleviate mental health conditions and so struggled in the help seeking process:

"I diagnosed it a long time ago. I did, but you know when you're not just sure of who to

talk to and who to ask, or where to go and stuff".

(Carer 02)

However, In contrast there was one example where a carer had explicit knowledge of mental health services due to her previous employment in the NHS (carer 05).

Another factor that impeded help seeking from external sources was the negative impact of carers own emotions. In many cases carers discussed how dealing with the symptoms of psychosis was a highly distressing experience. As a result, they experienced a level of emotional burden associated with trying to seek help from external agencies. Stress, depression, anxiety and relationship breakdowns were frequently mentioned as consequences of the illness and many carers felt fatigued by attempting to seek help for the patients, especially where there were a number of previous failed attempts:

"Interviewer: Did you ever go to anyone else for help, like family members that could have helped you out, any religious leaders or…?

Carer: No, no, because as I said, I was in stress as well, you know, my mind was all over the place, I was trying to hold it together, for him, but at the same time I had to try and hold it together for me as well, because I know, I ain't gonna go ask help from someone, if I know I ain't definitely gonna get help from them, because I was thinking that my family, there was nothing that they could have done, to help, and I did not want to go full up their heads with his problems, which would only stress me out more, and I couldn't take that.."

(Carer 02)

There were three examples of this, two from Black-Caribbean carers and one from a White-British carer (Carer 01, 02, 13). This theme exclusively applied in those cases where the history of the illness was long and persistent.

Dealing With Psychosis within the Family Unit

The final set of help seeking behaviours that emerged from the transcripts were the family's attempt to deal with the problems internally, within the family unit. There were three accounts where carers reported that they had tried to address psychotic behaviours within the household. This often involved trying to demystify delusional beliefs through reasonable logic, calming the patient down at times of heighten emotional stress, offering advice and counsel, bribing patients with gifts to subdue psychotic behaviour and taking them away on holiday to relax. The following example is of a sister's account of trying to demystify some of the persecutory ideas her sister had during the early stages of the illness about a college tutor:

"You know, I was just trying to make her understand basically from the tutor's point of view, so it was just things like that. So where she'll have certain points of view and be upset with someone, I'd say 'Well look at it from their point of view,' so that same thing, I would say that I was trying to help her".

(Carer 03)

There appeared to be some ethnic differences in dealing with psychological problems within the family unit, with 50% of Black-Caribbean carers describing this compared to 10% of other carers.

Theme 4: The Role of Services

Another recurrent theme that emerged from the carers' discourses, which influenced the pathway to compulsory hospital admission, was the role of services. It was clear that in most cases compulsory hospitalisation did not occur in isolation but was preceded by

the interaction with other statutory services. This overarching theme divided into two subthemes 1) The function of statutory services, and 2) Difficulties with statutory services.

The Function of Statutory Services

As mentioned earlier in the help seeking behaviours theme, primary care, emergency medical and police services were highlight as involved in the help seeking process of this group. Although some of their involvement occurred during the early stages of psychosis, most happened after the onset of a crisis, when symptoms became visible and disturbing. GP services were frequently mentioned in the referral pathway, however visits to an Accident and Emergency department most often lead directly to hospitalisation;

"So I had planned to go to the GP, but it wasn't open, so I took him to Solihull hospital on the morning. I said to [other son] I would take him up to the hospital; he needs help sort of a thing. The A&E on the Saturday morning - Solihull A&E"

(Carer 10)

Police involvement was also reported as being critical in the compulsory detention and was often facilitated by actions of the general public. There were however, instances where the police approached the patient, as one father stated his son was directly approached and put in a cell for the night after exhibiting strange behaviour on a night out with friends (Carer 09).

In total, there were 11 examples of this sub theme, across 8 different interviews. There was some ethnic variation in this, with the role of services more frequently mentioned in the Non Black-Caribbean sample (6 out of 9 transcripts).

Difficulties with Statutory Services

Another dominant theme that emerged from the transcripts was the various difficulties that carers and patients had with services. There were many examples where carers felt that the General practitioner was unhelpful, not understanding or 'incompetent' at assessing psychological symptoms (Carer 05, 09, 15). One carer suggested that a miss-communication in the referral process between their GP and the local community mental health service, delayed psychiatric intervention by six months, even after making repeated visits to chase up the delay (Carer 16):

> "I mentioned it like, I mentioned it, and then I mentioned it again to [Dr's Name] when I went to speak to him, and he gave me a number to a drug line, so then we left and we thought 'oh GOD'. And then like umm, we went over and saw the Doctor again and he did actually refer [Patient's Name] to [community mental health team], but then [community mental health team] said I had to get [Patient's Name] to agree for them to come over and speak to him, and this was last summer, when he had got off the cannabis and his behaviour had got a bit mad again. And ummm, because [Patient's Name] would not agree, saying that there was nothing wrong with him, and it was me that was mad. They would not come out. They said [Patient's name] would have to agree to it, so it got left again so it got left for another couple of months. I had already started talking to a counsellor, and she was sort of telling me that, you got to be careful the way

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you said to him and watch what you say to him. So you were still hitting brick

walls all the time"

This was also echoed in another interview (Carer 01).

'Timing' was also found to be another difficulty that carers had with statutory services. 'Waiting around' for other professionals to assess the patient was commonly mentioned, as one carer recalled his son walking off after waiting several hours for a psychiatric assessment, while another carer recalled that her son became increasing aggravated in a similar event (Carers 10). From the carers' perspective, these complications either prevented less coercive routes to care occurring or increased the likelihood of detention. The referral processes was often thought as being slow in particular cases when the patient was in crisis:

"Well, to my mind if it could have all have been speeded up. Like, because all of

this kicked off over a weekend, there is no real help seemingly available and then

the process is slow and to my mind, because I've got experience of psychosis, I

was pretty damned sure what was happening but a GP can't really do anything.

They've got to go to the next level and get a psychiatrist and I thought... He said

'Hopefully he'll come today' and I'm like 'Well, he needs to come.' You know, we

definitely needed somebody quickly and it was a short space of time really, but

for things to kick off when somebody is out of control in their mind, an hour is

too long. Do you see what I mean?"

In contrast, carers also suggested that complications within services were not only the fault of professions but related to the patients themselves. There were two cases where carers reported that patients actively avoided follow up assessments (Carer 10, 14), while another carer stated that their patient concealed the full extent of their problems during the assessment, 'pretending that he was perfectly fine'. A good example of this was from the account of a mother who reported difficultly in accessing services due to her son's non-disclosure of symptoms.

Theme 5: Other Factors of Importance
Finally the results revealed several other factors that could not be categorised into any of the other four overarching themes.

Living in Isolation

In four different interviews, carers mentioned that the patients were often living in isolation and that this inhibited efficient help seeking. In these cases, living status was highly varied, with patients living in fragmented circumstances (between friend and family), in temporary accommodation (e.g. youth hostels), away from close immediate family (Partners) or alone (Carer 05, 01, 04, 07). Two carers indicated that their loved ones ended up lived in fragmented livings situations after a disagreement occurred between the patient and the family during the early stages of the illness. This theme was only found in the Black-Caribbean sample.

"Yes, he did not always live with us, he lived with his friend, and he would be there so obviously I did not see what was happening to him. You could not get along with him, he

was arguing and he would not do what you were saying, him and his dad would have

upsets and arguments, and that time he was difficult to be around"

<div align="right">(Carer 05)</div>

The Role of the General Public

Another emergent theme that occurred in three transcripts was the role of the general public in the process of help seeking. A random lady at a train station, strangers passing by and a colleague at work were all listed as being influential in facilitating the pathway to care. In one case a mother stated her ill son's work colleague took him to the GP during work hours, which initiated the sectioning process (Carers 01, 07, 10).

"Yes. I still don't know who that lady was, or if she was one of the staff there or

somebody. She said to her to go to the doctor; 'Go to your GP and see them and tell the

doctor about what's happening"

<div align="right">(Carer 07)</div>

Stigma and shame

From the transcripts there were only two references to the influence of stigma and shame (Carer 01, 17). It is worth noticing however, that in both these cases, carers were unaware of the early signs of psychosis and only began help seeking during a crisis.

"You see things more clear, and then you say to yourself there is no shame in

having mental illness, because when you think about it we all have some to some

kind of degree, it's just that it becomes a problem when you need to seek help, so

to speak"

<div align="right">(Carer 01)</div>

Chapter Seven:

Discussion of Results from Empirical Chapters

Discussion of Results from Chapter Four: Sample Characteristics and Ethnic Comparisons of the Pathway to Care During First Episode Psychosis (FEP)

FEP patients from Black-Caribbean backgrounds are significantly more likely to experience compulsory hospital admission in the pathway to care. Despite the consistency of these findings over the last 20 years, existing research can only partially account for these differing rates and hence more comprehensive understanding is required (Morgan et al., 2005a, Harrison et al., 1989). The purposes of this empirical chapter were two fold; 1) to identify ethnic differences in the rates of compulsory hospital admission during FEP and 2) to identify ethnic differences in the factors and influential processes important during the pathway to care. It was thought that this initial wave of analysis would highlight areas of divergence between the groups that could later be used to explain ethnic differences in detention rates.

In total, 122 consecutive FEP cases were recruited over the two-year period, spilt between three ethnic groups; meeting the sample size calculation estimated. The sample was diverse in terms of social and demographic related variables, such as living status, religious affiliation and migrant generation. It was clear that Asian-Pakistani sample were highly religious, and that Black-Caribbean patients were more likely to live in isolation- however, few other differences were observed (e.g. educational attainment

and employment status). The elevated proportion of Black-Caribbean patients living in isolation was an interesting and note worthy finding. In terms of deprivation rates, the IMD levels were high overall, suggesting that this sample was severely deprived. This was especially true for both the Black-Caribbean and Asian-Pakistani sample in contrast to the White-British sample. In comparison to the broader intake of all FEP patients over the study period, the thesis sample was roughly comparable, however, the Black-Caribbean sample was slightly older and the White-British sample had fewer females.

Ethnic Differences in Pathway to Care Encounters

The results of this study confirmed the assumptions derived from the systematic review chapter. In particular, Black-Caribbean patients were almost 5 times and 4 times more likely to experience compulsory hospital admission in their pathway to care than White-British patients and Asian-Pakistani patients respectively. The study also demonstrated that Black-Caribbean patients were significantly less likely to have GP Involvement in their pathway to care in comparison to the Asian-Pakistani sample. In addition, Black-Caribbean patients were almost four times more likely to have emergency medical contact in their pathways to care in comparison to Asian-Pakistani patients, however, no difference was found between Black-Caribbean and White-British patients. Conversely, no difference was found between the three groups in relation to criminal justice agency involvement. Finally, the study demonstrated that Asian-Pakistani patients were 28 times more likely and Black-Caribbean patients 7 times more likely to have Folk Sector encounter in their pathway in comparison to White-British patients.

It is clear that there are many ethnic differences in the encounters made during the pathway to care, above and beyond that of compulsory hospital admission. Non the

less, the results surrounding ethnic differences in compulsory hospital admission is alarming, and exceeds both the excessive rates found for Black-Caribbean patients in the meta-analysis conducted in Chapter Two and the broader psychiatric literature in the review by Singh et al. (2007). It is therefore established that even when psychosis is controlled for, Black-Caribbean patients are significantly overrepresented in their rates of compulsory hospital admission, which supports the primary assumption of this thesis.

Ethnic variation in General Practitioner and emergency medical involvement has also been supported in this sample as shown in other work (Ghali et al., 2012, Morgan et al., 2005a). It was clear that Black-Caribbean patients were significantly less likely to encounter GP involvement and more likely to experience emergency medical involvement in their routes to psychiatric treatment for FEP. The adapted Goldberg and Huxley (1980) model highlights the importance of primary care services in being a pivotal step in the route to psychiatric treatment with the NHS. However, this work suggests that there is a shortage of these routes for Black-Caribbean patients in replace of Emergency Medical Services. Initial thoughts indicate that this dichotomy in service use is problematic, especially as primary care services are a 'gateway' in specialised mental health services. For this reason, these findings are very important and should be explored in detail when attempting to understand excessive rates of detention for Black-Caribbean patients.

The result surrounding criminal justice agency referral is however surprising, and diverges from existing paradigms about the involvement of the police and other criminal agencies in the routes that Black-Caribbean patients take to care (Morgan et al., 2004). Morgan et al. (2005a) reported a 33% rate of criminal justice agency involvement in

their Black-Caribbean sample, in comparison to 12% in the White-British sample. Similarly Ghali et al. (2012) reported a 33% in Black-Caribbean patients and 23% rate in the White-British – both studies were FEP cohorts. In this study, a slightly higher rate of 38% was found in the Black-Caribbean sample and 30% in the White British; however this difference between these groups was not significant.

There are several reasons for the altered rate of criminal justice agency involvement found in this study. In other research, medical notes are the primary method of capturing information about how patients come to care. However, in the study, the augmented encounter form and associated semi-structured interview required patients to give comprehensive list of all encounters along the pathway to care, which could have resulted in more accurate levels of criminal justice involvement reporting. Anecdotally, there were instances where patients recalled having police involvement quite early on in their pathways. These were often omitted from official medical records later created. The other explanation could be due to ethnic differences in historical changes in local service utilization. The last published piece of FEP research exploring ethnic differences in criminal justice involvement in Birmingham is more than 20 years old (Birchwood et al., 1992) . Regional patterns of FEP service usage may have varied since this time, which in turn could result in the modified criminal justice service involvement observed. The findings presented in this study should therefore be taken in light of both the influences, and should not prevent criminal justice agency involvement being included from the higher level analysis conducted later.

With regards to the Asian-Pakistani samples, it is clear that the notion of adverse routes to care is less problematic for this population. The results demonstrated that there was

little difference in rates of each of the four key pathways to care outcomes (compulsory hospital admission, Criminal justice, GP and emergency medical involvement). However, a pattern did emerge suggesting that Asian-Pakistani sample were the least likely to have emergency medical contact in their pathway to care than the other groups. These findings are novel, as the systematic review conducted in Chapter Two found no study that had explored ethnic differences in the pathways to care amongst the Asian-Pakistani patients specifically. In the broader psychiatric literature however, Singh et al. (2007) reported that South-Asian patients were roughly twice as likely to experience compulsory hospital admission as White-British patients. This finding differs from the results found in this study, which may due to cultural (i.e. focusing on all south Asian groups) or clinical variation (all psychiatric disorders not just First Episode Psychosis) in the groups under observation. Non-the less, what is important about the finding in the context of this work, is that ethnic minority status does not necessarily equate to adverse and coercive routes to care. Instead it is likely that each ethnic group has its own unique patterns of service utilisation, more closely tied to cultural factors rather than being from a non-White British subculture.

Folk sector involvement was the only encounter type found to vary significantly between the three groups; which was shown to be more common amongst Asian-Pakistani and Black-Caribbean patients than White-British. The notion of faith based help-seeking with the FEP population is not a novel finding and has received some investigation within the international literature (Srinivasan and Thara, 2001). Nationally, the Cole et al. (1995) study reported that 18% of their sample sought help from alternative sources, such as religious, vocational and youth services, while Johnstone et al. (1986) reported that 13% sought help from religious organisations. What remains

unique about the work of this thesis is the ability to make valid comparisons of faith based help seeking between different ethnic groups within a specific service context. It is therefore likely that in comparison to White-British patients, ethnic minority groups in Britain have a great propensity to seek help from religious and faith based organisations. Limited qualitative work has begun to unpick this phenomena, suggesting that alternative beliefs about the cause of symptoms promote help seeking from other agencies (Tanskanen et al., 2011). What remains now is to explore how differences in folk sector help-seeking, influence the routes to compulsory hospital admission for Black-Caribbean patients, if at all.

Ethnic differences in Clinical Factors

The chronological development of psychosis and the types of symptoms experienced are thought to be essential in influencing the routes that patients' take to care. However, existing research has found that ethnic differences in clinical factors only partially account for excessive rates of detention amongst Black-Caribbean and other ethnic minority groups (Morgan et al., 2005a). It was therefore apparent that exploring ethnic variation in other clinical factors may be useful in answering the research objectives set out, especially in areas yet to be researched.

