Final Project: IPL5320

Title of Project: An investigation of Black Minority Ethnic service users' perception of their needs within a North London Mental Health NHS Trust

A project submitted to Middlesex University in partial fulfilment of the requirements
for the degree of Doctor of Professional Studies

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February 2021

Word Count: 70,968

Contents

List of Figures

List of Tables

Abstract

This study was conducted to find out from service users from a black and minority ethnic background (BME) how they perceive their needs were being met when being cared for in the Mental Health Trust. The participants were drawn from the black ethnic group including Black African, Black Caribbean, Black British and Black Mixed Race.

The study was a descriptive phenomenological study whereby the participants were interviewed using a semi structured interview via the use of a topic guide. The study was informed by the mental health trusts' priorities under the Race Equality Scheme to meet the needs of the diverse group which it serves.

The interviews were tape recorded and the data collated was transcribed verbatim. Six themes and subsequent sub-themes were identified following thematic analysis of the data. The findings from this research study suggest that BME service users did not express any negative views about the care they received by the mental health trust. Some of the BME participants however stated that they had to wait varying lengths on time before they received specialist psychological services. The participants expressed that they experienced stigma and discrimination by the police, criminal justice system, employment and the wider public.

A few recommendations were made including the development of a 5-day training programme to support the police in enhancing their knowledge and skill about mental illness. Mental health professionals to continue to challenge discrimination through campaigns, video, leaflets. There was also a recommendation made regarding the 6Cs - Care, Communication, Compassion, Courage, Competence and Commitment. In that the term 'Consistency' should be added to make a 7th C. Other Implications for practice were also noted.

Key Words: BME service users, needs, mental illness, support.

Acknowledgements

I want to make a special mention of Professor Kay Caldwell (former academic supervisor) who would always make time for supervision and constructive feedback and would remind me: “Veronica you are racing along!”- That gave me more impetus to keep going. My appreciation also goes to my academic supervisors, Dr Gordon Weller and Dr Catherine Kerr for their guidance and direction. Gordon, I want to say a special thank you for your understanding over the years, especially when I needed to take time off during my period of illness.

A special thanks also goes to the participants who gave up their time to be part of this study. I would like to thank the Service Managers, Community Mental Health Team Managers, Care Coordinators for their help in making this study possible.

I would like to say a special thank you to my daughter Vanessa for her help as my ‘’IT technician’’ and fierce critic. To my other wonderful children Leema and Maclee for their continuous support throughout my academic journey. To my grandchildren, my partner Canisius, my sisters Linda and Andrea and brother Terry I thank you for you unwavering kindness and encouragement.

For other family, friends, and colleagues, in particular Dr Patricia Shanahan, Mrs Rosalind Glancy and Mrs Doreen Parris who have supported me over the years I say thank you. Ultimately, I give thanks to God for his grace and mercy.

Glossary of Terms

Advocacy: Process of supporting and enabling people to express their views and concerns, access information and services, it defends and promotes their rights and responsibilities and explore choices and options.

Aftercare services: These are services for people who have been detained because of their mental health and for those on Community Treatment Orders.

Anxiety disorders: People with anxiety disorders find it difficult to control their worries. Their feelings of anxiety can be strong, constant, and enduring when there is no real threat, and this can interfere with their everyday life. They may also have panic attacks.

Bipolar affective disorder: A mood disorder once known as manic depression, it involves severe mood swings (high/manic episodes and low/depressive episodes) that are far beyond what most of us experience in everyday life.

Black and Minority Ethnic (BME): A term commonly used in the UK to describe people of non-white descent.

6Cs: Care, Compassion, Courage, Communication, Commitment, Competence are the core values and expectations that have been drawn up by NHS England Chief Nursing Officer Jane Cummings which were initially launched in December 2012. They have become core values in patient care within the National Health Service (NHS).

Care coordinator (CC): A named individual who is designated as the main point of contact and support for a person who has a need for ongoing care. This can be a nurse, social worker, or other mental health worker; whoever is deemed appropriate for the person’s situation.

Care Programme Approach (CPA): is a package of care that may be used to plan a service user’s mental health care.

Care Quality Commission (CQC): The independent regulator of health and social care in England.

Clinical Commissioning Groups (CCGs): were created following the Health and Social Care Act in 2012 and replaced Primary Care Trusts on 1 April 2013. They are clinically led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. As of 1 April 2019, there were 191 CCGs in England.

Cognitive behaviour therapy (CBT): is a talking therapy that can help manage problems by changing the way you think and behave**.**

Community Mental Health Team (CMHT): Supports people with mental health problems in the community. CMHT members include community psychiatric nurses (CPNs), social workers, psychologists, occupational therapists, psychiatrists, and support workers.

Community Psychiatric Nurse (CPN): A nurse who specialises in mental health and can assess and treat people with mental health problems.

Community Treatment Order (CTO): A Supervised Community Treatment Order is part of the Mental Health Act - it was introduced as part of the 2007 amendments and was designed to enable some service users who are detained under longer sections of the Mental Health Act to be discharged earlier if possible with conditions to support their stability and prevent relapse. It gives a “back up” option of early recall to treatment which can promote early recovery and shorter periods in hospital.

Crisis services: Mental health crises include suicidal behaviour or intention, panic attacks, psychotic episodes or other behaviour that seems likely to endanger oneself or others. Crisis services provided by the NHS and local social services respond to these types of situations.

Crisis Team/Crisis Intervention Team: Mental health professionals whose job is to work with people with mental illness who are experiencing a crisis. The aim of the team is to bring about a rapid resolution of the problem and prevent admission to hospital.

Crisis Resolution and Home Treatment (CRHT) Team:
Consists of mental health professionals with the aim of providing people with the most suitable, helpful, and least restrictive treatment possible, in order to prevent or shorten hospital stays.

Cultural Competence: Cultural competence includes knowledge, attitudes, and skills that support caring for people across different languages and cultures.

Equality Diversity Scheme (EDS): The EDS is a toolkit and framework for assessing how NHS organisations are performing regarding equality, diversity, and human rights; how they can improve; and how they get to where they want to be.

Early Intervention: is an evidence–based approach that combines psychosocial treatment with medication.

First Episode Psychosis (FEP): a first episode of psychosis usually occurs in teens or early adult life. Psychosis is a medical condition that affects the brain where there is some loss of contact with reality.

Independent Mental Health Advocates (IMHA): IMHAs provide information on rights that a person has under the Mental Health Act. Information on IMHAs and how to contact them should be given to a person if they are admitted to hospital or accepted into guardianship.

Individual Placement and Support (IPS): is internationally recognised as the most effective way to support people with mental health problems and/or addictions to gain and keep paid employment.

Joint Health and Wellbeing Strategies (JHWSs): support clinical leadership and elected leaders to deliver the best health and care services based on evidence of local needs.

Joint Strategic Needs Assessments (JSNAs): provide information about local levels of health and social care needs and their broader determinants to enable local authorities, NHS, and partners to provide the most appropriate services to meet those needs.

Mental Capacity Act (2005): Legislation aimed at protecting and providing a legal framework for acting and making decisions on behalf of adults who lack the capacity to make particular decisions for themselves. 'Capacity' is the ability to understand and take in information, weigh up the relative pros and cons and reach a sensible decision about the issue.

Mental Health Act (1983) amended 2007: Legislation governing the compulsory admission and treatment of people with mental health problems in England and Wales. People are usually admitted to hospital as informal patients, meaning they have agreed to go. Compulsory admission may occur when someone has severe problems that pose a risk to them or others.

Mental health crisis: An acute or very severe episode of mental distress requiring urgent support. This includes suicidal behaviour or intention, panic attacks and extreme anxiety, psychotic episodes (loss of sense of reality, hallucinations, hearing voices) or other behaviour that seems out of control and that is likely to endanger them or others.

Mental Health Services Dataset (MHSDS): The official source of national statistics on the use of the Mental Health Act.

Mental Health Nurse (MHN): provides support to people living with various mental health conditions. This can involve helping the patient to recover from their illness or to come to terms with it in order to lead a positive life.

Methodology*:* is the general research strategy that outlines the way in which research is to be undertaken and, among other things, identifies the methods to be used in it. These methods, described in the methodology, define the means or modes of data collection or, sometimes, how a specific result is to be calculated (Howell, 2013).

National Institute for Health and Clinical Excellence (NICE): Gives evidence-based recommendations developed by independent committees, including professionals and lay members, and consulted on by stakeholders.

The Organisation for Economic Co-operation (OECD): was established in 1961 as a forum for governments to share experiences and seek solutions to common economic and social problems. Today, approximately 50 industrialised and emerging-economy countries have joined the OECD as members or adherents.

Panic attacks: Sudden unpredictable and intense attacks of anxiety and terror which are often accompanied by unpleasant physical symptoms such as trembling, shortness of breath and dizziness, often resembling a heart attack.