Firstly, this study found limited differences in the chronological illness factors. There was no difference in either the Duration of Untreated Psychosis (DUP) or Duration of Untreated Illness (DUI), which suggests that the period of illness experienced is very similar between the three ethnic groups. The findings on DUP have been replicated by others (Morgan et al., 2006a, Ghali et al., 2012); confirming that these findings are indeed genuine and exist on a national level. Research on the DUI is less common within

the literature (Fisher et al., 2008), and to the best of the author's knowledge, no study has attempted to explore its association with ethnicity. In short, it would appear that as there was little variation between the ethnic groups in DUP and DUI, these factors would have a limited role in explaining ethnic variation in detention rates through a direct influence.

Conversely, this study did demonstrate that ethnic differences exist during the Prodrome; with Black-Caribbean and Asian-Pakistani patients shown to have significantly shorter prodrome lengths in comparison to White-British patients. Although the reasons for such differences are unclear, the presence of ethnic variation in the early stages of psychological disturbance does trigger an interest into its association with variation in detention rates. It has already been established in this thesis that Black-Caribbean patients have reduced GP contact and increased emergency medical involvement in the pathway to care. It would be interesting to see how these factors are theoretically linked to shorter periods of psychological dysfunction prior to psychosis, giving rise to excessive rates of detention for Black-Caribbean patients.

Secondly, this study found limited ethnic difference in the components of DUP. Between the three groups help seeking was comparable (help seeking delay variable), which suggested that all three groups came to medical contact within a similar time frame. However, caution must be made when interpreting this variable, as the semantic meaning of the term 'help seeking delay', implies the delay is voluntary. In truth the variable is a reflection of a delay in medical involvement from the onset of psychosis, and should be interpreted as such. Likewise, the study found no difference between the

groups in relation to treatment-delay, the time between mental health service involvement and the onset of anti-psychotic medication.

Conversely, the study did demonstrate shorter service delay amongst Black-Caribbean sample, suggesting that once medical contact was made they more quickly receive mental health intervention. In understanding disproportionate rates of detention this finding may be an important explanatory variable, especially as Black-Caribbean patients have diminished early medical help seeking. It is likely that shorter service delays would correlate with a lack of GP involvement, as those patients not seeking help from primary care are likely to have shorter journeys to psychiatric contact; due to the reduced time taken for interagency liaison, referrals and assessments. In the next chapter, further statistical analyses will need to conducted to explore this notion in detail, and also investigate how it may account for excessive rates of detention for Black-Caribbean patients.

Finally, the study explored ethnic difference in diagnosis and the types of symptoms that patients reported. This study found no evidence of ethnic differences on any of the symptoms experienced, diagnostic categories or mode of onset of psychosis. It is therefore unlikely that these factors are key mechanisms in understanding the primary research question of this thesis; however, in the call for objectivity, future research should still explore these variables in higher-level analysis.

Ethnic Differences in Symptom Attributions
Both Razali et al. (1996) and Broadbent et al. (2008) argue that individual belief systems are likely to influence the patients journey to care (Burns et al., 2011). Kleinman (1980) work on 'Explanatory Model of Illness' states that beliefs about a nature of cause and

severity of the problem, self-prognosis and treatment preferences can influence how a person utilizes the health care systems. Within the FEP pathway to care literature in Britain, research has begun to highlight that there are ethnic differences in attribution of symptoms (Harrison et al., 1989), however, there is a dearth of information about how these differences are associated with varying rates of detention. For this reason, this chapter aimed to see if there were ethnic differences between patients in symptom attribution, which may help explain ethnic differences in detention rates.

In this study, symptom attribution during the development of psychosis was a complex process, as patients simultaneously held multiple and contrasting beliefs about the aetiology of symptoms. During the prodrome, patients were most likely to attribute the symptoms in the social domain (i.e. difficulties with relationships, peoples and social experiences in their lives). This is in stark contrast to the psychotic phase of the illness (DUP) where patients reported 'not attributing' symptoms.

In relation to ethnicity, it was clear that there were greater similarities between the three ethnic groups than dissimilarities. During the prodrome, all three ethnic groups predominantly held 'social world' attributions, followed by 'not attributing' symptoms at all. During the DUP, Asian-Pakistani and Black-Caribbean patients were significantly more likely to hold 'Supernatural world' attributions in comparison to the White-British patients.

The existence of supernatural attributions for psychosis is not a novel finding. In an international FEP study conducted on the South-Asian subcontinent, Saravanan et al. (2007) found that 70% of patients held 'spiritual and mystical beliefs', while in another

study in East Timor, 73% held supernatural beliefs (Silove et al., 2008). In East London McCabe and Priebe (2004a) found that West African patients had the highest proportion of 'Supernatural world' beliefs (28.6%), followed by 26.9% in the Asian-Bangladeshi group, 10% in the Black-Caribbean and 0% in the White-British. The results of the thesis found high rates of supernatural beliefs in the Asian-Pakistani (39.06%), Black-Caribbean (18.37%) and White British sample (7.25%), which may reflect regional differences within England. It is clear that there is a real existence of alternative explanations for the cause of psychosis in ethnic minority groups in Britain which may help account for ethnic variability in the pathway to care. Ethnic variation in attribution has already been linked to help seeking from religious sources (Tanskanen et al., 2011); it would therefore make sense to explore if such variability in beliefs can also account for the disproportionate rates of detention within the Black-Caribbean community.

Ethnic variation in Help Seeking and Social Network involvement

In this study very few differences were found between the groups in the period when help was first sought. It was evident that the majority of patients began to seek help during the DUP, where help was primarily sought from the General Practitioner (47%) - a finding consistent with other FEP research (Johnstone et al., 1986, Etheridge et al., 2004, Bhugra et al., 2000). Additionally, all groups had a similar pattern in the persons initiating help seeking; which was shown to be predominantly conducted by the patients' social network and then by the patient themselves. Notwithstanding, there was slight ethnic variation in this help seeking initiation, as Black-Caribbean patients had more statutory-services initiated help and fewer social network. This finding was also mirrored in the research from the AESOP study (Morgan et al., 2005a), which suggested that this was the result of elevated levels of isolated living amongst Black-Caribbean

patients; reducing meaningful contact with established social network contacts. This idea has also been suggested by others, which highlights the critical importance of the family and friends in help seeking through less coercive channels (Tanskanen et al., 2011, Etheridge et al., 2004).

The study also explored ethnic differences in the support in attending appointments by the patients' social network. Overall, this study demonstrated that carers attended 44.57% of all encounters; however, the Asian-Pakistani sample had the greatest proportion of carers' support (60.01%) in comparison to 42% in the White-British sample and 37.8% in the Black–Caribbean. It is therefore evident that there is ethnic variation in the support available to patients when actual help seeking is attempted. This is significant because it goes beyond previous notion of help seeking initiation, as actual support through attendance is likely more meaningful than simply arranging or suggesting a patient to seek help.

Finally, the study explored the notion of unsuccessful help seeking attempts - encounters where no further referral was made that halted the pathway to care. The results demonstrated that Black-Caribbean patients were roughly 2.5 times more likely to have greater amounts of unsuccessful help seeking than White-British patients. However, no difference was found between South-Asian and the White-British sample.

As suggested by others the role of family and friends are critical in the utilization of services. It is clear from this chapter that in comparison to other ethnic groups, Black-Caribbean patients have diminished social network involvement in their pathway to care. It is possible, that such lack of support would complicate the pathway to care

increasing the need for detention. At this stage, only limited research has comprehensively explored the influence of social network support as a possible explanation for ethnic variation in detention rates. It would therefore be invaluable to explore further the interconnections between this idea and disproportionate rates of detention in the Black Caribbean community – an idea that will be explored in the subsequent chapter.

Appraisal of Methodology

There are several strengths and weaknesses with this study. Firstly, a relative strength of the study lies in the comprehensive data set achieved. Roughly half of the yearly intake of all the Black-Caribbean and a third of Asian-Pakistani and White-British sample were recruited into the study. Although other FEP studies have been able to recruited large sample sizes (Morgan et al., 2005a, Ghali et al., 2012), it was often the case that only a proportion of the patients included in these studies had individual assessments. Medical case notes were frequently used as the only source of information in these instances, which may impede to richness of data collected. As one of the aims of this study was to develop in-depth chronological understanding about ethnic variation in the pathway to care, it was deemed suitable to obtain the fullest data set possible, giving each patient a face-to-face interview. Within the constraints of both resources and NHS ethnical guidelines surrounding consent, it was felt that a smaller, richer dataset would better answer the research objectives set, especially as this work had many exploratory components.

The notion of ethnic differences in pathway to care is complex, involving multiple dependent variables across multiple ethnic groups. As a result, the sample size was

calculated by using the most consistent data for estimation. As there were no published research on the Asian-Pakistani population, the convention set out by Bhui et al. (2003) was used, which rated studies with more than 30 participants per ethnic groups as 'good'. This study exceeded this target. Although there is strong support that there are ethnic differences observed in the study beyond differing rates of detention, caution must be taken when interpreting results found in areas where the study was not specifically powered. As with all good sciences, these results should be investigated further, in larger samples for replication. Notwithstanding, this study was primary exploratory in nature and to that extent the findings presented here should be taken in light of this.

Another significant methodological strength of the study is the choice of ethnic categories. As demonstrated in Chapter Two, studies vary in their categorisation of ethnicity. This proves problematic as crude racial categorisation is often used (Black vs. White), which overlooks the nuanced importance of cultural and key processes involved in help seeking during the pathway to care. This study attempted to overcome this by focusing on distinct homogenous ethnic groups that incorporated both racial and cultural designations. Rather than lumping Black-African and Black-Caribbean together, Asian-Indian, Bangladeshi and Pakistani together and, White British, Irish and Other, this work focused on three distinct groups. The findings generated from this work can therefore be attributed to specific communities within the population, which has enhanced usefulness when conducting further research and giving recommendations for policy and intervention.

A limitation of this chapter is related to the accuracy in comparisons made with other work. As Compton et al. (2007) states, there is a lack of consensus about the definition of variables employed within the FEP pathway to care literature. This study attempted to overcome this by developing a rigorous, logical and objective method when collecting data, comparable to other key studies in the area. As many studies failed to define key variables in the articles, it is hard to assess how much non-significant results found are a product of actual differences to significant or methodological artefacts.

Summary of Discussion From Chapter Four

Firstly, this chapter again confirms that Black-Caribbean patients are significantly overrepresented in their rates of compulsory hospital admission during FEP. In addition it has also evidenced there are ethnic differences in many other factors and influential processes during the pathway to care, namely; prodrome length, unsuccessful help seeking attempts and the influence of GP, Faith organisational, emergency medical contact and social network involvement. It stands within reason that there are clear differences in the ways in which Black-Caribbean, White-British and Asian-Pakistani patients come to psychiatric services above and beyond their variation in compulsory hospital admissions. The chapter has begun to identify how such differences are interlinked and lead to excessive rate of detention for Black-Caribbean patients. In the subsequent chapter, this notion will be explored in detail through statistical analysis.

Discussion of Results From Chapter Five; Explaining Excessive Rates of Compulsory Hospital Admission amongst Black-Caribbean Patients

As established in Chapter Four, Black-Caribbean FEP patients were roughly four and a half times more likely to experience compulsory hospital admission in their pathway to care. Although this finding is congruent with the meta-analysis conducted in Chapter Two, very little research has attempted explain the why such disparities persist (Morgan et al., 2005a, Harrison et al., 1989). It is therefore clear that our existing knowledge of factors leading to excess is limited, as even the known determinants can only particularly account for the excessive rates of detention. In addressing this, Chapter Five built on the descriptive work from Chapter Four, by achieving the following two objectives, 1) to identify variables from the data set that hold crude associations with compulsory hospital admission and 2) to use the insights from the previous objective to explain excessive rates of detention amongst Black-Caribbean patients. The results of this chapter successfully identified many new factors that accounted for the relationship between ethnicity and detention, and confirmed some of the results from the existing research (Morgan et al., 2005b, Harrison et al., 1989a). In this next section, each of the key findings will be discussed in detail, theorising its importance and comparing it to what is already known.

The roles of socio-demographic factors

Previous research has suggested that socio-demographic factors are key in explaining ethnic variation in detention rates. In particular, unemployment, poor educational attainment, age and gender have been shown to be important when understanding Black-Caribbean's relationship with detention (Morgan et al., 2005a). In this study socio-demographic factors had little role in explaining excessive detention rates, which was

also shown for unemployment and education attainment. Likewise, deprivation levels, although being higher in the ethnic minority samples, had no influence, which was also mirrored in the work on marital status, religiosity and country of birth. It was therefore evident that these social factors had little explanatory power in accounting for the disproportionate detention rates experienced by Black-Caribbean patients.

Age and gender have also been shown to be important explanatory variables; however, there has been some confusion around their function in leading to disproportionate detention rates in other work (Morgan et al., 2005b, Harrison et al., 1989a). In this study both younger and older Black-Caribbean patients showed excessive rates of detention. This was also true for both male and female Black-Caribbean patients. It is therefore clear that while detention occurs more frequently amongst male and younger patients, neither variable was essential in explaining away disproportionate rates of detention. In the wider literature, many studies have empirically shown the importance of age and gender in the utilization of psychiatric services (Mackenzie et al., 2006), however, it stands to reason that these factors have limited bearing on the excessive hospitalisation of Black-Caribbean patients specific to FEP.

Living status was found to be the only socio-demographic variable that explained excess rates of detention in this chapter. In particular, living alone significantly increased a patient's chances of detention by almost three times. This finding is novel. There are several possible reasons for this. The first may be due to a reduction in the meaningful contact with family members. Both Tanskanen et al. (2011) and Etheridge et al. (2004) have demonstrated that family members have an important role to play in the utilization of psychiatric services during FEP. For those living alone, daily contact with

family members may become diminished and as a result social support in the help seeking process is likely to become inhibited- resulting in poor help seeking success. There is some empirical evidence in support of this; with the previous chapter demonstrating that Black-Caribbean patients had the lowest level of social support (35.78%) and a greater proportion of unsuccessful help seeking attempts. Likewise, Morgan et al. (2005a) found that self-initiated help seeking was high amongst Black-Caribbean patients and confounded their relation with detention. Another explanation of why living alone may lead to detention is due to the suitability of their living arrangements for recovery, as those severely unwell are unlikely to live in environments where their 'risk' can adequately be monitored or where treatment can safely be administered.

Clinically Related Variables

There have been many hypotheses surrounding the notion of clinical factors in leading to the excess of detention rates for Black-Caribbean patients. Rwegellera (1980) argues that Black-Caribbean patients are more likely to present to service with greater clinical disturbance and thus more readily require detention. There has been mixed results with regards to this theory in the literature (Owens et al., 1991, Pipe et al., 1991), however, the AESOP study did demonstrate that diagnosis and perceived risk of violence predicted detention. However, it is worth noting that neither completely accounted for Black-Caribbean's relationship with excessive detention rates. In this current study, clinical variables were measured in three main ways; 1) symptoms reported by the patient, 2) diagnosis and mode of onset, and 3) illness chronology (DUP, DUI, Prodrome, and mode of onset). In relation to the symptoms reported, hostility and aggression in

both phases of the illness (DUP and prodrome) had no direct association with either ethnicity or detention; neither did diagnosis nor mode of onset.

Conversely, in this study other clinical variables were found to be important. Short prodrome length was shown to mediate Black-Caribbean's relationship with detention, accounting for a proportion of the excess observed. One explanation of this may be due to the fact that the 'Prodrome' variable is a proxy for the speed at which frank psychotic symptoms appear after the start of low-level psychological disturbances. For those individuals with short prodromes, a first psychotic episode may appear more sudden, alarming and exaggerated than in those cases where the pre-illness is long, on-going and persistent. The transition from low-level psychological disturbances to 'full blown' psychosis in these cases are less likely to be gradual; with the change into psychosis stark and highly noticeable. As a result, the psychotic first episode for individuals with short Prodromes may be more likely to be seen as a 'crisis', which may result in a series of crisis related actions. If this variable more frequently occurs in the psychosis of Black-Caribbean patients, treatment may therefore mirror the nature of service presentation, and hence lead to compulsory detention.

Finally, the study also demonstrates the importance of a decline in social functioning and hallucinatory behaviour during the prodrome, as these variables reduced Black-Caribbean patients' excess. It is likely that the experience of these symptoms early on in the illness are more likely to alert the patient and their significant other that something is wrong, in comparison to cases where these symptoms are not present or occur later on. Early help seeking strategies are more probable in cases where noticeable behaviour

symptoms emerge early, averting the need for compulsory detention through early medical involvement.

Symptom Attribution

The study did find that symptom attribution was important in explaining excessive detention rates, which is another novel contribution of this work. Not holding 'within the individual' attribution during the prodrome, (i.e. biological, psychological and physiological beliefs) partially mediated the relationship between Black-Caribbean ethnicity and detention. In addition, the decision tree analysis showed that 'not attributing' symptoms (i.e. Unawareness of psychosis) during DUP was also important. It is therefore likely that the ways an individual interprets symptoms during the earlier stages of illness is important in accounting for the observed ethnic variation in detention. There are two possible explanations for this. Firstly, it is likely that those who hold 'within the individual attribution' during the prodrome have a conceptualisation of their 'problems' in line with that of the medical services, and hence seek early help accordingly. Secondly, 'not attributing' symptoms can work in an opposite way, preventing individuals to seek help at all from medical services or elsewhere. This is further more likely to be important in cases when patients live in isolation, outside of the help seeking support of the close family network.

Although these factors were important in explaining excessive detention rates, many of the other attribution types were not. Black-Caribbean patients were significantly more likely to hold supernatural world attribution during psychosis; however, this was not shown to be important in explaining detention rates. In the wider psychiatric literature, the work of McCabe and Priebe (2004b) suggest that Black-Caribbean patients typically

hold more social explanation for mental illness in comparison to White-British patients. This study did not support this notion, or find social attribution scores partially accountable for excessive detention rates. From this perspective, cultural differences in the unique ways symptoms are conceptualised have a limited role in explaining excessive detention rates.

Encounters during the Pathway to Care

The results demonstrated that emergency medical services mediated Black-Caribbean ethnicity's relationship with detention; which was also mirrored in the decision tree analysis conducted. To the knowledge of the author, this finding is a first. The notion that Black-Caribbean patients fail to seek statutory services voluntarily prior to hospitalisation is therefore not supported by this work, and leads us to the re-examination of why this occurs. What is clear however is that this help seeking for this group is urgent.

In the previous chapter, Black-Caribbean patients were significantly less likely to make contact with the GP than other groups, which may provide a potential explanation. A correlation revealed a negative relationship between both emergency medical involvement and overall GP contact (r=-.199, n=122, p=.028) and GP contact during the DUP (r=-.218, n =122, p=.016). Put slightly different, those patients who had emergency medical contact in their pathway to care were less likely to have GP contact. It therefore appears as though there is a medical help-seeking dichotomy prior to psychiatric intervention, which is a probable mechanism for the excessive detention rates observed amongst Black-Caribbean patients. A question that now remains is why this dichotomy occurs. As explored in the previous chapter there are no differences between the groups

in the help seeking delay, which infers that emergency services utilization is not a function of a delay in help seeking or poor help seeking strategies, but other factors

Theoretically, the notion of crisis may play an important role here. As stated earlier, if psychosis is experienced as a 'crisis', a series of help seeking behaviours are likely to occur. The involvement of emergency medical services may be the result of this, and as suggested by others (Morgan et al., 2005a) criminal justice agency involvement (although this was not supported as an explanatory variable in this study). In support of this idea, Morgan et al. (2005b) found that Black-Caribbean carers were significantly more likely to seek help directly from the police in comparison to White-British patients. It is likely that in a state of crisis, patients and carers' help seeking behaviours increase in desperation, requiring immediate attention from the state during a time of bewilderment and confusion. As result all available state based help and intervention is sought, as the presentation of psychosis is perceived as too serious to contain or to deliberate on. Support found in primary care, involving the advanced booking of appointments and referrals to specialized care is likely to be perceived as less acceptable in these cases, in contrast to the emergency medical care which is immediate. Immediacy is therefore an important notion here.

Limitations

At this stage of the study some limitations need to be highlighted. As explored in the literature review, the pathway to care is influenced by carers and significant others in the patients' social network. However, a limitation of the analysis presented in the chapter, is its inability to empirically demonstrate the role of carers. Help seeking initiation (self vs. others); social support in attending appointments; and help seeking

suggestions by a family member, were all uncorrelated with detention. They were therefore excluded from the higher-level analyses. It is therefore apparent that the influence of carers in explaining ethnic variation in detention rates is deficient in this work at this stage, which goes against the theoretical importance of carers supported by others. Despite this, the previous chapter demonstrated that Black-Caribbean ethnicity was independently associated with a lack of social support during the pathway to care, which could be a potential explanation to the function of carers in explaining excessive detention rates. In the next chapter, carers' accounts will be explored in greater detail, which may support this idea and uncover a more comprehensive understanding of their role.

As demonstrated in the final logistic regression model, ethnicity's relationship with detention diminished when other mediator variables were accounted for. In addition, the model also showed a reduction in the odds of detention for ethnicity by almost half of its unadjusted level. Despite the importance of these findings, caution must be given as its p value was only marginally non-significant and the confidence interval relatively large. Given the exploratory focus of this work, the final model should be taken as one possible evidence-based account of excessive rates of detention in the Black-Caribbean community. Other studies have found that diagnosis and clinical presentation are also key explanatory factors, however, these were not statistically included in the final model presented, due to their limited association with detention in the lower order analyses.

The final limitation of the quantitative work presented is related to the multiple comparisons conducted. From the outset, this work attempted to investigate the role of unknown variables in accounting for excessive rates of detention. As a result multiple

independent variables were tested against either detention or ethnicity. Methodologically this can be problematic; as such methods often run the risk of increasing a Type I error, due to the increased probability of discovering an effect through chance. Although Bonferoni corrections were used to account for this when making pairwise comparisons between ethnic groups, this criticism does stand for the other variables explored. In light of this limitation and the exploratory focus of this thesis, the findings from this chapter should not be taken as a definite explanation of the excessive rates of detention; but rather an explanation, one that should be retested more rigorously through the scientific process.

Summary of Discussion From Chapter Five

This chapter confirmed and identified new factors that account for the excess in detention amongst Black-Caribbean patients, on a range of different levels. There are those factors at the clinical level, like symptoms experienced and pre-occurring length of psychological (Prodrome) illness; factors related to symptom attribution and those related to encounters made during the pathway to care. From this perspective it is clear that the reasons behind excessive detention rates are multi-faceted and complex, and cannot be reduced to a single causal explanation. Theoretically however, these factors can be collectively linked through the notion of 'crisis', which suggests that excessive detention rates are due to a greater proportion of Black-Caribbean patients experiencing a FEP as explicit, stark and highly disturbing in comparison to those whose transition into psychosis is more gradual. Poor symptom awareness and shorter periods of low level psychological dysfunction are likely to be the causal mechanism of this, which result in a series of crisis type behaviours, such as emergency medical treatment, criminal justice agency involvement help seeking and a lack of GP involvement when

psychosis emerges. As an analogy, psychosis for a greater proportion of Black-Caribbean

patients is likely to be viewed similarly to that of a heart attack, without prior warning,

viewed as alarming and subsequently resulting in emergency forms of help seeking.

Discussion of Results From Chapter Six: Carers' Account of the Processes Leading To Compulsory Hospital Admission, With Specific Focus on Black-Caribbean Ethnicity

From the qualitative pathway to care literature, carers' accounts have proven insightful in explaining how FEP patients come to services. However, little research has used such approaches to gain a better understanding into ethnic disparities in detention rates exclusive to FEP. The purpose of this study was to address this obvious gap, by making ethnic comparisons in carers' narrative accounts of processes that lead to detention. The aim of this chapter are two fold: 1) to explore carers' experiences of the processes that lead to compulsory hospital admission and 2) to examine similarities and differences in experiences between carers from different ethnic groups.

The results of the analysis revealed a multitude of processes that occurred prior to the patients being compulsory detained. There were factors related to the patient's own actions, those of the carers and wider family network, those of services and many connections in-between. From this initial revelation, the reasons leading to compulsory detention should be perceived as a multi-dimensionally occurring phenomenon, through an interaction of factors across different spheres. Simple explanations of ethnic variation in detention rates are therefore not supported through the work generated in this chapter.

Key Themes In Relation To Previous Literature

Many key insights emerged from carers' accounts in this study, which clearly describes the various processes that lead to compulsory detention for FEP patients. The first key insight highlighted the significance of appraising early signs of psychosis. It was clear that many carers reported how the early symptoms of psychosis were often missed,

misconstrued or misunderstood and as a result inhibited early help seeking from external sources. This theme does follow suit with both the national (Etheridge et al., 2004, Johnson and Weich, 2010, Tanskanen et al., 2011) and international research (Boydell et al., 2006, Judge et al., 2008, Monteiro et al., 2006) conducted in the area, and indicates that these finding hold some validity to the illness of psychosis. In particular, a qualitative study of FEP patients in London, (Tanskanen et al., 2011) found that carers often reported difficulty in the recognition of symptoms, which delayed help seeking from medical agencies. Czuchta and McCay (2001) work also supports this, and found that an average of 20 weeks passed from the time parents noticed the first signs of illness in their children, which in turn, delayed help seeking. There was also support from the wider literature for some of the associated subthemes within this category. This included the notion that patients often hid symptoms (Boydell et al., 2006, Tanskanen et al., 2011) and that symptoms were often attributed to stress, drug usage and the changes of adolescence development (Corcoran et al., 2007). It is therefore clear that symptom recognition by the patients' social networks is key in the process of help seeking. In specific cases where patients experience compulsory detention, it is likely that poor recognition of early symptoms inhibits early medical help seeking, which increases the chances of psychiatric intervention through compulsory hospital admission.

The second key insight that emerged from this study is the notion that psychosis often expressed itself through a crisis. It was clear that the alarming presence of a psychotic episode was shocking for many carers which initiated emergency help seeking from medical agencies (e.g. Criminal Justice agencies, A/E departments). Evidence from the wider FEP pathway to care also supported this. In the qualitative study conducted by

Tanskanen et al. (2011), carers reported that bizarre and uncharacteristic behaviors often promoted medical help seeking. The work of Corcoran et al. (2007) showed in a mixed sample of patients and carers, that positive symptoms such as hearing voices and bizarre or violent behavior resulted in mental health system entry. There is therefore strong support for the influence of alarming clinical presentation being influential in medical service entry during FEP. The qualitative work in this chapter builds upon this notion, and further establishes that significance disturbed presentation in the pathway to care those patients who are compulsory detained. Another important insight from this study is that family members play an important mediatory role between clinical presentations of patients and the 'hows' and 'whys' of medical services utilization. Carers reactions to symptoms are therefore an important piece of the puzzle in the process towards detention and should therefore be seen a key mechanism.

The final key insight that emerged from carers' accounts is the variety of actions that family members attempted to use to help their ill relative. Seeking help from both within and outside the family unit was an extremely common practice amongst many of the interviews. Religious organizations, police services, general practitioners, emergency medical professionals and mental health services were all listed as agencies involved prior to hospitalization. Again this finding is consistent with the broader pathway to care literature and was a key theme in the qualitative review conducted by Boydell et al. (2006). It therefore stands to reason that carers have a pivotal role to play in the processes leading to care, regardless of mode of service entry (compulsory vs. non-compulsory). Moreover, this work indicates that family members of detained patients are concerned with the wellbeing of their loved ones, and put much effort in seeking *appropriate* help, although this appropriateness is a subjective one. This theme was also

found in the work of Corcoran et al. (2007) The work of the chapter also suggests that there are many barriers that prevent carers from getting appropriate medical help efficiently. A lack of knowledge about where to go for treatment, patients' self-concealment of symptoms and service related complications all prevent the initiation of treatment, which in turn could lead to compulsory admission. It therefore stands to reason that the interaction between services and the patients' social network has a role to play in the processes leading to detention.

How Can This Qualitative Study Help Explain Black-Caribbean Excessive Detention Rates?
Another aim of this study was to compare and contrast ethnic differences in carers' accounts of factors leading to compulsory admission. It was thought that by isolating the factors that are more common in Black-Caribbean cases, patterns may begin to emerge that could explain the unique ways compulsory hospital admission occurs in this client group and consequently provides greater insight into why detention is more frequent. As a result, specific attention was made to highlight the dominance of each theme and subtheme across the two main ethnic groups.

In summary, the results of the study found many more similarities than differences between the Black-Caribbean, White-British and Asian-Pakistani cases. There was evidence to suggest that all carers had difficulty in the appraisal of the early signs of psychosis, exhibited a range of help seeking behaviours and utilized a variety of statutory (medical, criminal justice agencies) and non-statutory services (Faith organisation). It was also true that both groups had equal difficulty with services in the assessment and referral process. Despite this, the analysis did reveal four themes that

were unique or more prominent in the accounts of Black-Caribbean carers, which may explain the excessive rates observed.

The first theme dominant amongst Black-Caribbean patients was related to the appraisal of early signs of psychosis. In five of the eight Black-Caribbean carers' accounts, patients often articulated psychological distress through the discourse of 'life difficulties', 'personal worries' and challenging 'life events'. As a result, signs of early mental disturbance were masked, which some carers' felt prevented the initiation of help seeking from external sources. The second prominent subtheme that occurred more frequently in the Black-Caribbean transcripts was the ability of carers to deal with the symptoms of psychosis within the family unit. There were many instances where Black-Caribbean carers described nursing their ill family member at home, providing counselling and practical support prior to help seeking from external agencies. One Black-Caribbean carer mentioned nursing her daughter continually for four days and nights before taking her to the accident and emergency department at her local hospital. The third theme that occurred exclusively in the Black-Caribbean sample was the influence of isolated, fragmented and temporary living circumstances on help seeking. As a result of not living in close proximity to the patient, carers often found it difficult to identify and assess the full extent of the patients' psychological problems and therefore could not seek help accordingly. The final theme that was predominant amongst the Black-Caribbean transcripts was the significance of a crisis event. Of the eight interviews, seven reported the importance of a crisis in the help seeking process. From the carers account, it was the abrupt and highly alarming appearance of psychotic symptoms that prompted medical help seeking treatment.

As this is the first study to qualitatively explore Black-Caribbean carers' accounts of factors leading to detention specific to FEP, it is hard to make comparisons to the wider literature. However, some of the themes here have been observed in other quantitative work, such as the existence of isolated living situation (Morgan et al., 2005a). In addition, two international studies have showed that intra-familial coping strategies were common in their sample, which suggests that such behaviours are not specific to Black-Caribbean community in Britain (Wong, 2007, Corcoran et al., 2007) but may be cross cultural.

Synthesizing Key Themes from the Black-Caribbean Accounts

Collectively, these four points do marry well in providing an initial explanation of the unique processes leading to compulsory hospital admission for some Black-Caribbean patients. Firstly there appears to be the existence of a diminished response in early external help seeking amongst this group. It is likely that this is the result of inhibited early symptom awareness by carers and a greater propensity of the family network to self-manage the early signs of a psychotic illness. In addition, external help seeking is likely to be diminished where the patient is living outside of close family networks, in temporary, isolated or fragmented living situations. Hypothetically, the consequence of each of these points would have drastic ramifications for the patients' health. Symptoms are likely to increase in severity and frequency due to a lack of appropriate medical intervention, and reach a point where there existence is explicit, frank and abrupt. For carers this sudden change is likely to appear shocking and viewed as a crisis, resulting in the family making drastic and frantic attempts to seek help for a condition that was previously unnoticeable or containable. When such patients present to services

in this way, compulsory hospital admission is more readily required as it provides a more suitable mode of treatment than that available in the community.

Reflexivity of The Researcher

Malterud (2001) states that "a researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions". It is therefore important for the qualitative researcher to reflect upon their own backgrounds in order to be transparent about how it could have shaped the ways in which the qualitative data were collected and understood.

Like the majority of the participants in this study, I was also born and raised in Birmingham in the north of the city. I identify with being British, as this Is the country that I was born and raised; Black, as this is the social construct that is most commonly used to describe those who share similar visual traits as me; and Caribbean, as both my paternal and maternal grandparents emigrated to this country from Jamaica. I would say that I have had a relatively privileged background, with little experience of prolonged emotional distress or financial hardship, and have been lucky enough to obtain two degrees in Psychology.