Phenomenological research: is to describe the world as experienced by the participants of the inquiry in order to discover the common meanings underlying the different facets of particular phenomena.

Psychiatrist: A medically trained doctor who specialises in mental health problems and is trained to deal with prevention, diagnosis and treatment and can prescribe medication.

Psychologist: A professional who is interested in how people think, act, react, interact, and behave. Psychologists who have undergone specialist training in the treatment of people with mental health problems are called clinical psychologists.

Psychotic disorders: These involve distorted awareness and thinking. Symptoms can include agitation, over-activity, lowering of inhibitions, over-familiarity, sleeplessness, and irritability. Hallucinations (hearing, smelling, feeling, or seeing something that isn't there) and delusions (unlikely beliefs that are held despite evidence to the contrary) are common symptoms.

Qualitative Research: is a form of social enquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live.

Quantitative (positivist) research: collect facts and study the relationship of one set of facts to another.

Race Equality Act (2010): legally protects people from discrimination in the workplace and in wider society.

Recovery: involves finding hope, and developing one's self-esteem and resilience, having a sense of purpose and meaning in your life building healthy relationships with people in your community and gaining independence in your life.

Schizophrenia: A psychotic disorder which affects how people think, feel, behave and how they perceive their own intense thoughts, ideas and perceptions. It can develop slowly, and people may become withdrawn, lose interest in things and possibly have angry outbursts. They will often have symptoms of psychosis.

Second generation antipsychotic (SGA): these are the Newer or atypical antipsychotics and include: amisulpride, aripiprazole, clozapine, olanzapine, quetiapine and risperidone. Antipsychotics are a group of medicines that are mainly used to treat mental health illnesses such as schizophrenia, or mania (where you feel high or elated) caused by bipolar disorder. They can also be used to treat severe depression and severe anxiety.

Sectioned: When someone is admitted, detained, and treated in hospital under compulsion. The legal authority for admission to hospital comes from the Mental Health Act, usually because of an inability or unwillingness to consent. It refers to the use of a 'section' or paragraph from the Mental Health Act as the authority for detention.

Service user: Someone who uses or has used services related to their mental health.

Severe mental illness (SMI): is defined as a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities.

Shared decision making (SDM): is a collaborative process in which patients are supported by their healthcare professional to select which of the available options they wish to choose.

1.0 Chapter 1: Introduction to the study

In 2005 the Department of Health (Department of Health, 2005a) put forward a comprehensive plan for eliminating discrimination and achieving equality in mental health care for all people of Black and Minority Ethnic status (BME). The publication of this document was a significant change in supporting the work within Mental Health Trusts when considering the needs of service users from a BME background. This was fully supported by the Equality Act (2010) which made it a legal requirement under the Act, that NHS Trusts publish an annual report on their performance in the delivery of fair and equitable services, promoting equal opportunities and fostering good relationships between the different groups of service users and staff.

More recently, a review was commissioned by the former Prime Minister Teresa May in 2017 and was conducted in 2018. The report noted with concern the disproportionate number of people from black and minority ethnicities detained under the Mental Health Act 1983 (Department of Health, 1983). Whilst experiences vary across different ethnic minority groups, the report highlighted that the reviewers were "*particularly concerned by the excessively poorer experiences and outcomes of individuals from black African and Caribbean communities,"* (Department of Health, 2018, p. 58). In seeking reasons why this is so the report emphasised that research has evidently aligned health inequalities to racism as well as socioeconomic factors (such as inequalities in housing, local neighbourhoods, education and employment), (Department of Health, 2018, p. 163).

Nonetheless, in keeping with its legal requirement, the Trust used the NHS-wide Equality Delivery System (EDS) as a framework in managing its performance in delivering equal opportunities for service users and staff. The EDS was launched in October 2011 and is a developmental framework which asks those with an interest in the Trust–service users, carers, staff, and their representatives to grade the work of the evidence it provides. One of the challenges of implementing such a system is that the data captured by a national system need to be in a meaningful format to local practice areas in order to make changes to service provision which will lead to improvement in practice.

I worked in a North London Mental Health NHS Trust (NLMHT) which served three boroughs: -North London Borough 1 (NLB1), North London Borough 2 (NLB2) and North London Borough 3 (NLB3). 28,694 service users were registered as receiving services from the Trust. From those registered as receiving a service from the Mental Health Trust, 11,674 classed themselves as white British/English and 17,020 are classed as belonging to an ethnic minority group. Hence, the rationale for this study took into consideration the number of people from a BME background who use the service, as well as literature discussed subsequently in this project, (CQC, 2018; Department of Health, 2018; Memon *et al*. 2016; Brui and Singh, 2004; Bhui and Bhugra, 2002), that people from a BME background encounter difficulties in accessing and using mental health services.

The Trust recognised that it serves a multi-cultural population and put forward its priorities under the Race Equality Scheme to meet the needs of this diverse group by identifying its key priorities as:

- Improving information about the mental health needs of a diverse population which the Trust serves.
- Improving quality and cultural capability of inpatient care.
- Forming a partnership with local agencies to develop stronger links with the community.
- Continuing to enhance the early intervention and prevention services and improving access to the range of services that people need.

The study will aid in responding to the key priorities and help to inform practice within the Trust and within Mental Health Practice. The sample for the study will be drawn from the Black Ethnic Group which will include Black African, Black Caribbean, Black British and Black Mixed Race. The study will include Social, Physical, Psychological, Spiritual and Cultural factors thereby achieving the objectives.

Distinguishing between individual needs and the wider needs of the community is important in the planning and provision of local health services, (Wright, Williams and Wilkinson, 1998). This is suggestive of a comprehensive assessment of needs and service, which are delivered in a non-discriminatory manner. Therefore, users of community mental health services are entitled to have care which is based upon knowledge and understanding of their specific mental health needs. In addition, the care should be based on practices which can demonstrate service user participation and involvement, (Hannigan *et al*. 2018, p. 1).

Millar *et al.* (2015, p. 209) noted that the history of service user involvement in mental health bestrides at least five decades. In 1983, the Griffiths Report spoke about the difficulties in hearing the authentic voice of the ultimate consumer of psychiatric services and suggested that health care should be measured by how it is perceived by users. In 1985 patients' councils in psychiatric services and mental health advocacy projects began to develop in the United Kingdom (UK), adopting an approach which broadly aimed to change mental health services dialogue and discussion, (Millar *et al.* 2015; Peck and Barker, 1997, p. 269). In that same year, *'survivors speak out'* (British mental health service users' group), was formed which took a more campaigning stance (Peck and Barker, 1997, p. 269). This approach brought to light the personal stories of mental health service users in a wider political context. To this end, it could be argued that the emphasis of user involvement in decisions about their care has arisen from a number of factors: the perceived remoteness and unresponsiveness of services to the needs and wishes of users, an increasing diverse and discerning public and the demands of various groups, (Sharma *et al*. 2016).

Various authors (Bee *et al.* 2015, p. 1834; Hickey and Kipping,1998, p. 84) asserted that these factors found expression in a range of initiatives such as the NHS and Community Care Act (1990) (Department of Health, 1990), the Patients Charter (Department of Health, 1992) and Working in Partnership (Department of Health, 1994). Equally the government emphasised further commitment to user involvement in more recent policies such as the NHS Constitution, (Department of Health, 2015). No Health without Mental Health, (Department of Health, 2011) and Refocusing the Care Programme Approach (CPA), (Department of Health, 2008).

User involvement defines the process whereby individuals become actively involved in their health care, rather than be passive recipients of such services, (Neech *et al.* 2018; p 328). Notwithstanding, Gee, Mcgarty and Babfield (2016, p. 233), identified systemic barriers to user and carer participation. However, the concept of working in partnership with service users is well established in health policy. To this end, the NHS Constitution pledged to patients that NHS staff will *"work in partnership with you, your family, carers and representatives",* (Department of Health, 2015, section 7).

Mental health needs include broad domains of health and social functioning, which are necessary to survive and prosper in the community. Needs can be assessed from different perspectives, including staff, patient or carer, and have been differentiated into unmet needs (current serious problems, whether or not help is given) and met needs (no or moderate problems because of the help given), (Phelan *et al*. 1995). A consensus emerged across Europe and Australasia that mental healthcare should be provided on the basis of need, with an intended goal of improving subjective quality of life, (Department of Health, 2011; Lasalvia *et al.* 2000, p. 366). Hence, the participants in the study will be asked what they perceived their needs to be and how those needs are being met within the Mental Health Trust.

On a strategic level the department of health allowed for the assessment of need via Joint Strategic Needs Assessments (JSNAs) (Department of Health, 2012b) which should provide information about local levels of health and social care needs and their broader determinants to enable local authorities, NHS and partners to provide the most appropriate services to meet those needs (Department of Health, 2011). A further legislative document the Health and Social Care Act (2012) (Department of Health, 2012c), presented duties and powers for health and wellbeing boards in relation to JSNAs and Joint Health and Wellbeing Strategies (JHWSs) which support clinical leadership and elected leaders to deliver the best health and care services based on evidence of local needs, (Campion, Coombes and Bhaduri, 2017). Campion, Coombes and Bhaduri (ibid), asserted that local authorities and clinical commissioning groups (CCGs) have equal and joint duties to prepare JSNAs and JHWSs through their health and wellbeing boards.