From the outset, I have been aware of how my own ethnicity has influenced the ways in which I make sense of this area of research. My father has worked in mental health services in the city for many years, in both a professional and voluntary capacity and so his experiences have partly shaped my passion and interest in the subject area. On the

other hand, my background in psychology has also taught me of the importance of objectivity in the production of scientific knowledge. I have tried to balance these two influences equally throughout my work; ensuring that I do justice to the accounts of the carers I have interview, whilst also remaining true to the data. It is surprising however, that no theme highlighted explicit cultural issues or experiences of discrimination as being a barrier to care. Instead more subtle beliefs and behaviors about help seeking were evident from the interviews.

The distinction between material and non-material culture is often used within sociological research. Material culture is reflected in the objects in one's group that are tangible and that hold significance. Non-material culture describes invisible aspects of one's culture, such as beliefs, traditions, actions and particular kinds of behaviour.

In reflection, it could be possible that being British, Black and from Birmingham enabled me to better identify with the more subtle forms of non material culture in the carers' interviews. There were times during the interview when carers would make reference to specific places in the city or situations that I had prior knowledge of. At these times I would often give implicit cues that I understood the reference made, which I felt positively facilitated the flow of the interviews. Additionally, patois (an Jamaican-English dialect) was sometimes used interchangeably with 'correct' English to express feelings of anger, confusion or upset. These could be interpreted as reflecting a deeper level of trust and openness between the participants and I, which could have further improved the depth of data retrieved.

Strengths and Limitations

There are several strengths and weakness to this work. Firstly, it is worth noting that this qualitative work is based in a constructivism paradigm, and hence the finding here should not be taken to be completely representative of all Black-Caribbean FEP patients everywhere. Instead, the results point to the unique ways that carers from different ethnic groups come to receive psychiatric intervention and can further help to enrich understanding of the reasons behind excessive detention rates. Although generalizability, at least in the ways constructed in quantitative research, is not a specific claim of this study, this work does hold methodological rigor. Specific attention was made to recruit a homogenous group of carers with a similar set of experiences in the utilization of psychiatric care. The purpose of which was to increase the internal and external validity of claims generated, by analysing relatively similar accounts of a defined and specific experience. In terms of the accuracy of theme generation, initial categories were checked by an external party, outside of the Ph.D. process, in a bid to increase both objectivity and consistency in the final output of the study.

Despite this, some clear methodological gripes should be considered when evaluating this research. With regards to recruitment, roughly a third of all detained FEP patients had a relative or carer recruited into this study. There were various reasons for this, including patients not willing to allow their carer to participate in the study; complications in arranging interviews or the simple fact that some patients had no family or social network to speak of. As a result, it is likely that the themes generated in this study may not be best applicable to those severely isolated or those with difficult relationships with immediate family. Although patients were told that carers could include close friends or significant others, none were recruited into the study. As a

translator was not available, the accounts of carers who were not proficient in English were absent from the study. It is possible that this group will have had different experiences to interviewees, in specific, those of Asian-Pakistani backgrounds. Additionally, only two Asian-Pakistani carers were recruited into the study and so caution must be taken not to generalise the comments presented here to the wider Asian-Pakistani community.

Bias may have also been introduced through ethnic variation in the dominant types of carer-patient dyads recruited. In the Black-Caribbean group, the carers and patients were a mixture of female-to-female and female-to-male relationships (mothers and daughters, mothers and sons), in contrast to the White-British groups, where carer patient dyads mainly consisted of mothers and sons. It is possible that such differences in relationship could have influenced the themes generated due to nature of these relationships, therefore skewing the ethnic specific themes found. In light of this, future research may wish to explore the findings from this chapter in more depth, looking explicitly at some of the themes identified via ethnicity and by increasing diversity in the types of care-patient dyads recruited.

In terms of strengths, this study does hold some improved benefits over previous research. As established in the literature review (Chapter Two) only three qualitative studies have explored the processes leading to psychiatric intervention, specific to FEP in England and Wales. In terms of recruitment, the numbers of participants recruited in these studies were relatively small (ranging from 6 to 12), interviewed both carers and patients together, and explored a range of different clinical experiences (i.e. those with both adverse and non adverse pathways to care). In this study 17 participants were

recruited, and to the knowledge of the author is the first study to focus specifically on carers' accounts of the experiences leading to detention. As a result, this study is likely to have obtained richer accounts of factors involved in the utilization of services specific to this group, in comparison to other qualitative studies with heterogeneous recruitment strategies.

Summary of Discussion From Chapter Six

This study has clearly demonstrated that the processes leading to detention during FEP are diverse and complex. In attempting to understand why certain ethnic groups are more likely to be detained than others, this study has identified the many features unique to the Black-Caribbean cases. Poor early help seeking, facilitated by a lack of early symptom recognition and fragmented living situation, in conjunction with a crisis event, appears to be the specific ways that Black-Caribbean patients come to be compulsory detained - which can be used to account for the disproportionate rates of detention experienced by this group. On the surface there appear to be many commonalities between the themes emerged in this study and statistical ones generated in the previous chapter, in particular the potential unifying explanation of 'crisis'. In the following chapter the interconnection between all three empirical chapters will be interrelated and discussed, to help provide a comprehensive understanding of why Black-Caribbean patients are more likely to be compulsory detained during FEP than their counterparts.

Chapter Eight

An Introduction To The 'Crisis Hypothesis': A Synthesis Of Key Findings

Background to Thesis

The relationship between ethnicity and psychiatric services in Britain has been an extremely contentious issue over the last 20 years. Research has consistently found that Black patients, in particular those from Black-Caribbean backgrounds, are significantly more likely to experience compulsory hospital admission in the pathway to care than their White-British counterparts. In a systematic review, Newton-Howes and Mullen (2011) reported that patients and their families typically held negative views about their experience of compulsory detention, most frequently described as distressing. For this and other associated reasons, compulsory hospital admission is the non-preferred way for patients to receive psychiatric care, and many have argued that treatment in this way can lead to greater problems, such as disengagement from services, which may further impede recovery. Quite naturally, the notion of ethnic disparities in the use of detention is highly alarming, and as a result has received a substantial amount of interest from both governmental and third sector agencies. Moreover, the area is highly politicized and there has been much contentious debate between prominent academics in the field. Claims of institutional racism, poor quality of services and factors related to the Black Caribbean community itself, have all been sighted as the cause for

this phenomenon – however, much is still not understood (Cantor-Graae, 2008, Singh and Burns, 2006).

Despite this, there have been some positive steps to address this (Lau, 2008, Department of Health, 2005), however these measures have resulted in little attenuation in the rates of compulsory hospitalisation for Black minority groups (Department of Health, 2009). Some have argued that ethnic disparities in detention rates are simply due to elevated rates of psychosis amongst certain BME groups. Although elevated rate have been confirmed (Morgan et al., 2006b), previous research has shown that ethnic difference in detention rates persist even after controlling for diagnosis. Moreover, FEP patients are unique in that they have little contact with psychiatric services prior to service entry in comparison to those patients with chronic disorders. They therefore are likely to have unique mechanisms that create ethnic disparities in detention rates that are seldom accounted for in the literature. Taking these two points in conjunction with each other, knowledge of why there are ethnic differences in detention rates during FEP is unclear.

Understanding Ethnic Differences in Detention Rates Specific to FEP
In addressing this limitation this thesis aimed to explore the factors that lead to excessive rates of compulsory detention for Black-Caribbean patients specific to FEP. Firstly, a systematic review and meta-analysis were conducted to identify all studies that had explored ethnic differences in detention rates. The result showed that Black-Caribbean patients were roughly two and half times more likely to be detained In relation to comparative samples. Secondly, two studies (Morgan et al., 2005b, Harrison et al., 1989) from the review gave empirically supported explanations.

Previous Explanation of Disproportionate Rates of Detention for Black-Caribbean patients.

In total, four empirically supported explanations emerged. The first was related to socio-demographic factors. Age and gender were both mentioned as variables important in creating ethnic disparities in detention. However the exact function of these factors was unclear as there appeared to be inconsistencies between the studies.

The second group of explanations that emerged from these studies were related to the ethnic differences in clinical presentation. The arguments from this group stated that ethnic differences in detention rates were due to Black-Caribbean patients presenting to services in a more disturbed way than their White counterparts. In exploring this notion specific to FEP, Morgan et al. (2005a) collected a range of possible proximal variables of clinical disturbance, including; violence and perceived threat; diagnosis; and actual and perceived risk of violence. The results showed that although diagnosis and perceived risk were independently associated with compulsory admission, neither fully accounted for the excess of compulsory admission among Black-Caribbean patients.

The third explanation from the FEP literature was related to social isolation. In the wider psychiatric literature unemployment and living alone were shown to be associated with compulsory hospital admission (Cole et al., 1995, Burnett et al., 1999, Szmukler et al., 1981, Harrison et al., 1989). It is thought that these variables were proxies of social isolation, and increased the risk of detention through a lack of facilitated help seeking support. In specific to FEP, Morgan et al. (2005b) found that Black-Caribbean patients were significantly more likely to live alone and be unemployed than White-British patients; in addition, both these variables were associated with compulsory detention.

However, on further examination these variables did not account for ethnic variation in proportions of compulsory admission.

The final group of explanations were related to the role of the pathway to care. It has been argued that ethnic differences in the way service contact is made can influence the chances of compulsory hospital admission. Both the work of Morgan et al. (2004) and Harrison et al. (1989) have laboured this point with particular reference to the criminal justice system. However, in the empirical work conducted in these studies, criminal justice involvement could only partially account for ethnic differences in detention rates.

In summary it is clear that there is a serious lack of understanding of the reasons behind excessive rates of detention during FEP for the following reasons. Firstly, there appears to be ambiguities around the role of age and gender and the function that they have in leading to excessive detention rates. Secondly, variables shown to have strong associations with compulsory hospital admission can only partially account for excessive rates of detention amongst Black-Caribbean patients – which suggests that other factors with better explanatory power must exist. Finally, current empirically supported explanations are static and mono dimensional, and fail to comprehensively account for key known processes. The purpose of this thesis was to address these shortcomings and begin to develop a greater insight into the reasons behind this phenomenon.

Thesis aims

1. To further identify the factors that best explain excessive rates of detention amongst Black-Caribbean patients exclusive to First Episode Psychosis (FEP).

2. To use the findings from aim 1 to develop a theoretical model of the processes

   which lead to excessive rates of detention amongst Black-Caribbean patients.

Box 4: Summary of Key Findings from Thesis

Chapter Four – Quantitative results 1: Sample Characteristics, Descriptive Statistics And Ethnic Comparisons.

1. Black-Caribbean patients were roughly 5 times more likely to experience compulsory admission in comparison to White-British patients, and 4 times more likely than Asian Pakistani patients.
2. Black-Caribbean patients were significantly more likely to have Accident and Emergency department involvement in their pathway to care than other groups.
3. Black-Caribbean and Asian-Pakistani patients had significantly shorter prodromes.
4. No difference in overall criminal justice between the groups
5. Black-Caribbean patients had significantly less GP involvement than White-British patients.
6. Black-Caribbean patients had significantly shorter service delay.
7. During Prodrome, all patients most frequently attributed symptom in the social domain in comparison to the DUP, when patients did not attribute symptoms.
8. There was slight ethnic variation in this with Asian-Pakistani and Black-Caribbean patients significantly more likely to hold supernatural attributions.
9. There were similar help seeking behaviours across all groups, however, Black-Caribbean patients had significantly more unsuccessful help seeking attempts than in comparison to White-British patients and lacked social support in help seeking.

Chapter Five – Quantitative Results 2: Explaining Excessive Rates of Compulsory Hospital Admission Amongst Black-Caribbean patients.

1. When comparisons were made via age and gender, both older and younger Black-Caribbean patients were significantly more likely to be detained than their counterparts. This was also true for both male and female Black-Caribbean patients.
2. Five variables were shown to **mediate** Black-Caribbean patients' relationship with detention, these were; Living alone; Short Service Delay; Short Prodrome; Emergency medical services contact; and Not having 'within the individual world attribution' during the Prodrome.
3. Hallucinations and decline in social function during the Prodrome were shown to **negatively moderate** ethnicities relationship with detention.
4. Criminal justice agency involvement was shown to positively moderate ethnicities relationship with detention. The significance of criminal justice involvement was also shown to be key during the decision tree analysis, but was not found to be important in understanding the routes to detention for Black-Caribbean patients.
5. ***Ethnicity was no longer significant in the final regression model when sig. mediation and negative moderation variables were included as covariates.***

Chapter Six – Qualitative Results: Carers' Narrative Account Of The Processes Leading To Compulsory Hospital Admission, During First Episode Psychosis (FEP) – With Specific Focus On Black-Caribbean Ethnicity

1. Black-Caribbean carers reported barriers to the appraisal of early signs of psychosis.
2. Black-Caribbean carers reported inhibited early medical help seeking attempts.
3. Black-Caribbean carers reported alternative help seeking strategies, such as dealing with the problems of psychosis inside the family. This prevented external medical help seeking.
4. A crisis event was important in triggering external medical help seeking.

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The Crisis Hypothesis- An Explanatory Model of the Excess Rates Of Detention of Black-Caribbean Patients with FEP

After comparing and contrasting the outcomes of each chapter through a iterative process, a potential theme began to emerge which built on some of the key findings in the work of Harrison et al. (1989) and Morgan et al. (2005a) - see above. The theory generated, which from here onwards will be referred to as the 'Crisis Hypothesis'; states that ethnic disparity in detention rates is likely due to the fact that…

> For a greater proportion of Black-Caribbean patients, a sequence of associated processes results in a first psychotic episode presenting itself through a crisis. Consequently, a series of crisis-response help seeking attempts are initiated by various actors within the health care system (patients, carers and professionals); which leads to urgent forms of psychiatric intervention, suitably found through compulsory hospitalisation.

This model is extremely diverse and includes factors on a range of different levels. The purpose of this chapter is to now detail each stage of this theory as it relates to the empirical work collected, drawing on associations and comparisons wherever possible.

The Five Steps of the 'Crisis Hypothesis'

There are five steps to the crisis hypothesis (Figure 38), these are: 1) A diminished awareness of the early signs of psychosis, which leads to; 2) Inhibited and alternative early helps seeking strategies. As a result, symptoms are left untreated until; 3) psychosis is manifested through a crisis event. Crisis-response help seeking attempts are therefore initiated 4), which when the patient presents to services lead them to be, 5)

rapidly propagated through to compulsory hospital admission due to their clinical presentation. In this next section each of these steps will be described in detail, including the empirical evidence to support it.

Figure 38: The Five Stages of the 'Crisis Hypothesis'[1]
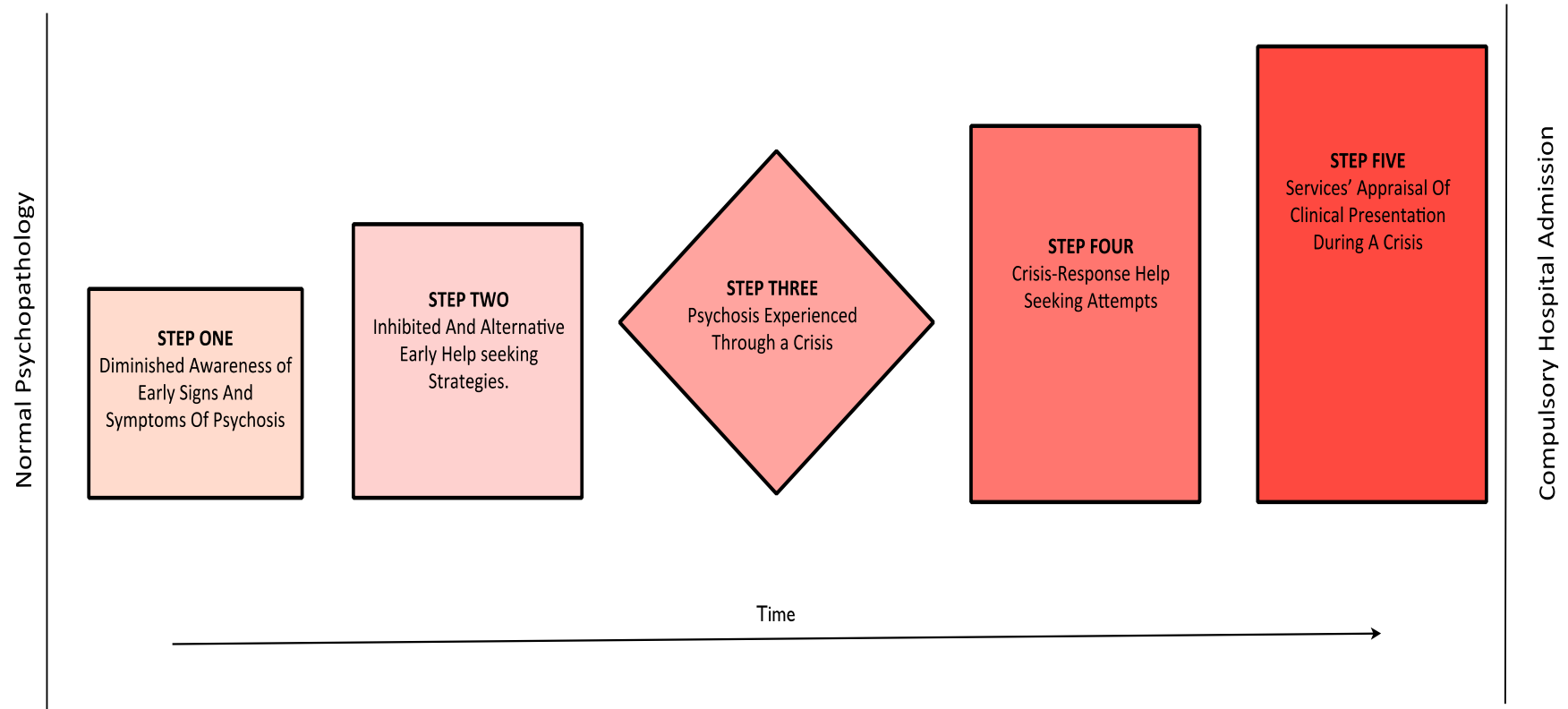
[1] DISCLAIMER: Although the steps of the crisis hypothesis build upon each other, they may also independently lead to excessive rates of detention rates on their own. Totally mechanistic interpretation of the model should therefore be avoided.