Campion, Coombes and Bhaduri, (2017), conducted an audit to assess the level of inclusion of mental health in JSNAs of 23 local authorities covering more than 6 million people across north London and the surrounding region. An online search for JSNAs was conducted during October and November 2013. They found that mental health information within JSNAs was both difficult and time consuming to locate. Despite the high prevalence of mental disorder and low coverage of evidence-based treatments, only a minority of JSNAs mentioned most mental disorders for child and adolescent mental disorder. Drug misuse was mentioned in more than 50% of JSNAs. The proportion of adult mental disorders mentioned in more than 50% of JSNAs included depression (72%), psychosis (67%), dementia (100%), alcohol dependence (83%), drug dependence (78%) and suicide (100%). However, many JSNAs mentioned mental disorder only as figures in tables and did not cover in further detail in the body of the text, (Campion, Coombes and Bhaduri, 2017, p. 814). The authors felt that the assessments should include mental disorder and wellbeing particularly in view of the large impact of mental disorder and poor mental wellbeing as well as the poor coverage of public mental health interventions.

Arguably, the assessment of need among people with mental illness is complex. It covers areas such as self-care, social activities, accommodation, physical health, psychological distress, information, safety to self and others, finance, intimate relations, communication, and spiritual needs. On close observation it can be said that those needs reflect the needs of the general population and could be likened to Maslow's Hierarchy of needs (1943) which include physiological, love/belonging, safety. For service users accessing the mental health service a structured assessment is conducted and allocated within a mental health cluster. A treatment plan is then formulated using the Care Programme Approach (CPA) to ensure service users' needs are met. Part of that process is to establish any needs relating to an individual's culture or ethnicity.

Ethnicity or ethnic group has been defined as a group of people whose members identify with each other through a common heritage, often consisting of a common language, common culture (which can include a religion) and or an ideology which stresses a common ancestry, (Institute of Race Relations, 2019). It is the way that most countries and peoples choose to delineate groups and has superseded the biological idea of 'race' (Institute of Race Relations, 2019). McKenzie and Crowcroft, (1994), contended that,

> *"race is often used interchangeably with ethnicity or culture, though race is thought to be biologically determined and ethnicity and culture are ideas derived from social theory"* (McKenzie and Crowcroft, 1994, p. 286).

Culture is a social construct which is characterised by the behaviour and attitudes of a social group (Fernando, 1991). In a similar vein, Radcliffe, (2004, p. 28), suggested that the precise nature of ethnicity is highly contested. Radcliffe, (2004, p. 28), felt that as with race the term tends to be used loosely to imply commonalities of language, religion, identity, national origin and or even skin colour.

Notwithstanding, Bhopal, (2003), suggested that,

> *“ ethnicity is a multi-faceted quality that refers to the group to which people belong, and/or are perceived to belong, as a result of certain shared characteristics, including geographical and ancestral origins, but particularly cultural traditions and languages”* (Bhopal, 2003, p. 441).

The features that define ethnicity are not fixed or easily measured, so ethnicity is imprecise and fluid. Ethnicity varies from race, nationality, religion, and migrant status, sometimes in subtle ways, but may include aspects of these other concepts. (Bhopal, 2003, pp. 441-442). While race and ethnicity are different, they are overlapping concepts that are often used synonymously (Nittle, 2020), a trend fostered by the increasing use (particularly in the United States) of the compound word race/ethnicity.

In keeping with the terms race and ethnicity there is an ongoing discussion on the use of the acronyms ‘BME’ or ‘BAME’. In a recent blog Zamila Bunglawala, Deputy Head of Unit and Deputy Director Policy and Strategy, Race Disparity Unit, Cabinet Office commented on her observation of the different acronyms used to describe people from ethnic minority background. She contended that, whilst acronyms are very *‘catchy’* and ‘*convenient’* they are not always well thought through, (Bunglawala, 2019).

She stated that they have found evidence that the terms are not widely understood, have negative connotations or are hurtful to people. She suggested that it is right that the acronyms are revisited, (Bunglawala, 2019). In a similar vein, Okolosie, *et al.* (2015) shared their thoughts on the use of the acronyms. They highlighted pros and cons on the use of the acronyms and pondered on the fact that if the acronyms are scraped what would they be replaced with. However, for the purposes of this study the acronym ‘BME’ will be used to identify the participants who took part in the study.

1.1 Summary of Chapter 1

Chapter 1 included an introduction and gave some background to this study. In this chapter the Mental Health Trust duties under the equality scheme were also highlighted and a discussion ensued on how the Mental Health Trust proposed to meet its requirements under the race equality scheme. The key priorities set by the Trust in order to meet its requirement under the race equality scheme were highlighted. The chapter noted that the Trust serves three boroughs and highlighted the number of service users registered as receiving a service from the Mental Health Trust. This was further broken down to show the number of service users who class themselves as belonging to an ethnic minority group. A discussion ensued about needs and joint strategic needs assessments.

The concept of service user involvement and working in partnership with service users was discussed. Concepts such as race and culture were also discussed. This chapter gave a definition for the term ethnicity and discussed the differences in the terms race and ethnicity. A discussion also ensued on the use of the acronyms BME and BAME noting current thinking about the terms. Chapter one will end with a reflective account on the chapter. A reflective account will also be given at the end of each of the chapters within this study.

1.2 Summary of the Chapters

Chapter 1 gave an introduction to the study and discussed the Mental Health responsibility under the race equality scheme. Concepts such as race and ethnicity were explored, and differences were noted.

Chapter 2 incorporated the terms of reference and highlighted the aims and objectives of the study. A discussion was given using some key literature emphasising the needs of BME service users and how this has informed my thinking in carrying out this research study.

Chapter 3 gives a discussion on the methodology used in this research study and gave a rationale for using the qualitative research method. In this study it was my intention to find out the lived experience of the participants, hence consideration needed to be given as to the most appropriate design. Phenomenology allows for the lived experience of participants to be explored hence for this study this was the chosen methodology.

Chapter 4 gave a discussion on the research location followed by a reflection on the steps taken in conducting this study. A critical detailed reflection regarding the participants was given in this chapter.

Chapter 5 presents the themes as they emerged from the analysis of the data. Those themes were supported by verbatim statements of the participants. Pseudonyms were used to maintain anonymity which is in keeping with ethical practice.

An in-depth discussion was given in chapter 6 on the themes and sub themes highlighted in chapter 5. The idea of this chapter was to give a critical discussion, considering the themes and highlighting previous research on the identified themes.

Chapter 7 gives a conclusion on my interpretation of the evidence elicited from this study and responds to my research question. It also has some recommendations with the hope of making the appropriate change in practice. This chapter highlighted other contributions to practice and lessons learned to support service users, mental health professionals, employer's, policy makers and the general public.

1.3 Reflection on Chapter 1

Chapter 1 gave me the opportunity to set the scene of what the study would be addressing and the context within which it would do so. The literature suggested that BME service users were encountering higher rates of admission and having poorer service outcomes than their white counterparts. Hence, the government attempted to redress the imbalance through the race equality scheme. The scheme required that all Mental Health Trusts should publish an equality and diversity report to show how they are meeting their requirement under the scheme. Whilst it was pleasing to see information regarding the ethnic mix of staff in the most recent Equality and Diversity report from the NLMHT published in 2018, it was unfortunate that the ethnic breakdown of people who use the service was not given. The main thrust of the report was regarding staff working in the Trust.

From the literature it appeared that service users' participation has been very much on the agenda within healthcare over the past three decades. That is because service users themselves were asking to have more of a say in terms of how their care is provided. Whilst it may well have been difficult for health professionals, it is a requirement that they encourage service user participation. The concept is also driven by the government health policies.

The other facet of care is that of needs and needs assessment. The literature showed that needs were assessed at a strategic and local level. However, the study by Campion *et al.* (2017), as seen on page 17 had a startling revelation. The fact that the mental health information could not be found in most joint strategic need's assessment supports the view of a lack of parity between mental and physical health.

A further issue that was elicited was to do with race and ethnicity. The literature highlighted that there are differences between race and ethnicity, however both terms share commonalities. It appeared the more recent discussion about race and ethnicity is about the use of the acronyms 'BME' or 'BAME'. My view is that much work has been done to ensure that appropriate statistical information is collated within health and social care. This helps to understand where the gaps are, and which members of the population are being disadvantaged. Hence, having the acronyms to identify specific groups within society is extremely helpful.

2.0 Chapter 2: Terms of Reference/Objectives and Literature Review

2.1 Aims of the study

Chapter 2 will give a description of the aim and objectives of the study. It will give a critical discussion on the literature regarding the chosen topic. This chapter will also give a rationale as to how the literature on the needs of BME service user in mental health practice has shaped my thinking to carry out the research project.

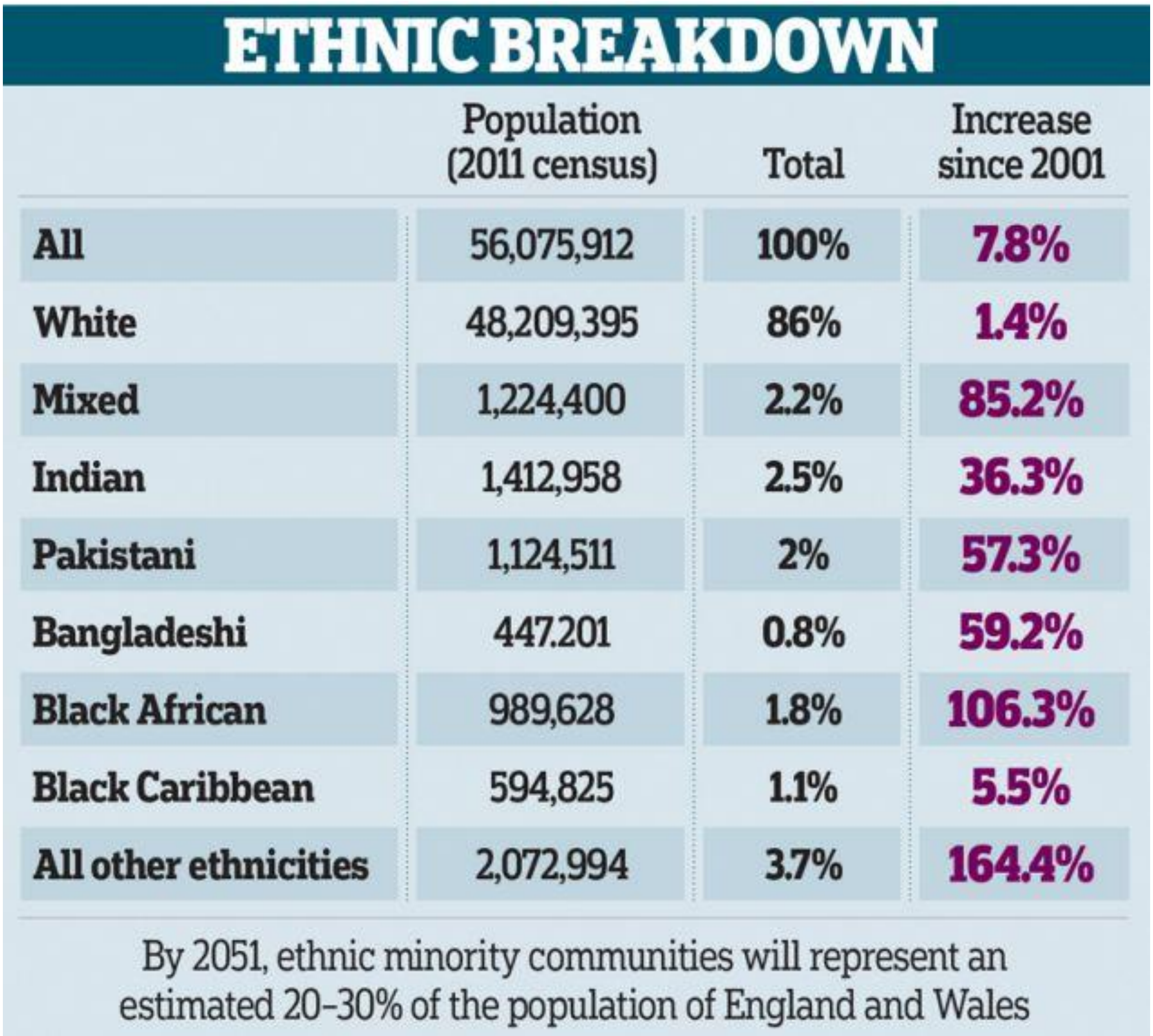
This study was conducted to enquire from service users from a BME background on their perception of what their needs were and whether those needs were being met when being cared for in the Mental Health Trust. Several authors, (Halvorsrud *et al.* 2018; Brui and Singh, 2004; Bhui and Bhugra, 2002; Keating *et al.* 2002), have expressed concern that service users from a BME background encounter barriers both in accessing and using mental health services. Therefore, the aim of this descriptive phenomenological study will seek to provide an in-depth description of the BME service users perception of their needs when being cared for by the Community Mental Health Teams in the NLMHT. Hence, the research question is: do service users from a BME background perceive that their needs are being met within the Mental Health Trust?

Whilst there were 17,020 service users from a BME background recorded as receiving a service from the Trust the study will be based on one ethnic group. Equally, a search through data bases such as MEDLINE, PsycINFO and CINAHL also revealed that much has been written about service users being treated less favourably when accessing and using mental health services. Hence, it is hoped that the information drawn from the study will give further insights into the needs of this specific group and address ways in which those needs could be met. Therefore, the objectives for the research are:

- Identify service users from a BME background who would be willing to participate in the research in NLMHT.
- Critically consider the concept of need.
- Describe service users' experience.
- Critically appraise service users' perception of need.
- Make an appraisal as to whether those needs are being met.

It was reported by the Policy Exchange that Britain's black and ethnic minority communities could account for almost a third of the population by 2050 as seen in table 1 below, (HMSO, 2011). The number of people from minority groups could as much as double by then. One in four children under the age of ten in the UK is already from a minority group and over the next few decades the proportion will soar, according to think-tank Policy Exchange. Currently, eight million people or 14 per cent of the UK population are from ethnic minorities. But they now account for 80 per cent of population growth, while the white population remains constant.

Table 1: Ethnic minority projection in England and Wales



ETHNIC BREAKDOWN

	Population (2011 census)	Total	Increase since 2001
All	56,075,912	100%	7.8%
White	48,209,395	86%	1.4%
Mixed	1,224,400	2.2%	85.2%
Indian	1,412,958	2.5%	36.3%
Pakistani	1,124,511	2%	57.3%
Bangladeshi	447.201	0.8%	59.2%
Black African	989,628	1.8%	106.3%
Black Caribbean	594,825	1.1%	5.5%
All other ethnicities	2,072,994	3.7%	164.4%

By 2051, ethnic minority communities will represent an estimated 20-30% of the population of England and Wales

Source: HMSO (2011)

The above trend seems to mirror the population distribution in London. Between 2016 and 2041 the total London population is projected to increase by 1.98 million (22 per cent) to 10.8 million. The White British population is projected to increase by 203 thousand (six per cent) to 3.76 million. The BAME (all ethnic groups except the three White groups) population is projected to increase by 1.19 million (32 per cent) to 4.94 million. The White British group will remain as the biggest individual ethnic group, by a significant margin, over the 2016 to 2041 period. Over the projection period the second-biggest individual ethnic group will be Other White. The next largest groups will be Black African (increasing by 31 per cent to 828 thousand in 2041), Indian (increasing by 32 per cent to 811 thousand in 2041), and Other Asian (increasing by 42 per cent to 671 thousand in 2041), (GLA, 2016b, p.3).

2.2 Context of current policy

2.2.1 Literature Review

A review of the National Service Framework by the Mental Health Taskforce, (Department of Health, 2003), proposed reformation of the outcome for people from BME groups who experience mental ill health and come into contact with mental health services as users or carers. The Department of Health also stated that social exclusion of minority ethnic groups is complex and varies according to the economic, social, cultural, and religious backgrounds. Research on the mental health care experience of minority ethnic groups and commitment to commission is scarce, (Department of Health, 2003).

Nevertheless, national surveys conclude that there is enough evidence to suggest that people from BME groups are subject to inequalities in the availability and accessibility of services offered. What followed was a comprehensive plan for eliminating discrimination and achieving equality in mental health care for all people of Black and Minority Ethnic status, (Department of Health, 2005a). It could be suggested that the process of eliminating discrimination in mental health care has not worked as a recent review of the Mental Health Act revealed that,

> "*profound inequalities exist for people from ethnic minority communities in accessing mental health treatment, their experience of care and their mental health outcomes"* (Department of Health, 2018, P.163).

Similar evidence has been found by Nazroo, Bhui and Rhodes (2019) who posited that,

> "*ethnic minority people are more likely to be diagnosed as having a severe psychosis related mental illness than the white majority in the UK and this is particularly the case for those with Black Caribbean or Black African origins"* (Nazroo, Bhui and Rhodes, 2019, p. 262).

Notwithstanding, in reviewing the evidence of why those disparities exists Nazroo, Bhui and Rhodes (2019) recommended that, there needs to be a cohesive approach to understanding how racism increases the risks of experiencing severe mental illness for race/ethnic minority people. Also, how their more adverse pathways through care permits a deeper understanding of causal processes,

> *"one that goes beyond a singular focus on individual experiences of discrimination, or institutional practices and instead situates an enquiry within a wider analysis of racism, racialisation and inequality"* (ibid, p. 272).