STEP ONE: Diminished Awareness of The Early Signs and Symptoms of Psychosis

The first stage highlights the importance of the early symptoms of psychosis. It appears as though Black-Caribbean patients and carers experience diminished early symptoms in comparison to their counterparts. Empirically the following two strands of evidence supports this. The first is through the mediation analysis; which showed that shorter prodrome length accounted for a proportion of the excess in detention rates amongst Black-Caribbean patients. The second piece of evidence was from the qualitative interviews, and demonstrated that Black-Caribbean carers found it difficult to notice the early signs of psychosis. Carers also explicitly stated that diminished awareness prevented help seeking from external sources, which in turn led to compulsory detention. There is therefore good evidence to suggest that there are ethnic differences in the early signs of psychosis, which influence hospitalisation. A question of importance at this stage is whether this is due to ethnic differences in the phenomenological development of the disorder or in the ways that symptoms are perceived.

The empirical work from this thesis suggests the latter, for a number of reasons. Firstly, not having low-level hallucinatory behaviours or a decline in social functioning during the prodrome reduced the amount of excess found in the Black-Caribbean sample. Theoretically, It is possible that the presence of these symptoms are most influential in effecting the daily lives of patients, and hence are more noticeable in comparison to depressive and neurotic symptoms. In cases where these symptoms are not present, the prodrome may appear subtle; diminishing its perceived presence, nature and severity. Secondly, evidence from the attribution data also supports this idea. Few differences were observed between the groups in terms of the attribution scores given (Chapter Four) however, not having 'within the individual' world attribution during the prodrome

accounted for a proportion of the relationship between Black-Caribbean ethnicity and detention. Put slightly different, failing to attribute symptoms to within one's self accounted for the excessive detention rates found. Finally, qualitative evidence from carers' accounts suggests that Black-Caribbean patients often articulated early signs of psychosis through the discourse of life complications, rather than problems within one's self, which would also support this notion.

Taking each of these points in conjunction with each other, it appears as though the diminishment in the early signs of psychosis is likely due to ethnic differences in appraisals and perceptions. However, as this was not a primary aim of this research study, its conclusively is still questionable. There is much debate within the psychiatric literature about the influence of culture on psychopathology (Tseng and Streltzer, 1997, Draguns, 1995, Lewis-Fernández and Kleinman, 1994, Draguns and Tanaka-Matsumi, 2003, Canino and Alegría, 2008). This idea has been brought to light through the etic vs. emic discussion, which has questioned the influence of culture on the development and prognosis of psychotic illness. Applying this point to understand ethnic differences in the appraisal of symptoms could add another layer to help understand elevated detention rates. It could be that perceptions of abnormal psychopathology are tied into cultural assumptions of general normal psychopathology (i.e. the threshold at which psychological disturbance is culturally unacceptable). If individuals live in communities where psychological ill health is common and high, the tolerance of their own psychological health may be raised and hence influence their own awareness of the times when they are clinically unwell. In other words, the subjective component to early symptom awareness is likely to be influenced by cultural acceptability. If this postulation

is true, it may therefore be difficult to accurately assess if ethnic differences in the early appraisal of symptoms is related to either phenomenology or cultural perceptions.

STEP TWO: Inhibited and Alternative Early Helps Seeking Strategies

The second stage to the crisis hypothesis is the existence of inhibited and alternative early help seeking behaviours. As a result early medical help seeking is reduced, which in turn increases the chances of compulsory hospital admission. Such behaviours are likely to be the results of inhibited awareness of early symptoms as mentioned in step one.

There are several examples of this step from the empirical work conducted. Firstly, there was a genuine sense of self-reliance within the Black-Caribbean family unit when dealing with unusual symptoms. Counselling, nursing and supporting the patient were all common practices in the qualitative carer interviews. As a result the need for help seeking from medical agencies was abandoned which in turn led to detention. Secondly, the qualitative work also suggested that early medical help seeking was a consequence of diminished appraisal of early signs of psychosis. Not knowing that there was a 'problem' was frequently mentioned as a reason why external help was not sought. The notion of poor early medical help seeking was also evidence in the quantitative work, which showed that GP contact during the DUP was less common in Black Caribbean patients. The final strand of evidence supported by the empirical work of this thesis is the impact of living in isolation. Both quantitative and qualitative work identified the significance of patients' fragmented and isolated living status in influencing external medical help seeking. In Chapter Five, the mediation analysis showed that living in isolation accounted for the relationship between Black-Caribbean ethnicity and detention. In Chapter Six, carers reported that patients living away from the family unit

prevented help seeking as they were unable to accurately assess the full extent of their loved ones' illness. An alternative explanation of why living in isolation could lead to detention is that patients' psychotic experiences are likely to go unchecked outside the regular contact of loves ones. More research is therefore needed in the understanding of this feature.

STEP THREE: Psychosis Experienced Through a Crisis

The most pivotal stage to the hypothesis is the notion that Black-Caribbean patients are significantly more likely to exhibit a first episode of psychosis through a crisis. Black-Caribbean carers commonly described this crisis event as alarming, abrupt and disruptive and typically consisted of; visual and alarming psychotic behaviours; rapid verbal articulation of thoughts; responding to psychotic phenomenology and greater clinical disturbances in behaviours.

The reason behind this may be the result of other factors within stages one and two of the crisis hypothesis. Firstly, a first psychotic symptom is most likely to be perceived as alarming or shocking when the patient or carer has diminished awareness of the early signs preceding it. As a result, visual displays of the illness occur as if they have just appeared out the 'blue', and hence can be highly alarming for both the patient and those individuals in the patients' social and family network. The second factor that may explain the presence of a crisis is likely due to a lack of early contact with medical professionals (step two). Encounters with health care services early on in the illness may help reinforce patients and carers to the gravity of the illness, and hence circumvent the alarming appearance of psychosis through a crisis. Likewise, involvement from services

early on may reduce parental anxieties and distresses experienced through a crisis, as they may feel that their burden is already shared.

STEP FOUR: Crisis-response Help Seeking Attempts

The fourth stage of the crisis hypothesis is a series of crisis response help seeking behaviours. As a result of experiencing psychosis through a crisis event, various actors within the health care system (Patients, Carers and Professionals) initiate rapid and immediate forms of external help seeking, in substitution for help seeking from primary care and other referral based agencies. This notion was evident in the qualitative work of carers, in specific seeking help from the Accident and Emergency department. Likewise, in the quantitative research, having contact with emergency medical services was shown to mediate ethnicities relationship with detention, accounting for a proportion of the excess observed. Further analysis also revealed a significant negative correlation between accident and emergency involvement and GP contact, suggesting that those patients without GP referral were more likely to have accident and emergency referral.

The AESOP study also supported this notion and suggested that criminal justice agencies, most typically characterised as involvement from the police, also accounted for ethnic differences in detention rates. Likewise this study also demonstrated that Black-Caribbean carers were significantly more likely to seek help directly from the police than their White-British counterparts (Morgan et al., 2005b) however, this was not replicated in this study.

STEP FIVE: Services Appraisal of Clinical Presentation through Crisis

The final stage of the crisis hypothesis is related to factors within services. When patients present to services in crisis, they are then quickly propagated through to specialised psychiatric intervention, which in turn is followed by compulsory hospital admission. Evidence in support of this was explored in chapter five, where short service delays accounted for excessive detention rates amongst Black-Caribbean patients. One possible explanation is that assessing psychiatric illness is easier when a patient present to services in crisis. As a result, the need for psychiatric intervention is more apparent, and hence patients are speedily propagated through to psychiatric assessment. As the patient arrives through crisis, the notion of risk is an additional factor of importance. Psychiatric services may be less willing to begin treatment within the community for those patients severely disturbed. Attributions of symptoms may also be another important factor here. As revealed in a previous subsection, most FEP patients do not attribute the symptoms of psychosis when acutely unwell. In cases where patients are presented with choice of voluntary hospitalisation, a lack of awareness of symptoms may increase the likelihood of patients declining care. As a result compulsory hospitalisation would be the only suitable course of action.

Support for this notion may also follow the ethnic differences in clinical presentation argument, previously outlined. The AESOP study (Morgan et al., 2005a) demonstrated that manic presentation and perceived risk to others, reduced Black-Caribbean ethnicity's relationship with compulsory hospital admission in comparison to it's unadjusted level. It is likely that crisis and disturbed clinical presentation could be different measurements of the same phenomonon, further supporting the claims of this step.

Strengths and Limitations of the Crisis Hypothesis

There are several main strengths to this work. The first is the ability of the model to provide a multidimensional understanding of a complex dynamic phenomenon. There have been many criticisms of existing research in the area at trying to explain excessive detention rates through static and mono-dimensional viewpoints. Such approaches are limited as they attempt to place the cause of excessive detention rates down to one particular area; simultaneously ignoring other important components. To the knowledge of the author, the crisis hypothesis is the first to go beyond this limitation, and incorporates and integrates an array of factors at different levels, using a chronological perspective. Furthermore the model is highly grounded in empirical knowledge gathered from a range of different perspectives in this thesis, rather than relying solely on theoretical or philosophical ideologies.

The second strength to this work is its sensitivity to culture. A criticism of the empirical and hypothetical work previously conducted on ethnicity and detention is the lack of applicability to specific ethnic groups. During statistical analysis, ethnic minority participants are typically grouped inappropriately and as a result, the cultural uniqueness and nuances of each of the groups becomes lost. If research in the area is to truly understand and alter ethnic differences in detention rates, the method of ethnic comparison should adequately reflect the ethnic communities as they are assembled within society, and not some lose approximation. It was clear that Asian-Pakistani and Black-Caribbean patients (although both ethnic minority groups) had different rates of compulsory hospital admission and unique factors which influenced their pathway to care. Combining these groups under the umbrella of being an 'ethnic minority' in this study could have serious reduced the new insights gained.

Despite these benefits, some important limitations should be acknowledged. Firstly, although ethnicity was no longer significant in the final regression model created; the covariates included could only account for roughly half of the excess in detention rates. It therefore appears as though there must exist other factors not included in this study, which may also play an important explanatory role in accounting for excessive rates of detention. In part the qualitative work attempted to address this and highlighted many important features that were not explored in the quantitative research. Furthermore insights from previous literature have also help to fill this gap, and identified the significance of clinical presentation and manic diagnosis. Despite this, insights from a service level perspective are still drastically missing from the crisis hypothesis. In this thesis, the bureaucratic components of the sectioning process were not examined, which could greatly add insight and a new layer to the proposed hypothesis. Likewise, interviewing clinicians about the processes that lead to detention may prove helpful, a perspective currently missing from this work.

The second limitation relates to the types of data collected. In this study, retrospective information was routinely used in both the quantitative and qualitative arms. The subjective accounts of carers, patients' recollection of symptoms and attributions during the pathway to care were all assess retrospectively once patients had entered services. There is much criticism of retrospective data collection within the psychiatric community, as many argue the approach is too heavily subject to participant bias. In this study, prospectively exploring the processes that influence a patients' journey to care would be difficult, as identifying and recruiting those individuals in the transition to psychosis would raise logistical and ethical dilemmas. From this perspective, a retrospective approach was deemed the most suitable method and was therefore

chosen. In addressing the limitations of retrospective data, special attention was made to augment the participants' accounts with other source material. Medical records, correspondents from other health carer professionals and various validation techniques were used to increase the accuracy of information obtained. Prior to the interviews conducted with both carers and patients, a rough timeline of key date and symptoms were collected in line with the NOS protocol. This helped more accurately frame the information obtained during the interview, in turn increasing the reliability of accounts.

Institutional Racism – What Does The Crisis Hypothesis Add To The Debate?

As mentioned in the introduction to this thesis, the topic of ethnic disparities in the pathway to care is highly politicized. The place where this has seen the most vitriolic forms of debate is within psychiatry itself. As present, two main polarising views exist. The first argues that excessive rates of detention are due to factors unique to the Black-Caribbean community. It has been suggested that psychosis for this group is of a different nature, commonly described as florid, anti-social and dangerous, increasing the justified need for detention. It has also been suggested that ethnic disparities in detention rates are due to cultural differences in the perception of illness, treatment and greater stigmatizing beliefs about care. The alternative position argues that ethnic variation in detention rates is the results of factors within psychiatric services. Claims of institutional racism are often cited here, which argues that excess amongst Black Minority Ethnic (BME) patients is the product of racial discrimination by health care practitioners, who inappropriately detain patients through prejudicial actions. It is further argued here that psychiatric treatment should not be solely viewed in terms of its efficacy, but rather its equality. If psychiatric services through its operations cause such clear disadvantage in the experience of care, it is clearly a product of discrimination

and hence racist. A further point argues that psychiatry can be seen as institutionally or structural racist when choices of service configuration inadvertently lead to disparities.

To many the arguments raised on both sides of debate are highly compelling; however both could easily be conveying different sides of same phenomenon and thus could be perceived as an argument of differing perspectives. Before contributing to this on-going debate, it is worth noting that the crisis hypothesis neither proves nor disproves the positions set out above, but instead proposes a complementary view.

The crisis hypothesis could be seen as a transitional model, as it focuses factors at the symptom level, right through to the service level. From this perspective the cause of excessive detention rates cannot be clearly defined to one definite fact, but rather a series of multidimensional associated factors, acting on a range of different levels. As a result of this diverse approach, the crisis hypothesis can contribute the following two points to this debate. Firstly, it is clear that there *are* differences in presentation, help seeking and the experiences of psychosis between Black-Caribbean and White-British patients. Acknowledging that this difference is genuine is first important in understanding excessive rates of detention. Once there is agreement on this point we can now begin to agree on how best to respond to such differences, leading to useful solutions. From this standpoint blaming psychiatry or the Black-Caribbean community is not useful; instead, effort should be made in finding way to adapt to such differences. Equality in service provision cannot be reached by treating all patients in the same manner. Instead services should begin to treat patients in light of their specific cultural needs.

The second contribution of this thesis to the debate is that ethnic differences in detention rates in not solely due to psychiatric services, as much of the causal mechanisms shown to be influential occurred prior to service entry. From this perceptive psychiatric services cannot be totally culpable for Black-Caribbean's excessive detention rates during FEP. This then draws our attention to the whole health care system, including primary and emergency medical care services. The National Health Service on a whole therefore needs to present a joined-up solution, which incorporates its entire structure. The diversification of psychiatric expertise throughout its services may therefore be a potential route of interest. In part there has been a slow move towards this in recent years, which has seen an increase in the presence of psychiatric services within emergency medicine (RAID teams in Birmingham), and access to psychological therapy through primary care. These recent innovations may help improve the access to care, which should be empirically explored on its impact to disproportionate detention rates. Despite these breakthroughs, there still remains limited direct access to psychiatric services from other routes, such as community and faith based organisations.