In 2007 Lord Ara Darzi was asked to conduct a review on health services in England by the Department of Health. The review found that while the NHS was two thirds of the way through its modernisation programme as set out in the NHS Plan in 2000, in that the health service had increased capacity and driven down waiting times, quality and outcomes needed to be improved. Further aims of the Darzi review included ensuring that services were better joined up, care was more accessible and integrated, and services provided more patient control, choice and local accountability. The review culminated in a policy document High Quality Care for all and was published in June 2008, (Department of Health, 2008). It sets out how the NHS should move from centrally driven, target-based management to one of empowered local services focused on quality as well as activity.

A further policy document was published in October 2009 called New Horizons: Towards a shared vision for Mental Health, (Department of Health, 2009). The aim of that document was to promote good mental health and wellbeing and to further improve the quality and accessibility of services for people who have mental health problems. It is suggested that New Horizons would build on the work from the National Service Framework for Mental Health (Department of Health, 1999a) by reinforcing its commitment to key mental health policy aims.

In 2011 the Department of Health published the mental health strategy- *No Health* *without Mental Health,* (Department of Health, 2011). This document was put forward as an outcomes strategy where the Government would work with all sectors in the community to achieve a set of shared objectives to improve mental health outcomes for individuals and the population. The strategy sets out six objectives one of which is that fewer people will experience stigma and discrimination. This was further clarified by stating *'public understanding of mental health will improve and as a result, negative attitudes and behaviours to people with mental health problems will decrease'*, (Department of Health, 2011, p. 7). This was a positive step in tackling stigma and discrimination of people who use mental health services. However, it did not seem to address the issue that people from a BME background encounter barriers in accessing and using mental health services.

The *Count Me In* census had been undertaken annually since 2005 in support of the Department of Health's five-year plan for improving mental health services for people from ethnic minorities via Delivering Race Equality in Mental Health Care (DRE) which has now ended. In their report the Care Quality Commission (CQC), (CQC, 2011), found that people from ethnic minorities remain disproportionately represented on mental health wards with no signs of this reducing. This statement was echoed following the sixth and last *Count Me In* census which found that 23% of 32,799 people receiving in-patient care in England and Wales were from ethnic minority groups as of 31 March 2010. This proportion went up by a percentage point from the previous year's census and above the baseline of 2005 which was 20%, (Dunning, 2011).

The census found admission rates to hospitals were at least two times higher than average for people from black Caribbean, black African and mixed white/black groups in 2010 (CQC, 2011, p 23). The census also found that detention rates were 6% lower than average among White British patients, and between 19% and 32% higher than average among the Black Caribbean, Black African, Other Black and White/Black Caribbean Mixed groups. (CQC, 2011, p. 22). The CQC noted that whilst the census has been conducted via a valued one-day snapshot, "*ethnicity recording must be seen as an all-year round statutory requirement, not a one-day annual event",* (ibid, p. 44).

The CQC said the findings did not in themselves show that mental health services were failing to meet the needs of BME service users, but ethnic differences in rates of mental illness, pathways to care, and factors such as socio-economic disadvantages were contributory factors. The chair of CQC Dame Jo Williams in commenting on the report stated that there is a need to comprehend more about these factors and for greater cooperation in working across sectors. She commented further by saying:

> "*We are again highlighting the need for all involved to try to prevent mental ill-health by addressing these contributory factors and intervening early. This must be done by organisations not only in healthcare but also in other sectors, working collaboratively and with people from black and minority ethnic communities' themselves"* (CQC, 2011).

Nearly a decade on from the above report the CQC (2020) noted that the overrepresentation of some Black and minority ethnic (BME) groups detained under the MHA continues to be a particular cause for concern. National data from the 2018/19 Mental Health Services Dataset (MHSDS) showed that known rates of detention for Black or Black British people in 2018/19 (306.8 detentions per 100,000 population) were over four times higher than for White British people (72.9 per 100,000 population), (CQC, 2020, P. 13).

The findings by CQC is not dissimilar to what has been found in a review of the use of the Mental Health Act 1983 amended November 2007 (Department of Health, 2018). One of the measures strongly supported by the reviewers of the Mental Health Act 1983/2007 is the development of the Patient and Carer Race Equality Framework (PCREF), and an Organisational Competency Framework (OCF) to tackle racial disparity to improve mental health service access and outcomes in ethnic minority people.

The report suggested that OCFs can be developed in all organisations, such as the police and local authorities, to improve outcomes in ethnic minority people with mental health problems (Department of Health, 2018, p. 58). The OCF should focus on several core areas of competence: awareness, staff capability, behavioural change, data and monitoring, and service development. The report indicated that:

> "*it is expected that there will be a role for regulatory bodies to monitor compliance and attainment at a national level, with patient and carer*

> *representatives having an active role in the assessment*" (Department of Health, 2018, p. 308).

In the NHS Mental Health Implementation Plan 2019/20 – 2023/24 (NHS England, 2019) recognised that inequalities in mental health care exist and suggested that it is linked to wider cultural and societal systems of disadvantage. Noting that aspects such as stigma, discrimination, housing can have a significant impact on a person's wellbeing. To address this NHS England declared, that a collaborative approach is needed and suggested that,

> "*NHS England and NHS Improvement will support local health systems to better address inequalities in access, experience and outcomes by supporting, incentivising and assuring targeted, localised actions to address them"* (NHS England, 2019, p. 14).

Previous authors such as Chakraborty *et al.* (2009), stated that people from African-Caribbean origin with psychosis in the UK, are reported to have different related service outcomes and increased rates of psychosis relative to their white counterparts and indicated that one of the reasons for this could be explained in part by racism. Similarly, the Department of Health noted that there was a marked ethnic variation among mental health service users across the UK and adverse experiences are widely reported among BME service users, (Barnett, Mackay and Matthews *et al.* 2019; Department of Health, 2018; Department of Health, 2005a; Sharply *et al.* 2001).

Memon *et al.* (2016, p. 2), asserted that in general, people from ethnic minorities are less likely than their White British counterparts to have contacted their general practitioner (GP) about mental health issues in the previous year, to be prescribed antidepressants or referred to specialist mental health services. Similarly, Mohammed (1999) lamented that there has been a growing body of evidence indicating that Black people receive a qualitatively and quantitatively worse service. In order to address this, NHS Organisations have focussed on cultural and linguistic differences of several Black populations settled in this country.

Mohammed (1999) explained that the effects of these initiatives developed by the health services and others completely disregarded the effects of racism, consequently compounded racism. Similar evidence has been put forward by Knifton (2012) who conducted a study with Pakistani, Indian, and Chinese heritage communities in Scotland, UK. Knifton (2012) emphasised that national anti-stigma programmes must develop more effective partnerships with communities or risk magnifying existing inequalities. Moreover, it has been noted by Peate (2014) that inequalities in mental health care exist. He propounded that,

> "*BME groups generally have worse health than the overall population, some groups faring much worse than others, with patterns varying from one health condition to the next''* (Peate, 2014, p. 28).

In a review of all primary studies published in the last five years on ethnic differences in pathways to care for psychosis in England, Halvorsrud *et al.* (2018), identified 40 studies. These studies revealed that relative to the white majority population, people of black Caribbean or African origins were, on average, over 3 times more likely to come to the attention of psychosis services as a result of compulsory admission under the current Mental Health Act (specifically, via civil Section 2 detentions). People from Asian backgrounds were also 1.5 times more likely to come to the attention of services via this pathway. Kirkbride, (2018), commented that:

> *"perhaps unsurprisingly these figures were echoed in police contact and involvement of the criminal justice system in pathways to care"* (Kirkbride, 2018, P. 2).

The care pathway in which care was delivered in the NLMHT was divided into seven service lines. This way of working came into effect in January 2010. However, following another service redesign in 2015, mental health services are now borough based. This change was made to improve the Trust's relationships with GPs, local communities, and partners. The Trust also operate Specialist Services including Child and Adolescent Mental Health Services (CAMHS), Forensic Services, Eating Disorders and Drug and Alcohol services.

As part of the governance of the Trust an Equality and Diversity Report is completed annually. NLMHT had seven Clinical Service Lines and in the Equality and Diversity 2011 Annual Report (NLMHT, 2011), it was noted that White British, White Irish and White Other are the largest groups amongst service users. The largest non-White ethnic group was Black Caribbean and Black African groups. The Report stated that the mix does vary between Service Lines. In both Acute and Forensic Service Lines the Black Population is higher than White British. In all other Service Lines, the White British is significantly higher than all other ethnic groups (NLMHT, 2011, pp 6-7). This could support the view that in the UK black patients have more compulsory admissions to hospital, (Codjoe, Barber, and Thornicroft 2019; CQC, 2018; Department of Health, 2018; Mann, Fisher and Major *et al.* 2014).

Those findings resemble that which have been reported in other countries including America and Australia. Atdjian and Vega (2005, p. 1600) stated that inequalities exist in access to and quality of mental health care for racial ethnic minority groups in the United States. They suggested that those disparities included the under-utilisation of psychiatric services by people from ethnic minority groups. There were problems in treatment engagement and retention of people from minority groups, the over diagnosis of schizophrenia among African American and depression in Latinos, the inappropriate use of antipsychotic medication among African Americans (and the use of these medications at higher dosages among African Americans and lower dosages among Latinos), and very high rates of substance use disorders and completed suicide among Native Americans.

Atdjian and Vega (2005) further indicated that in addition to access, barrier factors such as inadequate insurance coverage (to pay hospital fees) have been found to affect minority patients' utilisation of mental health services. Equally, inadequate recognition of psychiatric conditions by primary care physicians and under referral of these patients to psychiatric care constitute fundamental discrepancies. Even for those who gain access to treatment, may dropout early, frequently after just the first session. There was also a record of high rates of missed appointments for psychiatric treatment, (Atdjian and Vega 2005, p. 1600).

It has been reported that racial and ethnic minority Americans comprise a substantial and vibrant segment of the United States (US) population, enriching the society with many unique strengths, cultural traditions, and important contributions. As a segment of the overall population, these groups are growing rapidly; current projections show that by 2025, they will account for more than 40% of all Americans (U.S., Department of Health and Human Services, 2001). The report, *Mental Health: Culture, Race and Ethnicity, A Supplement to Mental Health: A Report of the*

Surgeon General, highlighted striking disparities in mental health services for racial and ethnic minority populations. For example, these populations:

- Are less likely to have access to available mental health services.
- Are less likely to receive needed mental health care.
- Often receive poorer quality care, and
- Are significantly under-represented in mental health research.

Equally, Mallinger and Lamberti (2010) conducted a study in the United States which was to assess psychiatrists' awareness of racial disparities in mental health care, to evaluate the extent to which psychiatrists believe they contribute to disparities, and to determine psychiatrists' interest in participating in disparities-reduction programs. They felt that psychiatrists may perpetuate racial-ethnic disparities in health care through racially biased, albeit unconscious, behaviours. Changing these behaviours requires that physicians accept that racial-ethnic disparities exist and accept their own contributions to disparities.

The result of the survey showed that most of the 374 respondents said that they were not familiar or only a little familiar with the literature on racial disparities. Respondents tended to believe that race has a moderate influence on quality of psychiatric care, but that race is more influential in others (colleagues) practices than in their own. One-fourth had participated in any type of disparities-reduction program within the past year, and approximately one-half were interested in participating in such a program. The study concluded that psychiatrists may not recognise the pervasiveness of racial inequality in psychiatric care, and they may attribute racially biased thinking to others but not to themselves. Mallinger and Lamberti (2010) believed that interventions to eliminate racial-ethnic disparities should focus on revealing and modifying unconscious biases. Lack of physician interest may be one barrier to such interventions. In making comparison of the healthcare system in the UK and United States it is worth noting that there are clear differences between the UK and USA health care systems; in the USA there is a significant barrier to all healthcare due to it being individually funded, whereas in the UK the NHS offers healthcare free to all citizens.

A study was conducted by Boydell *et al.* (2012) in reference to reported concerns about the level of satisfaction with mental healthcare among minority ethnic patients in the UK. The aim of the study was to determine and compare levels of satisfaction with mental healthcare between patients from different ethnic groups in a three-centre study of first onset psychosis. Data was collected from 216 patients with first episode psychosis and 101 caregivers from South London, Nottingham, and Bristol, using the Acute Services Study Questionnaire (Patient and Relative Version) and measures of socio-demographic variables and insight.

The results showed that no differences were found between ethnic groups in most domains of satisfaction tested individually, including items relating to treatment by ward staff and number of domains rated as satisfactory. It showed that Black Caribbean patients did not believe that they were receiving the right treatment and were less satisfied with medication than white patients. Black African patients were less satisfied with non-pharmacological treatments than white patients. These findings were not explained by lack of insight or compulsory treatment. The study found that black patients were less satisfied with specific aspects of treatment, particularly medication, but were equally satisfied with nursing and social care. Understanding the reasons behind this may improve the acceptability of psychiatric care to black minority ethnic groups.

Viewpoint Service User Group conducted a UK survey among 740 Black and Minority Ethnic people experiencing mental health difficulties in February and March 2013. Ultimately, the project hoped to create a legacy of positive experiences for both young African and Caribbean men and statutory staff. The result showed that most common areas of mental health discrimination for Black and Minority Ethnic communities are making and keeping friends (68%), being shunned by people that know they have a mental health problem (68%), keeping a job (67%) and in social life (67%). This indicates that mental health problems are becoming life limiting for some people. In a previous study Viewpoint found that people using secondary services experienced the highest levels of stigma from being shunned, amongst family, friends, in their social life and with mental health staff. However, in all areas, discrimination was experienced by a noticeably lower percentage compared to Black and Minority Ethnic communities surveyed here, (Time to Change, 2013).

The development of the Mental Health Implementation Framework which links to the No Health without Mental Health strategy (Department of Health, 2011), made provision that members of the Black Mental Health Group would work with members of the ministerial advisory group to take up issues concerning BME communities and make the strategy more effective. The aims were to address the diversity of identities and experiences within communities while delivering services; develop systems to involve BME communities in policy making at the top level; support community led social marketing campaigns to challenge inequalities and raise awareness; and recognise and respect the cultural heritage, identity and belief systems of BME communities, (Dunning, 2011).

Davie (2014) purported that African and Caribbean people are far more likely to be diagnosed with a serious mental illness. Black men in Britain are 17 times more likely than white counterparts to be diagnosed with a psychotic illness. Davie (2014) reported that in Lambeth, with the country's biggest black population, they launched a commission which will help to end the above situation. Davie (2014) posited that while 26% of Lambeth's population is black, nearly 70% of the borough's residents in secure psychiatric settings are of African or Caribbean heritage. Equally, Knifton (2012) postulated that mental illness prevalence is higher amongst communities that face multiple prejudices and disadvantages within society, including Black and minority ethnic communities who may experience migration trauma, racism, acculturation, and adverse social circumstances.

In a UK Household Longitudinal study, data from 4 waves during (2009–2013) was collated from approximately 40,000 households, including an ethnic minority boost sample of approximately 4000 households. The study examined the longitudinal association between cumulative exposure to racial discrimination and changes in the mental health of ethnic minority people in the United Kingdom. The researchers noted the *"corrosive effect that the cumulative experience of racial discrimination has on the mental health of ethnic minority people"* (Wallace, Nazroo and Becares 2016, p. 1298). They concluded that,

> *"they were able to show how repeated exposure to racial discrimination over time, and accumulation of exposure across domains, affects the psychological distress of ethnic minority people in the United Kingdom and contributes to persistent ethnic inequalities in mental health"* (Wallace, Nazroo and Becares , 2016, pp. 1299-1300).

Lwembe *et al.* (2016) conducted a study to evaluate the role of co-production in the development of a novel community mental health service for black and minority ethnic service users. They used qualitative research methods, including semi-structured interviews and focus groups. The study found that out of the 25 patients enrolled into the study; 10 were signposted for more intensive psychological support. A 75% retention rate was recorded (higher than is generally the case for black and minority ethnic service users). They stated that early indications showed that the project has helped overcome barriers to accessing mental health services. Although small scale, this study highlights an alternative model that, if explored and developed further, could lead to delivery of patient-centred services to improve access and patient experience within mental health services, particularly for black and minority ethnic communities.

Lwembe *et al.* (2016) also found in their UK study that stigma and fear of disclosure, were acting concurrently with an apparent suspicion of the service during the initial assessment session, to provide a substantial barrier to engagement. For a community suspicious of mental health services and with complex stereotypes and stigma around mental illnesses, co-production propositions a way to break down historical, systemic, and socio-cultural barriers and offer better services to those most in need (Lwembe et al., 2016, p. 20). Boyle *et al.* (2010) maintain that the fundamental principle of co-production is basically a commitment to a transformational approach to delivering services, one that assumes that people's needs are better met when they are involved in an equal and reciprocal relationship with professionals, working together to get things done. The transparency conveyed by the co-production process in this pilot changed the patient's attitudes and permitted Improving Access to Psychological Therapies (IAPT) workers to develop a personalised assessment system for each patient, (Lwembe *et al.,* 2016, p. 21).

2.2.2 The Meaning of Service User Involvement

Authors such as Hickey and Kipping (1998) have suggested that user involvement often takes place within a continuum, ranging from a 'traditional medical' approach, with care providers only explaining and supplying information and little or no active involvement on the part of the patient, to a 'democratisation' approach, where patients have a decisive say in decisions and fully and actively participate in their own treatment.