Clinical Implications

There are three main clinical implications to this work. The first is related to ethnic differences in the appraisal of the early signs of psychosis. For those professionals involved in the assessment process of Black-Caribbean patients, attention should be made to the way clinical symptoms are presented and how they are communicated; in particular the articulation of early psychological disturbance through the discourse of life difficulties. In addition carers' accounts should actively be sought in the assessment process wherever possible, to augment patients account- however, this may raise some

ethical concerns about patient-clinician confidentiality, which should also be acknowledged.

Secondly, there needs to be improved access to psychiatric care. As suggested by the hypothesis earlier, early psychiatric treatment is likely to prevent a crisis event from occurring, which in turn could reduce excessive rates in detention. In addressing this, mental health services may want to explore partnering with community organisation that the Black-Caribbean community regularly have regular contact with. Faith based organisations were frequently mentioned as being sought by Black-Caribbean carers in the qualitative work, so beginning to explore the referral processes through such organisation may be a logical place to start. Unemployment and fragmented living situations were also found to explain ethnic variation in detention rates. As with faith-based organisation, psychiatric partnerships with organisation routinely dealing with these agencies may also increase the chances of early psychiatric referral.

Finally, public health promotion may be another important tool to address this issue. Carers frequently stated that early signs of psychosis were missed and few had knowledge of where to go for help. In Birmingham at least, services should try and improve mental health literacy within the Black-Caribbean community, in specific, knowledge of the signs of early psychosis and of the avenues to get help. In this digital age, the use of social media may form part of this strategy. Commercial organisations have been very good at using this medium in targeting specific sectors of society; it would be interesting to see if a NHS campaign could also innovate in this way. It is also worth noting that this approach should be multi-generational, focusing on patients, carers and their wider family network. It was clear that help seeking from inside of one's

immediate family was common in the Black-Caribbean community, so providing information accessible to all is likely to increased early detection and appropriate help seeking.

Theoretical Contributions from This Thesis

There are two main theoretical implications that have emerged from this work. The first is related to methodology. Mixed methods research is slowly increasing in popularity with in the context of health care. In this study, a mixed method design was chosen as previous quantitative-epidemiological approaches had failed to fully account for excess. Commonly described as Black-box approaches (Morgan et al., 2004), it was clear that if new knowledge in the area was to be achieved, improvements in the methodology needed to be sought. Theoretically, the marriage of both quantitative and qualitative methods in the convergent parallel design selected (Chapter Three) have proven beneficial in understanding both the complexity and fullness of the phenomena. This approach therefore may be of some benefit in other areas of mental health research, looking to explore complex systems or events. This work therefore advocates the usefulness of combining different methods, especially in cases where there is a social component to the phenomena being investigated.

The second theoretical contribution of this work is the 'crisis hypothesis' itself. From the outset of this thesis there was much disagreement and unknowing of the reasons behind ethnic differences in detention rates during FEP. This study has therefore developed the first empirically supported model in explaining the phenomenon. Like with all sciences, the purpose of research is to generate new paradigms, which future research can reject, confirm or improve upon. A theoretical contribution of this work

therefore, is the beginning of this process, which may be further applied to similar areas of psychiatric research where ethnic disparities exist.

Future Research

As previously discussed, a limitation of the crisis hypothesis is that there is a lack of understanding of the influence of factors at the service level. Previous research has been used to fill this gap; however, there is still a lack of knowledge about the specifics during the assessment process. For this reason, the first recommendation of this thesis if for future studies to explore the sectioning process, specific to those patients' experiencing a First Episode of Psychosis. Such research may reveal which factors increase the likelihood of detention, highlight barriers that prevent the need for sectioning and uncover how clinicians construct the notion of risk (to self and others).

In the mental health trust that this research was conducted in, similar work of this nature has been successfully conducted and so adapting this work to understand ethnic differences in detention rates to FEP would require minimal effort. Over a given time frame, early intervention services could collect and identify all Mental Health Act assessments of new referrals, regardless of whether the patient was detained or not. Comparisons could be made between ethnic groups to explore the reasons why certain FEP patients are detained and why others were not. Ethnic comparison could then be made to identify factors specific to the Black-Caribbean patients in comparison to other defined groups. If the crisis hypothesis were true, we would expect to find some similarities between the findings presented in this chapter and the outcomes of such research. In a similar vein, interviewing professionals involved in the section process of FEP patients would also help complement this study. GPs, community mental health

nurses, approved mental health professionals and psychiatrists all have a wealth of experience in the area; and so drawing on their knowledge may also help enhance the model from a different perspective.

Another potential study that could come from this work is some pilot-feasibility work attempting to reduce the excess in detention rates. The crisis hypothesis has highlighted that there are differences in the appraisal of the early stage of psychosis within the Black-Caribbean community. In order to overcome the bias of this during the referral process, future research may wish to develop a new culturally sensitive tool for routine clinical practice. The notion of symptom attribution is also important here, and hence some in depth qualitative work could unpack the link between language, symptom articulation and symptom experience. In addition, pilot-feasibility work in attempting to reduce detention rates through developing partnerships between community organisations and statutory NHS services may be of use. Once these partnerships have been established it would be good to observe how many successful referrals came through community organisation and if this impacted excessive detention rates. This study could also include an economic component, exploring both the efficacy and cost-effectiveness of opening up referrals to non-statutory organisations (e.g. churches, schools, youth group and job centres).

Chapter Conclusions

The purpose of this thesis was to further understand ethnic differences in detention rates during FEP. Using a mixed method design, a potential model began to emerge that unified different findings throughout. The crisis hypothesis, as described in this chapter, is only the start of comprehensive explanation of the disparities in compulsory

hospitalisation, as there are still many questions left unanswered. Future research may

wish to test the model and develop it through the scientific process, which may give rise

to more complete ways of understanding in the future.

Chapter Nine

Thesis Conclusions

Over the last 30 years we have been aware of persistent ethnic differences in British psychiatry. Collectively, existing research has shown that Black patients are roughly 3.83 times more likely to be detained under the MHA in comparison to White-British patients (Singh et al., 2007). Some have argued that such variation in the use of compulsory hospital admission is the result of elevated rates of psychosis, which although may partly be true, cannot account for ethnic differences found in first episode psychosis, as diagnosis is controlled for. In the meta-analysis conducted in this thesis, Black-Caribbean patients were roughly two and a half times likelier to be detained, in relation to comparative samples. This finding was again supported in the empirical work conducted, and found that Black-Caribbean patients were up to 5 times more likely to be detained during FEP. While such rates are in themselves alarming, more concern should be taken to the lack of knowledge of how such disparities occur. It was this notion that this thesis aimed to address, building on existing research conducted in the area through a new exploratory lens.

Previous research has partially accounted for excessive rates of detention, with factors such as clinical factors, socio-demographics, and encounters with the criminal justice agency involvement. In addition to these variables, this work empirically identified a series of new explanatory variables such as, attributions, living status, prodrome length, service delay and emergency medical contact. In conjunction with the many insights derived from the qualitative work, a new comprehensive theoretical understanding

emerged. The theory (entitled the crisis hypothesis), states that for a significant proportion of Black-Caribbean patients, as series of associated processes result in first episode psychosis being experienced through a crisis event. As a result, a series of crisis response action are initialed, from various actors within the health care system, which in turn leads to excessive rates of compulsory hospital admission.

Although this model is the first to comprehensively explain excessive rates of detention during FEP, on a range of different levels, it is not without its limitations. Currently a lack of understanding of the processes at the service level is currently missing from this model. It could be that factors within services may account for the missing variance in excessive detention rates quandary. Caution should therefore be made in interpreting this model as an end-point of investigation. But rather, the model should be taken as a new paradigm, which future research should improve upon and redefined through the scientific process.

Politically the area of ethnicity and detention is still highly contentious, and there is much debate as to what the exact causes are. However, what can be taken from this work is that there are real ethnic differences in the pathway to care for ethnic minority groups in Britain, above and beyond that of compulsory hospital admission. Also, it is worth noting that these differences are inextricably linked to one another; and are differences that go beyond skin colour and country of birth alone. Activist groups, carers, clinical staff, commissioners, academics and policy makers need to be aware of this fact, and incorporate this notion into their respective fields when thinking about the best ways to deliver mental health care provision for Black-Caribbean patients. Now that we are aware of this fact, it is up to us to respond; simply highlighting differences can no

longer be our only recourse. Action must be taken to further understand the complexity of difference, which can further lead to strategies to reverse /equalise these differences. This action also needs to be one that outstretches both psychiatric and academia alike and involve all aspects of society, including the entirety of the NHS.

The notion of ethnic differences is psychiatric health care provision is extremely complex, which in part has been further highlighted by this work. For this reason, the approach used to address these differences must be equally as complex, and more importantly grounded in robust, scientific and evidence based practices. It also requires both the clinical and scientific community to work in unison, which could possibly be facilitated though collaborative research grants given directly to mental health trusts that champion good clinical research in the area. Although there has been the debate around specialist services for ethnic minority groups (Bhui and Sashidharan, 2003), many have argued that this may not be the best way forward. Instead research may wish to explore the benefits of clinical services being more closely embedded within the communities in which they serve, which in turn would improve the pathway to care, overcoming the barriers that exist.

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Appendices

Appendix 1: Methodological appraisal of ethnicity studies by Bhui et al. (2003)

Appendix 2: Patients' Socio-demographic information sheet

Appendix 3: Nottingham Onset Schedule (NOS)

Appendix 4: EPAS coding framework and interview guide

Appendix 5: Amended Encounter Form

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Appendix 8: Qualitative Interview topic guide

Appendix 1: Methodological Appraisal of Ethnicity Studies by Bhui et al. (2003)

Sample source and size	Score	Adjustment for confounding variables	Score	Ethnicity categorisation			
				Quality	Score	Use in the analysis	Score
Routine data (e.g. health authority, GP list data)	0	None	0	Third-party reports (e.g. ward staff categorisation, name-based methods, skin colour methods)	0	Inappropriate ethnic groups combined for major study outcomes (e.g. Blacks v. all others) or poor method of collecting ethnicity data	0
Project-specific data: <30 cases in ethnic groups for major outcomes	1	Age and/or gender	1	Self-reported ethnicity or use of census categories	1	Lumping of groups: reasonable combinations of groups collected by census/self-report method	1
Project-specific data: >30 cases in ethnic groups for major outcomes	2	Diagnosis or disease severity (give 1 point if this sample is selected by diagnosis)	1			All analysis done on ethnic groups without amalgamation, and self-report/census categories for categorisation	2
Project-specific data: total sample size >500	3	Comorbidity and risk factors for outcome of interest[1]	1–3				
Maximum possible[2]	3		5		1		2

1. Risk factors included socio-economic factors (deprivation score, employment, household size, marital status); comorbidity included drug and alcohol use, coexisting psychiatric conditions, violence to others.
2. Maximum possible score for all items=11; low quality 0–3; moderate quality 4–7; high quality 8–11.

Appendix 2: Patients' Socio-demographic information sheet

Service User General Information Sheet

Participants Name (Block Capitals)

_____

1. DOB: _____

2. Current age: _____

3. Sex: _____

4. Diagnosis (ICD-10 classification) _____

Ethnicity & Migrant Heritage

1. Self ascribed ethnicity (How would you define your ethnicity?):

_____

5. Census rating of ethnicity:

not known	Mixed White and Black African	Chinese
		Any Other Ethnic Group
White British	Mixed White & Asian	Welsh
White Irish	Mixed Other	Not Stated
White Other	Mixed White and Black Caribbean	Other
	Asian/Asian British - Indian	
Black/Black British - Caribbean	Asian/Asian British – Pakistani	
Black/Black British - African	Asian/Asian British - Bangladeshi	
Black/Black British - other	Asian/Asian British - Other	

7. Migrant generation:

1st generation	2nd generation	3rd generation	4th Generation	5th Generation	> 5th Generation	N/A

8. Country of Birth (specify):

_____ _____

9. Fluency in English:

Not Fluent	Fluent – spoken	Fluent – spoken and written
Fluent – other		

Faith (Religion)

10. Identified faith:

Christian	Muslim	Hindu
Sikh	Atheism	Agnostic
Catholic	None	Spiritual
Other…..		

11. Do you practice this religion: Y   N

Marital status

12. Current Marital status:

Married and cohabiting	Married, but separated	Cohabiting	Single	Widowed
Divorced	Civil Partnership	Other….		

Housing Situation: Living

13. Living Status:

Alone	With parents/ guardians	With partner
Alone with children	Other……	

14. Current Housing type:

Own Home/ parents home	Private rented	Supported Accommodation
Temporary accommodation	Psychiatric hospital	Council houses
Other……..		

Educational Qualifications Attained:

15. Education attainment:

No qualifications	CSE/GCSE/ NVQ level 1 or 2/O-levels	A-level/GNVQ/ BTEC/ NVQ level3
Degree/HND/ NVQ level 4 or above	Special Needs educational qualifications.	Postgraduate degree

Vocational information:

16. Current Job:
1. Paid Full time work
2. Paid Part time work
3. Home work (looking after family, house wife)
4. Training courses / Student
5. Job seeking
6. unable to work – long term sickness/disability
7. full time education
8. part time education
9. unemployed
10. Full time Voluntary Work/ work experiences

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11. Part time voluntary work/work experiences
12. Other

17a. Was the client in work or full time education before the First Episode: YES [   ] NO [   ]

17b. Clients Last occupation (if not currently working)

Caregiver

19. Primary care giver/s:

Mother Only	Father Only	Both Mother and Father
1 Other Family member	2 Other Family Members	Foster Parents
Social Services	Other two parent family	Other…

Geographical location:

20. Post code:

21. Clinical EIS team:

BEN	West	East	South

Social Networks:

22: How many people do you count as supportive at present (will listen/help/can be trusted)

Friends [   ]   Family [   ]

Most Concerning Symptoms for help seeking in FEP

P1	Delusions		G1	Somatic concern		G15	Preoccupation	
P2	Conceptual disorganisation		G2	Anxiety		G16	Active social avoidance	
P3	Hallucinatory behaviour		G3	Guilt feelings			Other Please specify	
P4	Excitement		G4	Tension				
P5	Grandiosity		G5	Mannerisms & posturing				
P6	Suspiciousness/persecution		G6	Depression				
P7	Hostility		G7	Motor retardation				
N1	Blunted affect		G8	Uncooperativeness				
N2	Emotional withdrawal		G9	Unusual thought content				
N3	Poor rapport		G10	Disorientation				
N4	Passive/apathetic social withdrawal		G11	Poor attention				
N5	Difficulty in abstract thinking		G12	Lack of judgement & insight				
N6	Lack of spontaneity & flow of conversation		G13	Disturbance of volition				
N7	Stereotyped thinking		G14	Poor impulse control				

Appendix 3: Nottingham Onset Schedule (NOS)

NOTTINGHAM ONSET SCHEDULE-DUP (NOS-DUP) version 4

Administration: Interview conducted by clinician at baseline.

Purpose: To record various time points in the onset of the psychosis.

Introduction.

i) *The Nottingham Onset Schedule-DUP version (NOS-DUP)* is short, guided interview for recording several time points in the onset of psychosis.

ii) *Concept of onset in NOS*: Onset is defined as the period between the first reported/observed changes in mental state/behaviour to the development of psychotic symptoms (transition into psychosis). Onset can be indicated by :

- Emergence of symptoms such as anxiety, depression, irritability etc.
- emergence of deficits such as psychological, cognitive, social or behavioural deficits
- emergence of unusual or bizarre behaviour
- decline in functioning in interpersonal, social, educational or occupational domains
- emergence of psychotic symptoms
- transition into psychosis (development of enduring psychotic symptoms)

Onset is conceptualised as comprising of

a)
 prodrome   a
b) emergence of positive psychotic symptoms ; and
c) Build-up of symptoms leading to a definite diagnosis **(transition into psychosis).**

Transition into psychosis is the point where the symptoms reach sufficient duration and intensity to provide a definite diagnosed of a psychotic illness. *Sufficient duration* is defined as symptoms occurring on most days for at least one week. *Sufficient intensity* implies that symptoms have a distinct impact on

the individual's functioning. Such a symptom would be scored 4 or more on the PANSS.

i)   *Prodrome P:* Prodrome is defined as the phase of illness before the emergence of frank psychotic symptoms. Prodromal symptoms usually include non-specific disturbance of mood, thinking, behaviour, perception and functioning. For such symptoms to be considered a part of the psychotic illness, there should be no return to premorbid functioning following onset of symptoms.

ii)   *First Psychotic symptom FPS:* Unequivocal presence of one or more positive psychotic symptoms. *Unequivocal presence equates to a rating of 4 (moderate) on the PANSS, characterised by the definite presence of the symptom which, though representing a serious problem either <u>occurs only occasionally or intrudes on daily life only to a moderate extent</u>. Within the SCAN (PSE) rating system, this would equate to a rating of moderate (2) on Rating Scale 2.*

iii)   *Definite Diagnosis DD:* Clear evidence of delusions, hallucinations, first rank symptoms, catatonic symptoms or thought disorder for at least one week **(transition into psychosis).**

START of TREATMENT

This is defined as the date when *antipsychotic treatment is commenced at clinically adequate dosage* for which there is *evidence of compliance*. If you are unsure whether the dosage is 'clinically adequate', please note the exact dose and check with a clinician later. Compliance is defined as: evidence that medication is being taken at 75% or above of the prescribed dosage; and for 75% of the prescribed time, or above.

Compliance may be assumed where a patient is on home treatment or is hospitalised, and there is no record of non-compliance. Where a patient has

initially been non-compliant, the date of start of treatment is at the point where the patient begins taking medication.

The NOS allows for several ways that DUP can be defined: from start of prodrome to start of treatment (duration of untreated illness); from emergence of first psychotic symptom to start of treatment; and from the date of definite diagnosis to start of treatment.

Conducting the NOS Interview and Rating

i) ***The NOS schedule is designed to be administered:***
a) with the patient *and* an informant,

b) as near to the time of onset of the illness as possible.

c) after other schedules (covering history and mental state,) have been administered.

The interview is determined overall by the structure of the NOS, but the order in which the sections are completed will be dependant upon the anchor dates and key events that have been provisionally established. The interviewer has a considerable degree of freedom about how to proceed.

Interviewees should be able to give valid consent and be well enough to concentrate and attend to an interview.

ii) ***Completing the Preliminary Assessment Sheet (PAS):*** Make sure that any provisional anchor dates and key events have been entered on the PAS before starting the interview. The PAS is completed from case notes and any other sources of information, prior to conducting the interview. Identify symptoms, life events or significant dates, any diagnoses

made, prescriptions given, any mention of compliance or side effects and any signs of recovery. Keep the PAS by you and use it as an interview guide.

iii) *Beginning the interview:* Explain to the subject that you already know something about how this illness started, and that you now want to get some more details to ensure that you have things in the correct sequence or order. For example;

"I am interested in finding out more about how you felt and what happened to you at each stage of your illness. I'm particularly interested in getting a clear idea of how you felt in the early stages, before it became quite obvious to you and your family that there was something definitely wrong with you."

Identify with the subject a few **anchor dates** and related **key events** that stand out as remembered clearly, and that have some relationship to any part of the onset. Build up as clear a picture of the components of onset as possible around these. When you are satisfied that the subject understands the purpose of this interview, then start with either the clearest or the first anchor date or event on the PAS and ask, for example;

"It says in your notes that you first came into contact with mental health services on [quote it]. At that time how did you feel?

"Did you feel that anything was wrong with you?"

"What sort of experiences were you having?"

"In what ways were you different from your normal self at that time?"

"So working backwards from that time, when was the last time you felt your normal self?...

It is important to remind respondents during the interview that onset of illness implies a *clear departure from premorbid functioning* with *no return to that level functioning.*

iv) ***Initial, open-ended questioning****:* If the NOS follows a psychiatric history-taking interview use an introductory statement like;

"You've told me that you knew that the Mafia were following you and were going to harm you. That started about 2 weeks before Christmas. Now what I want us to think about is what was going on and how you were feeling leading up to this ".

If the NOS doesn't follow a psychiatric history-taking interview then the interviewer should spend the first part of the interview finding out about the subject's positive psychotic symptoms and dating their origin. The interviewer should then pursue information using open-ended questions:

"Take me back to when you were feeling well and things were going OK for you, what happened first ....what was the first thing that you noticed had changed"

Once the presence of a symptom has been confirmed, dates can be clarified with direct questioning if necessary. It is useful to repeat back to the subject the information elicited, to ensure accuracy, for example;

"You remember enjoying your holiday in Cyprus in August, but about two weeks after starting back at sixth form in September you describe feeling very worried and down in the dumps about your work load. This preoccupied you so much that it stopped you getting to sleep until 3am. Is that correct?"

iv)   *Using checklists:* This incorporates the checklists in the schedule for the prodrome. The lists are not exhaustive but are for illustrative purposes only. You can use a set of cards, each with one of these symptoms listed and spread these before the patient. You can then ask them to pick the ones they experienced and attempt to find the time of occurrence.

Explore all relevant non-psychotic symptoms with direct questions if necessary:

"We've been through things in detail but I'd just like to make sure we haven't missed anything so I'm going to ask you a few specific things. Have you had the feeling of being restless, not being able to settle?"

v)   Start of Treatment: Confirm with the patient whether they are on medication. Check when medication was first prescribed. If needed, use the date of prescription from PAS as a probe.
Check whether medication was taken as prescribed. *" e.g. Some people tell me that they are not keen on taking their medication for one reason or another. How do you feel about taking your medication? Have you ever felt like missing the odd dose?"*

vi)   *Filling Out The Schedule*: Information can now be transferred to the schedule. Prodrome includes all non-psychotic symptoms that have been present in the prodromal periods; first psychotic symptom refers to

the time when an unequivocal positive symptom has been present, regardless of duration of the symptom.

vii)   Practical Points:

- Be flexible in your interview technique according to the subject. Sometimes it may be easier working gradually backwards from when the first positive symptom was apparent to the beginning of the prodrome.
- Dates will very often be vague despite trying to pin people down to birthdays, Xmas, summer holidays or important events in their lives. Around the beginning, middle or end of a month will very often be the closest estimate and often subjects will not be able to be this specific. If someone informs you of a month and gives no further information, take this to mean the middle day of that month, i.e. the 15th. Summer is taken as June, July and August; Autumn as September, October and November; Winter as December January and February; and Spring as March, April or May. Mid summer would therefore be July, mid winter January etc.
- Symptoms may be fluctuating and intermittent. Prodromal symptoms may start and then remit for a time. The start of onset is the time from where symptoms begin and original baseline functioning is never resumed despite symptoms waxing and waning. In some cases, especially with prominent negative symptoms at the outset, identifying a clear date of onset may be difficult. It is important to consult the family members and explore when the individual began to show a *clear departure from their usual premorbid functioning*.
- *Transition* into psychosis is the point where the symptoms reach the duration (one week at least) and intensity of impacting on an individual's functioning.

Reference: Singh, SP, Cooper JE, Fisher H et al   Determining the chronology and components of psychosis onset: the Nottingham Onset Schedule (NOS). *Schizophrenia Research 2005, vol 80, p 117-130*

NOTTINGHAM ONSET SCHEDULE: DUP Version 3 (NOS-DUP)

Name: **D.O.B:**   **Gender:**

Date:

Current psychiatric diagnosis (ICD-10):

Date of contact with mental health services:

Interviewer:

Check: informed consent obtained

Preliminary Assessment Sheet (PAS)

This sheet should be filled in before starting the interview, using all available information

Sources of information:

(1= Case-notes; 2= PSE; 3= GP letters; 4= History/MSE; 5= Informant/carer; 6= other, specify)

Prodrome (P)

Manifestations   Starting date OP (Onset of prodrome):

1.

2.

                                3.

4.

5.

6.

Date of First Psychotic Symptom (FPS)

Type of symptom:

TRANSITION - Date of Diagnosis of Psychosis from Notes:

Date of start of antipsychotics:

Antipsychotic used: Dose:

Compliance (Yes/No/Not known)

NOS Interview: Prodrome (P)

Key dates and/or anchor events.	Manifestations	Remarks/examples
Starting dates		

Prodrome checklist (this list is for illustrative purposes and is not exhaustive)

Please use cards as prompts

Thinking	Perception	Behaviour
Difficulty concentrating	Something has changed in you	Restless, can't settle, impulsive
Difficulty making decisions	Others have changed	Arguing more
Unusual thoughts	Senses seem sharper	Avoiding people, stays in more
People talking about you	Experiencing strange sensations	Seeking reassurance
People are against you	Seeing or hearing things	Becoming preoccupied
You cannot trust anyone	**Mood/Feelings**	Becoming frightened
You have special powers	Feeling unreal,	Speech muddled, and unclear

Receiving special messages	Feeling moody	Agitation, Inappropriate behaviour
Thoughts are being controlled	Feeling low and anxious	Unpredictable or rigid routine
Preoccupied with 1 or 2 things	Feel tired, lacking energy	Not doing well at work or school
Becoming increasingly religious	Feeling isolated	Poor sleep, appetite, weight loss
Others can read your mind	Feels empty, tense, irritable	Repetitive behaviour
You can read other people's mind	Elated, unduly cheerful	Neglecting hygiene
Thinking bizarre thoughts	Feeling guilty or suicidal	
People know what you are thinking	Feeling angry and aggressive	

Emergence of Psychotic Symptoms (FPS and DD)

Psychotic symptoms	Date	Examples/remarks
First psychotic symptom (FPS) Build-up of diagnostic symptoms *(delusions, hallucinations, thought disorder,* *FRS, Catatonic symptoms, negative symptoms, bizarre behaviour)*		
TRANSITION: Date of definite diagnosis from interview (DD)		

Start of Treatment (T)

Antipsychotic (s)	Dose	Date prescribed	Date taken regularly (at least 75% compliant) **T**

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Determining Durations

- **Prodrome**   *From OP to DD*
- **Emergent Psychosis**   *From FPS to DD*
- **Duration of untreated Psychosis**   *From DD to T*
- **Duration of untreated illness**   *From OP to T*

We recommend using the time period from Definite Diagnosis to Treatment (DD-T) as standard measure of DUP

Example probes for establishing DUP – to be used in conjunction with the NOS

These probes are being provided as a guide to questioning only. As per the instructions for completing the NOS, information should have firstly been gathered from the clinical file to direct the rater to the appropriate lines of questioning.

All sources of information should be utilised when administering this assessment – gather information from the clinical file, the informant and the patient themselves.

Note: While using the probes, use 'you' if interviewing client and he/she if interviewing the service user. For each question, you could ask questions of Onset-Duration-Frequency

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Probes for establishing onset of Psychosis

Did you notice any strange behaviour?
When was the first time this occurred?

Did you/ he/she talk about, or show in some way, that you/they had any strange fears or beliefs?
When was the earliest evidence of this?

Did he/she act as if they were seeing or hearing people or things that weren't there?
When did this first occur?

Did he/she talk without making sense?
When did you first notice this?

Did he/she say that something or someone was trying to make them do or think things that they did not want to do or think about?
When did this first occur?

Was there any other evidence of unusual experiences?
When did they first begin?

Which of the above changes were first?

Unusual perceptual experiences

Did you/ s/he report any strange or unusual experiences?
Did you/ s/he ever feel as

Did you/ s/he describe any visions?
Did you/ s/he say that objects or people looked different?
Did you/ s/he act as if s/he could see things or people that were not visible to others?

Did s/he describe hearing sounds or voices that others couldn't or when s/he was apparently alone?   317
Did s/he behave as though this were occurring?

Did s/he clearly misinterpret sounds?

Did s/he say that things s/he touched felt different or changed in some way?

Did s/he talk about unusual changes in (parts of) his/her body?

Did s/he ever describe sensing that some person or force was near him/her when there was apparently no one present?

Probes for establishing onset of Manic Syndrome

Did you notice any significant change in his/her mood?

Did he/she appear to be or describe feeling unusually elated or cheerful, or irritable or angry?

How long did this mood last?

When did the change in mood first appear?

Was there any evidence of any of the following:

Significant increase in activity and energy level?

Rapid speech that was difficult to follow or interrupt?

Marked increase in self-confidence?

Decreased need for sleep?

When did the earliest of these features occur?
Use the following probes to establish what a caregiver observed, then narrow the questions in order to assess in more detail.

Social isolation or withdrawal

Did s/he see any family members on a regular basis during that period?
Did s/he have regular contact with anyone else? (including friends, work colleagues, relationships)
    Who were they?
    How often did s/he see them?
    What did they do together?
Did s/he avoid being with others?
Was this a change for him/her?
What impact did this have on his/her life?

Marked impairment in role functioning

Was s/he working during that period?
How were things going for him/her at work?

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Was s/he involved in any educational activity?
How was his/her performance – attending classes, examinations/assignments, socially?

Was s/he involved in looking after the home (and family)?
Were there any problems identified with completion of tasks?

Markedly peculiar behaviour

Was there anything odd or unusual about his/her lifestyle during that period?
Did his/her behaviour change in any way?

Marked impairment in personal hygiene and grooming (tactful enquiry essential)

Did s/he have any problems looking after him/herself properly?
Was there any change in his/her standards of dress, grooming, or hygiene?

Blunted, flat or inappropriate affect

Was it difficult to know how s/he was feeling because s/he didn't show much facial expression?
Did s/he tend to avoid looking at people when speaking with them?
Did s/he have a monotonous way of talking?
Did s/he use his/her hands or body much as s/he was speaking to help express him/herself?
Did s/he tend to smile, or laugh for no apparent reason?

Digressive, vague, overelaborate or metaphorical speech

When s/he spoke was it difficult to follow?
Did s/he ramble on and on so that people got bored or confused?
What was the problem – too much unnecessary detail, frequent changes of topic, going off on tangents and never getting to the point?
Did s/he use words in odd or unusual ways?

Odd or bizarre ideation, or magical thinking (e.g. superstitiousness, clairvoyance, telepathy, 'sixth sense', overvalued ideas, ideas of reference)

Did s/he develop any unusual beliefs or convictions that were new and important to him/her?
Did s/he claim any special powers, such as telepathy or the ability to foretell the future?
Did s/he become especially interested in magic, the occult, or religion?

Marked lack of initiative, interests or energy

Did s/he find it hared to get going and decide to do anything?
Did s/he find s/he couldn't be bothered with or interested in things s/he previously liked or wanted to do?
Was s/he feeling weak and tired most of the time?

Thinking	Perception	Feeling angry and aggressive
Difficulty concentrating	Something has changed in you	**Behaviour**
Difficulty making decisions	Others have changed	Restless, can't settle, impulsive
Unusual thoughts	Senses seem sharper	Arguing more
People talking about you	Experiencing strange sensations	Avoiding people, stays in more
People are against you	Seeing or hearing things	Seeking reassurance
You cannot trust anyone	**Mood/Feelings**	Becoming preoccupied
You have special powers	Feeling unreal,	Becoming frightened
Receiving special messages	Feeling moody	Speech muddled, and unclear
Thoughts are being controlled	Feeling low and anxious	Agitation, Inappropriate behaviour
Preoccupied with 1 or 2 things	Feel tired, lacking energy	Unpredictable or rigid routine
Becoming increasingly religious	Feeling isolated	Not doing well at work or school
Others can read your mind	Feels empty, tense, irritable	Poor sleep, appetite, weight loss
You can read other people's mind	Elated, unduly cheerful	Repetitive behaviour
Thinking bizarre thoughts	Feeling guilty or suicidal	Neglecting hygiene

Appendix 4: EPAS coding framework and interview guide

Early Psychosis Attribution Schedule - EPAS

Within the individual	In the social world
1: Brain malfunctioning. 2: Problems of mind. 3: Personality / A part of who they are. 4: Physiological or biological malfunction. 5: Genetic/ Hereditary 6. Other within the individual causal beliefs	10. Negative Sexual Experiences During Childhood 11: Negative Physical Experiences During Childhood 12: Negative Psychological Experiences During Childhood 13: Negative Sexual Experiences During Adulthood 14: Negative Physical Experiences During Adulthood 15. Negative Psychological Experiences During Adulthood 16. Lack of Social Support Networks 17. Conflict with Culturally Defined Norms 18. Economic and Financial Issues 19. Family Disturbances 20. Death Of loved One 21. Other Social causal beliefs
In the natural world	**In the Supernatural world**

7. Medicine and Narcotic use/abuse
8. As the result of accident or injury
9. Invasion of Germs/infections
 	
66: Not attributed
   • The participant held no causal belief about illness.
88: Cant code:
99: No causal belief given:
   • participants were unable to give a causal belief
100: Other
	22. Punishment for sins/ wrong doings by a supernatural force
	23. Possession/ by Jinns/ Bhoot/ Demons/sprits within
	24. Supernatural Human Influence
	27. Science Based Occurrences outside The Natural Realms.
	26. Conspiracy Against The Individual
	25. Interaction With A Supernatural Force.
	28: Other Supernatural, Cultural, Spiritual Attributions

Appendix 5:Amended Encounter Form

Pathway Encounter Number ☐☐☐☐☐

A) Phase of illness

1	Non-specific symptoms	2	Psychotic pre-phase	3	First Episode Psychosis
4	In Remission				

B) Who was seen?