Millar, Chambers and Giles (2015) conducted a study in the UK where they sought to explore and analyse the concept of service user involvement within the field of mental health care. Following a literature review they retained and examined one hundred and thirty-four citations (n = 134) that were published in a variety of disciplines. A majority (27) originated from nursing (20.1%), but were also from psychiatry (15, 11.2%), written by a service user or a representative of a service user organisation (15, 11.2%), social work (15, 11.2%), psychology (13, 9.7%), multidisciplinary (12, 8.9%), sociology (7, 5.2%) and the National Health Service (6, 5.2%).

Just under half of the papers (5) with multidisciplinary, authors had service user input. Eighteen papers (13.4%) were categorised as other disciplines, such as primary care (4), health services studies (4) and health policy (2). The majority of the papers came from the United Kingdom (112, 83.6%), with 6 (5.2%) from the USA and the remainder (17) from other countries. Sixty-five (48.5%) papers were research studies, 49 (36.5%) were discussion papers, 9 (6.7%) were literature reviews, 4 (3%) editorials, 2 (1.5%) books and 5 (3.8%) other types of papers. One paper (0.7%) was published in the 1980s, 25 (18.7%) in the 1990s and 108 (80.6%) from the year 2000 onwards (Millar, Chambers and Giles, 2015).

The study revealed that the concept of service user involvement was used in policy and strategy, individual assessment, care management, service development, planning, delivery and evaluation, the education, training and recruitment of mental health professionals and at all stages in the conduct of research. The reviewed citations provided a rich picture of the concept of service user involvement in mental health from differing disciplines, perspectives and models. Almost 15% of the papers were written by service users or had service users input into the writing, providing a useful portrayal of the views of service users' as well as the views of mental health professionals. Five defining attributes of service user involvement within the context of mental health care were extracted from the literature sample retrieved from the electronic database search: a person-centred approach, informed decision making, advocacy, obtaining service user views and feedback and working in partnership (Millar, Chambers and Giles, 2015).

Stringer *et al.* (2008) conducted a literature review looking at the concept of service user involvement in mental health care. They found evidence which suggested that user involvement leads to improved patient satisfaction, a higher quality of care, better health, greater treatment compliance and a safer environment for patients and care providers. However, they felt that because of the lack of a uniform definition and validated instruments, a worthwhile activity within it, causes difficulty to make objective statements about the actual effects of user involvement (Elwyn, Edwards and Molwe, 2001; Lewin, Skea and Entwistle, 2001; Cahill, 1996).

Equally a systematic review conducted by Crawford, Rutter and Manley (2002), showed that the effects of involving patients are not unambiguously clear. The reviewers examined 40 papers, 12 of which were related to mental health care. They found no quantitative effect on studies, but did find qualitative case studies, mainly about variables such as health, quality of life and patient satisfaction. Several studies showed that an active involvement of patients in the provision of health services (that is through patient forums) contributed to changes in those services. Examples of new services commissioned at the request of patients included advocacy, initiatives aimed at improving opportunities for paid employment and crisis services. User involvement also led to cultural changes within organisations. Organisations and individual care providers became more open to involving patients in the provision of care and treatment. Finally, user involvement led to improved self-esteem in patients (Crawford, Rutter and Manley, 2002).

To this end Tait and Lester (2005) confirmed that there are a number of often interrelated reasons for believing that mental health service user involvement is more than a politically mandated *‘good thing’* and is a range of practical and ethical benefits as seen below:

- Users are experts about their own illness and need for care.
- Users may have different but equally important perspectives about their illness and care.
- User involvement may increase the existing limited understanding of mental distress.
- Users are able to develop alternative approaches to mental health and illness.
- User involvement may be therapeutic.
- User involvement may encourage greater social inclusion, (Tait and Lester, 2005, p. 168).

However, in order to establish whether health care services are making a difference in the lives of those who use them, they would need to audit or carry out research on those specific areas. In Mental Health Trusts such audits would be part of the governance of the Trust. Hence, in relation to my research project I set out to establish service users' perception from a BME background concerning their needs being met in the mental health service. In doing so I would need to understand concepts such as what are needs, health, service user involvement and resilience. An understanding of those concepts would afford me the opportunity to establish from the data collected using the semi structured interview schedule whether the participants perception is that their needs are being met or not.

For several years now the philosophy in mental health care has been that service users should be involved in their care. Several authors (Bee *et al.* 2015; Stringer *et al.* 2008; Florin and Dixon, 2004; Cahill, 1998; Hickey and Kipping, 1998), have inferred that the concept of service user involvement is about the patients' right to be involved in decisions that affect them and as a change of the patients' role from passive recipients to active participants. Further views on service users' involvement is that it is a broad range of relationships between those who provide healthcare services and those who receive them, (Poulton, 1999). More recently The Code: Professional Standards of Practice and Behaviour for Nurses and Midwives (Nursing and Midwifery Council, 2018) requires registered nurses to:

> *"prioritise people by listening to people and respond to their preferences and concerns', and that nurses must work in partnership with people to make sure you deliver care effectively"* (Nursing and Midwifery Council, 2018, p. 6).

The Department of Health has supported this notion through a number of policy documents, (Department of Health, 2018; 2010; 2009). Each of these documents emphasises the need to take account of the voice of the service user. In addition to service user involvement Gask *et al.* (2012) stated that although effective evidence is a critical basis for quality improvement in mental health, many individuals with high levels of mental distress are disadvantaged because of poor access, either because care is not available, or because their interaction with care-givers deters or diverts help-seeking ways that do not meet their mental health needs. Therefore, providing comprehensive improvements to quality of care require addressing both access and effectiveness (Dowrick *et al.* 2009). To this end Baillie (2016) contended that partnership working, and shared decision-making are largely linked to approaches to person-centred care.

A further example of user involvement has been cited by Obi-Udeaja, Crobsy and Ryan (2015) who described the involvement of service user trainers in the development and delivery of a short training course in physical restraint for mental health professionals. They suggested that user involvement in education of future mental health practitioners is seen as important in providing students with the opportunity for developing greater awareness and understanding through the unique insights of people's lived experience of mental health conditions, and of their contact with mental health services.

Patterson, Trite and Weaver (2014) conducted a National cross-sectional online questionnaire survey to describe activities, roles and experiences of service users involved in mental health research. The researchers found that the respondents wrote of an abiding respect for people categorised as 'mental patients' and wanting research to be empowering of, and for, service users. They noted that a particular kind of knowledge and unique insights resulting from experience were fundamental to ensuring research attained the goal of service improvement and life enrichment for people who use services. Many respondents (n = 28) explicitly attributed their own involvement in mental health research to a 'passion' for service and/or social change and commitment to ensuring the interests of service users were central to that change. For some, lived experience legitimised involvement in mental health research (Patterson, Trite and Weaver, 2014, p. 72).

The findings in the above study showed also that most of the respondents experienced involvement positively and many were keen to pursue and develop further opportunities for the future. However, the findings relating to the experience of stigma, discrimination and tokenism showed that, the potential of service user involvement will be only achieved with continued attention to deep-level cultural change and development of robust mechanisms, to ensure timely and meaningful engagement, (ibid, p. 74).

2.2.3 Concepts of disability/health

Working in the National Health Service (NHS) particularly in mental health has helped shaped my views when caring for service users. To fully understand what a need or health need is, it was incumbent for me to explore what it means to have a disability and its correlation to health needs. The World Health Organization (WHO) defined health as *“a state of physical, mental, and social well-being, and not merely the absence of disease and infirmity”,* (WHO, 2018: p. 1; 1948; P.1).

Mental health has been defined as:

> *“a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community"* (WHO, 2007, p.1).

Wing, Brewin, and Thornicroft (2001) suggested that the severity of disablement results from: (a) the severity and duration of impairment, that is, psychological and physiological dysfunctions; (b) adverse circumstances and disadvantages, both past and present, that can affect social functioning independently; and (c) personal reactions to the first two factors, including loss of self-esteem and motivation directly caused by impairments. Wing, Brewin and Thornicroft (2001) posited that need can be defined either in terms of the type of impairment or other factor causing social disablement or of the model of treatment or other intervention required to meet it; for example, hip replacement, insulin regime for diabetes and medication for auditory hallucinations.

Wing, Brewin and Thornicroft (2001) contended that if an individual is socially disabled, in association with a mental disorder for which an effective and acceptable form or model of care exists, either for amelioration or prevention, the individual needs that intervention. There will usually be a hierarchy of methods, at the top of which may be one that produces a complete and rapid recovery with no extra ill-effects. At the bottom, there will usually be methods of amelioration, or prevention of relapse or of amplification of disablement. Perhaps the clearest and simplest definition of need is the ability to benefit from care.