1	GP	2	CPN	3	Social services
4	Religious Leader	5	Casualty Dept	6	Private Psychiatrist
7	Police (POL)	8	Psychiatric Hospital	9	Home treatment team
10	Primary Care Team	11	CMHT (unspecified)	12	Psychiatrist
13	Psychiatrist (drugs service)	14	Neurologist	15	Counsellor/Therapist/ Psychologist
16	Support Worker	17	CAMHS	18	Other (specify)
19	Prison Services (CRIM)	20	Friend	21	Family
22	Community healers	23	School teacher	24	Educational psychologist
25	Secondary Care team	26	Early Intervention Service	27	Religious institutions
28	EDIT	66	Not known		

B2) How were they seen?

1	In person (Face to Face)	2	Phone Call	3	Letter
4	Via text	5	Internet based Communication	6	Other
66	Not known				

C) When was this person/team seen?
[Estimate to Beginning 1st /Middle 15th/End of month 30th if unable to give exact date]

_____/ _____/ _____ (dd/mm/yyyy)

C2) Who attended the appointment?

1	No	2	Client	3	Family Member/s
4	Friend/s	4	Client and Family Member/s	6	Client and Friend/s
66	Not known				

D) Who suggested that care ought to be sought?

1	Client	2	Family Member/s	3	Friend/s
4	Referred from previous Pathway No_____	5	Client and Family Member/s	7	Work colleague/s
66	Detained by Police (Section 135 & 136)	9	Pathway contact approached client		Not known

E) What was the main problem presented?
_____
_____
_____
_____

F) Do you (the researcher) consider the client's symptoms at this point to have been?

1	Psychotic (Psychosis)	2	Non-specific symptoms	3	Symptoms unclear
4.	Low level psychotic symptoms (Blips, Attenuated)	66	Not known		

G) Was medication prescribed/administered?

0	No	1	Antipsychotic	2	Anti-depressants
3	Other (Specify)	4	Not Known		

H) Was Treatment Compliance reached (TC)?

0	No	1	Yes	2	N/A

I) Was the client referred to other services?

0	No	1	Accepted by EIS	2	Referred to EIS - not accepted
3	Referred to other agency/ professional. Pathway No_____	66	Not Known		

J) Was other Intervention, Advice & Referrals offered?

0	None	1	Counselling/Advice/ Support	2	Regular Visits/ Assertive Outreach
3	Outpatients appointments	4	Religious intervention	5	Physical Health Checks
6	Admission – Sectioned (MHA-D)	7	Admission - Voluntary	8	Religious referral
9	Began to practice religion more	10	Changed life style activities	11	Was asked to take alternative medical (acupuncture, homeopathy)
12	Cultural Intervention	13	Other (Specify)	66	Not known
14	Given follow up appointments				

K) Did the patient/carer find this contact was useful?

0	Yes	1	No	2	N/A
66	Not Known				

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Appendix 6:Patient Information sheet and Consent Form

ENRICH

Birmingham and Solihull **NHS**
Mental Health NHS Foundation Trust

ENRICH
Research and Development
Radclyffe House
66-68 Hagley Road
Birmingham
B16 8PF

Consent Form for Service User

ENRICH, Study 1: Determining cultural determinants to care and help seeking behaviour in First Episode Psychosis (FEP).

Thank you for agreeing to participate in this study.

Please Initial box

1. I have read the information sheet dated 19-01-09 and was provided enough time to read and ask questions about it.

2. I understand, I am taking part voluntarily, all data will be kept confidentially and I am free to withdraw anytime without giving any reason and without my medical care or legal rights being affected.

3. I know that things I say may be published but that my confidentiality will be protected and my name and any other details which might identify me will be changed.

4. I agree to provide a name of someone close to me (usually a family member/carer) that the researcher can contact.

5. I would like a copy of the study findings.

6. I consent for the research team to contact _____, as my named carer.

7. I am aware that my Psychiatrist will be informed about my participation in this study.

....
Name of Service User   Date   Signature

....
Name of the Researcher   Date   Signature

Names of Researchers: Luke Brown.

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ENRICH
Research and Development
Radclyffe House
66-68 Hagley Road
Birmingham
B16 8PF

Information Sheet for Service User

Enrich Study 1: Determining cultural determinants of pathways to care and help seeking behaviour in First Episode Psychosis (FEP).

You are being invited to take part in a research study being carried out by a team of researchers within Birmingham and Solihull Mental Health Foundation Trust. Before you decide whether you want to participate or not, we would like you to understand why this research is being conducted and what it will involve. ENRICH comprises of five studies which aim at looking at ethnicity, detention and people's experiences of care within various services in BSMHFT. You have been invited to take part in one of these studies. Please take as much time as you need to read the following information carefully. Let us know if you require any additional information or have any questions, on the contact details below;

Luke Brown (Research Fellow)
Telephone: 0121 301 4336
e-Mail: Luke.Brown@bsmhft.nhs.uk

Thank you for reading this.

What is this study about?

We would like to understand whether ethnic and cultural differences influenced your pathways into care after your first episode of illness. We would like to look at when you started to experience your problems, what were your explanations of these problems at the time, and whom/where did you go to for help.

Why have I been contacted?

You have been contacted because you have been in touch with Early Intervention Services and live in Birmingham.

Do I have to take part?

Participation is completely voluntary. If, during the interview, you feel uncomfortable, you can ask the research staff to stop and your data will be withdrawn from the study. You choosing not to take part will not affect care you will receive, either now or in the future.

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What will I have to do?

If you agree to be contacted, a researcher will arrange a place and time to meet you. You can choose where the interview takes place and the researcher will invite you to sign a form to give your consent to the research. You will be given a copy of the consent form and an information sheet about the research and will be able to ask as many questions as you want.

The researchers will ask you some questions about the history of your illness, symptoms you' have experienced and the help that was provided to you at different stages. The assessment will normally last a hour, but you can end it earlier if you desire.

We would also like to talk to someone close to you (for example a family member or friend), to help us understand your case better and would be happy if you could name a carer on the consent form.

What are the benefits of taking part?

Travel expenses, if any will be covered. In cases, where interviews will be conducted in your home, £10 will be provided for hosting the interview. Also, by telling us about your experiences of care, you will play a role in helping to improve the care of people who might be in contact with mental health services in the future.

What will happen if I become unwell, while participating in the study?

If at any stage you become unwell, researchers will discontinue the research process with you. All data that you have contributed towards the study, at this stage, will be kept on record. When you are well enough to continue, the research team will then approach you.

Will my taking part in study be kept confidential?

Yes. All the information that is collected about you during the research will be strictly confidential. Interviews may or may not be recorded. In cases where interviews are recorded a digital recorder will be used. Each audio file will be uploaded to a secure computer and deleted from the portable recorder when the researcher returns to the office. The audio files will be stored securely (password protected) alongside the transcripts and separate from any identifiable personal data. The audio files will be destroyed after they have been transcribed. Any details we have about you will be kept in a filing cabinet in a locked office, accessible only to researchers on the study. We will make every effort to ensure that things you tell us can not be identified with you by name or indirectly.

What will happen to the results of the research?

The results of this research will be reported in scientific journals and mental health literature for service users, carers and health professionals. Please be assured that you will not be identified in any report or publication. If you would like a summary of the findings you can tick a box on the consent form and we will send it to you when it is finished.

Who is organising and funding this research?

The research is being organised by Professor. Swaran Singh, a Consultant Psychiatrist, within the Early Intervention Services. It is funded by National Institute of Health Research (NIHR). He can be contacted on 0121 3011850/ 024 7615 0190 and his email id is: s.p.singh@warwick.ac.uk.

If you wish to contact someone independent, please contact Dr Paul McDonald, Head of Research and Development, Birmingham & Solihull Mental Health NHS Foundation Trust on 0121 6782000.

Appendix 7: Carers' Information sheet and Consent Form

ENRICH

Birmingham and Solihull **NHS**
Mental Health NHS Foundation Trust

ENRICH
Research and Development
Radclyffe House
66-68 Hagley Road
Birmingham
B16 8PF

Consent Form for Carers

ENRICH, Study 1: Determining cultural determinants to care and help seeking behaviour in First Episode Psychosis (FEP).

Thank you for agreeing to participate in this study.

Please Initial box

1. I have read the information sheet dated 19th January 2009 and was provided enough time to read and ask questions about it.

2. I understand, I am taking part voluntarily, all data will be kept confidentially and I am free to withdraw anytime without having to say why. I agree to take part in the study.

3. I know that things I say, may be published but that my confidentiality will be protected and my name and any other details which might identify me or the service user will be changed.

4. I understand that the interview will be recorded, typed up and the tapes destroyed. Some of the things I have mentioned might be used by the researchers in the form of quotations, but my identity will be anonymised and protected.

5. I would like a copy of the study findings.

5. I give permission for the use of direct quotations from the interview in the write up of this study.

....
Name of the Carer

....
Date

....
Signature

....
Name of the Researcher

....
Date

....
Signature

Names of Researchers: Zoebia Islam, Rubina Jasani, Ruchika Gajwani and Luke Brown.

Appendix 1-C

ENRICH

Birmingham and Solihull NHS
Mental Health NHS Foundation Trust

ENRICH
Research and Development
Radclyffe House
66-68 Hagley Road
Birmingham
B16 8PF

Information Sheet for Carers

Enrich Study 1: Determining cultural determinants of pathways to care and help seeking behaviour in First Episode Psychosis (FEP).

You are being invited to take part in a research study being carried out by Birmingham and Solihull Mental Health Foundation Trust. Before you decide whether or not you want to take part in this study, we would like you to understand why this research is being conducted and what participating in it will involve. ENRICH comprises of five studies which aim at looking at ethnicity, detention and people's experiences of care within various services in BSMHFT. You have been invited to take part in one of these studies. Please take as much time as you need to read the following information carefully. Let us know if you require any additional information or have any questions on the contact details below;

Rubina Jasani (Research Fellow)
Telephone: 0121 301 4337
e-Mail: Rubina.Jasani@bsmhft.nhs.uk

What is this study about?

We would like to understand whether ethnic and cultural differences influence pathways into care after first episode of illness. We would like to know the different problems that you had when you noticed something was wrong, how you understood these problems, and what steps they/you took to seek help.

Why have I been contacted?

You have been contacted because you are a carer and your cared one has been under the care of Early Intervention Service, Birmingham.

Is it compulsory to take part in this study?

Participation is completely voluntary. If, during the interview, you feel uncomfortable, or wish to discontinue, you can ask the research staff to stop and your data will be withdrawn from the study. You choosing not to take part will not affect the care your family member/friend is receiving, either now or in the future.

Appendix 1-A

What will I have to do?

If you agree to be contacted, a researcher will arrange a place and time to meet you. You can choose where the interview takes place, and the researcher will invite you to sign a form to give your consent to the research. You will be given a copy of the consent form and an information sheet about the research and will be able to ask as many questions as you want.

The researchers will ask you some questions about the care you have been providing, the problems you faced, your perceptions of these problems and any help that you sought. The interview will normally last an hour, but if you want to end it earlier, your decision will be respected.

Appendix 8: Qualitative Interview topic

What are the benefits of taking part?

Travel expenses, if any will be covered. In cases, where interviews will be conducted in your home, £10 will be provided for hosting the interview. Also, by telling us yours and your cared ones experiences of care, you will be helping to improve the care of people who have contact with mental health services in the future.

guid

Will my taking part in study be kept confidential?

Yes. All the information that is collected about you or the person you provide care for, during the research will be strictly confidential. Interviews will be recorded using a digital recorder, so no audio tapes will be used. Each audio file will be uploaded to a secure computer and deleted from the portable recorder when the researcher returns to the office after the completion of the interview. The audio files will be stored securely (password protected) alongside the transcripts and separate from any identifiable personal data. The audio tapes will be destroyed after they have been transcribed. Any details we have about you or the service user will be kept in a filing cabinet in a locked office, accessible only to researchers on the study. We will make every effort to ensure that things you tell us can not be identified with you by name or indirectly.

What will happen to the results of the research?

The results of this research will be reported in scientific journals, mental health literature for service users, carers and health professionals. Please be assured that you will not be identified in any report or publication. If you want a summary of the findings you can tick a box on the consent form and we will send it to you when it is finished.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the way you have been approached, during this study, you can contact Dr. Paul McDonald, Head of Research and Development, Birmingham & Solihull Mental Health Foundation Trust on 0121 6782000.

LB – Ph.D. interview guide v3

Qualitative Study Topic Guide- Compulsory Hospital Admission Version

Introduction: Start with a brief introduction - Purpose of the study, confidentiality, informed consent and withdrawal rights etc.

Structure of the interview: Inform the participant that you are interested in talking about three things related to {patients name's} journey to psychiatric care and compulsory hospitalisation in a guided narrative format. Tell them that this interview will cover three main things; 1) how symptoms developed, 2) how symptoms were attributed, understood and made sense of and 3) help seeking that occurred and the pathway to care. Inform the carer that you have already talked to the patient and looked through their medical notes to developed a preliminary timeline of events, however, you are interested in hearing their account to gain a fully picture.

Guided Narrative Interview- it's best to be relatively flexible in this stage, as each carer will tell events in their own way.

Firstly, It's best off to get the carer to start from the events most recent, as this will be most fresh in their minds. You may want ask *'how did [patients name] finally come to early intervention services?'* and then work backwards or forwards from this event. It is likely that after this point carers will begin to give a narrative account of events in their own unique way – let them!!!, but try to make sure that the following three topics are covered in detail.

Topic Cluster 1 - How Symptoms Developed

Get the carer to talk about normalcy, when the patient was fine in their eyes, types of behaviours, activities they would engage in, friends, school and work life, living arrangements, mood, life experiences. What time and date was this roughly?. You may wish to use the timeline as a guide to help them where necessary (REMEMBER PATIENT CONFIDENDTIALITY AT ALL TIMES).

Then get the carer to talk about the first noticeable changes, when they were first aware that something was 'not quite right'. Establish a time frame, what did they think was going on. What were the things that they noticed? Try and identified if these behaviours were psychotic in nature or not, how long they went on for. Use probes around depression, anxiety, and social withdrawal in a similar way to the NOS.

Then cover how things progressed from there on, how did they develop, other changes, how more unusual symptoms emerged. Events and situations where symptoms became more noticeable or bizarre. Conversations that they had with the patients that were unusual, strange, disturbing.

Finally explore the behaviours and symptoms that lead to encounters with clinical services and the route to hospitalisation. Events and situations, risky behaviours, symptoms in the home life, what were the consequences of illness related behaviours.

Topic Cluster 2 - How symptoms and behaviours were attributed, understood, made sense of.

Try and probe carers to talk about how they made sense of what was happening to the patients in question. i.e. what did you think was going on? What did you think was causing it? Did you talk to anyone else about it, what did you say to them? It is important to be relatively flexible with regards to this topic cluster and interweave these questions in and amongst the narrative accounts of carers.

Topic Cluster 3 - Help seeking and the pathway to care

Talk about help seeking behaviours that may have occurred at different stages. Try and get an account of all encounters both small and big, at different stages during the illness. Use the encounter triangle to probe for each level (e.g. lay contacts, community and faith based help seeking and mental health). Explore the chronology of help seeking, and the experiences associated. Focus on the help seeking and events that lead up to compulsory hospital admission. Also attempt to link help

seeking to symptoms mentioned in the topic cluster 1 (e.g. ' so when you mention that (patients name) was acting strangely, did you try and get any help'). You may wish to talk about why certain help seeking actions were not taken.

Debrief-

Tell them of the nature of the research in detail, and allow for questions should they so require.