Wing, Brewin and Thornicroft (2001) went on further to suggest that the fact that needs are defined does not mean that they will be met. Some may remain unmet for the immediate future because other problems must be dealt with first; or because an effective method is not available locally, availability is limited by rationing, the person in need objects, or there are other reasons why the intervention should not be made.

Naidoo and Wills (2000) posited that health refers to a state of fitness and ability, or to a reservoir of personal resources that can be called on when needed. This suggests that mental health is the foundation of an individual and hence the community at large. Kalra *et al.* (2011, p. 81) purported that mental health has been conceptualised as a positive emotion (such as feelings of happiness or resilience). They further explained that positive mental health includes wellbeing, autogenic factors (like optimism), resilience (the capacity to cope with adversity) and quality of life defined by the World Health Organisation as seen above. Equally, Kalra *et al.* (2011) noted that the concept of mental health cannot be separated from that of overall health with the determinants of health closely aligned to the factors that create optimal or minimal mental health and wellbeing.

Arguably, in keeping with views on health highlighted by Kalra *et al.* (2011), one could argue that the concept of health need encompasses social, physical, psychological, spiritual and socio-economic dimensions. Hence, it is reasonable to suggest that there is interplay between these dimensions in order to maintain equilibrium. For example, if a service user is subject to social exclusion (social) s/he will experience feelings of unwantedness or alienation (psychological). Likewise, Hooper (1999) stated that health is a resource for everyday life, encompassing social and personal resources as well as physical capabilities. Hooper (1999) suggested that it is the extent to which an individual or group can satisfy basic human needs, realise aspirations and change or cope with the environment.

Hooper (1999) inferred that there are factors which affect health and grouped them as biological, behavioural, social community networks, physical and economic. Similarly, Seedhouse (1990) noted that the concept of health is defined in a social model as opposed to the medical model. Within the Organisation of Economic Countries (OECDs) countries (Figure 1) on page 42 tell the same story. People with mild to moderate mental illness, such as anxiety or depression, are twice as likely to be unemployed. They are prone to a much higher risk of living in poverty and be socially marginalised (OECD, 2015). To address those inequalities the OECD has developed a set of policy guidelines for an integrated approach to address the impact of mental health problems on health, education, employment and social outcomes (OECD, 2015).

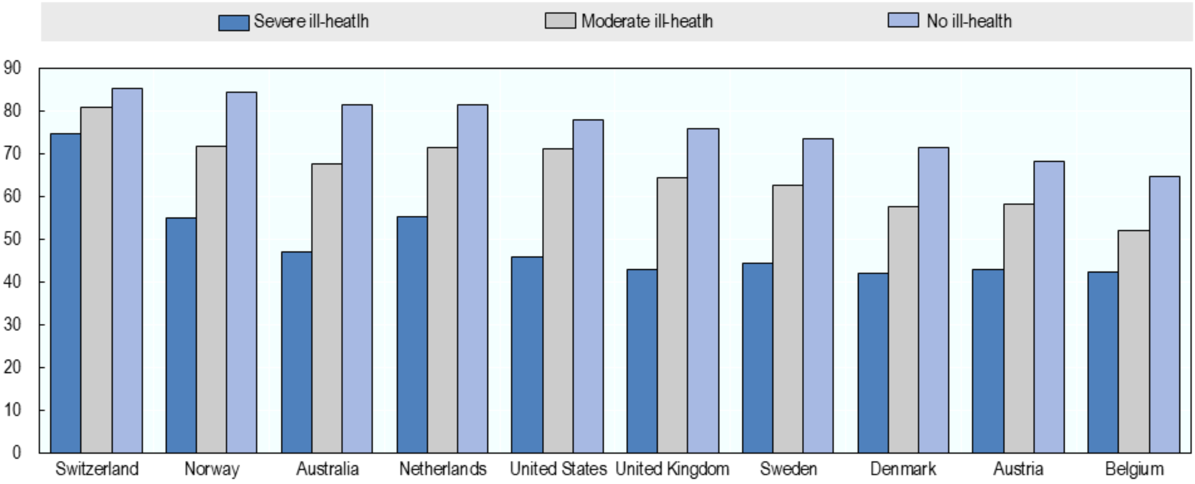


Figure 1: Employment and unemployment gaps are considerable for people with mental ill-health (OECD, 2015 p 31)

Notwithstanding this complex multi-dimensional view of health has allowed the concept to be viewed on a broader perspective. In that sociologists, epidemiologists and health economists have all defined needs from their own standpoint, (Billings and Cowley, 1995). Whilst sociologists have defined needs using Bradshaw's Taxonomy of needs which is expressed as normative, felt, expressed and comparative need, the epidemiologists' approach to need is to use morbidity and mortality data to measure ill health in a community. The health economists' viewpoint contrasts with the previous perspectives: they define need in the context of cost effectiveness, supply and demand (Billings and Cowley, 1995).

Broadbent *et al.* (2008) conducted a study in the UK regarding the needs of service users who use mental health services. A small number of patients tend to use a disproportionately high amount of mental health services. They asserted that understanding the needs and behaviours of this group were important in order to improve patient management. Few studies have investigated the role that patients' perceptions about their mental illness play in guiding coping responses and treatment-seeking. The aim of the study was to investigate how illness perceptions in high users of mental health services were related to unmet needs and treatment-seeking behaviours. A total of 203 high users of mental health services were interviewed using the Brief Illness Perception Questionnaire, the Camberwell Assessment of Need and the Drug Attitude Inventory, and these users were also asked to report the number of visits they had made to the general practitioner in the past year. District Health Board clinical staff completed the Camberwell Assessment of Need and the Global Assessment of Functioning for each user.

The results showed that more negative perceptions about mental illness were associated with higher ratings of unmet needs by both patients and staff. Negative perceptions were also related to poorer attitudes towards medication, and lower functioning. Perceptions about the personal ability to control the illness were consistently associated with better outcomes. Patients' causal attributions could be categorised as social, psychological, biological and behavioural. More frequent visits to the general practitioner were associated with perceptions of more severe symptoms, greater concern and higher emotional responses to the illness, and psychosocial causal attributions. The researchers deduced that illness perceptions provide a framework to assess patients' ideas about severe mental illness, and a means by which to identify maladaptive beliefs. Interventions targeted at changing these beliefs may encourage better self-management, (Broadbent et al. 2008, p. 153).

It could also be deduced from this research the concept of resilience has emerged as an ingredient in which a service user will thrive to maintain mental wellbeing. Although the term resilience was not explicit, the researchers reported that participants used the terms *'personal ability to control illnesses'*. This is suggestive of a strategy, an inner resource that which resembles resilience (Broadbent et al. 2008, p. 147).

Wright, Williams and Wilkinson (1998, p. 1311) purported that needs in health care is generally defined as the capacity to benefit. If health needs are to be identified, then an effective intervention should be offered to meet these needs and improve health. There will be no benefit from an intervention that is not effective or if there are no resources available. In addition, demand is what patients ask for; it is the needs that most doctors experience. General Practitioners have a crucial role as gatekeepers in controlling this demand, and waiting lists become a surrogate indicator and an influence on this demand. Demand from patients for a service can depend on the attributes of the patient or on the media's interest in the service. Supply is the health care provided. This will be contingent on the interests of health professionals, the priorities of politicians, and the amount of money available, (Wright, Williams and Wilkinson,1998, p. 1311). Notwithstanding, Clarke *et al.* (2019) proposed that a health intervention is:

> *"a combination of activities or strategies designed to assess, improve, maintain, promote, or modify health among individuals or an entire population. Interventions can include educational or care programmes, policy changes, environmental improvements, or health promotion campaigns"* (Clarke *et al.* 2019, p.1).

Indeed, Thompson (2014, p. 47) concluded that health needs assessment is used to set the policy agenda, plan services and target resources effectively to result in maximum health benefit for both individuals and populations.

2.2.4 Influences on health

Health needs include the wider social and environmental determinants of health, such as deprivation, housing, diet, education, employment. This wider definition makes it possible to look beyond the confines of the medical model based on health services, to the wider influences on health as seen below.

- Environment: housing, education, socioeconomic status, pollution
- Behaviour: diet, smoking, exercise
- Genes: inherited health potential
- Health care: including primary, secondary, and tertiary prevention (Wright, Williams and Wilkinson,1998).

Graham (2004) exclaimed that the last decade had seen major developments in public health policy in a number of older industrialised societies. The traditional focus on improving the population's overall health has been widened to include a commitment to reducing health differences between population groups. This commitment is often expressed in terms of reducing health inequalities, although in some countries, '*health inequities* and *health disparities'* are the preferred terms. What they all capture are the systematic differences in the health of groups and communities occupying unequal positions in society. Noting the importance, the Commission of the European Communities highlighted *that "health is important for the wellbeing of individuals and society, but a healthy population is also a prerequisite for economic productivity and prosperity"* (Commission of the European Communities, 2007, p. 5).

In keeping with the above, the Kings Fund (2018) put forward an approach termed Population Health which is a method that aims to improve physical and mental health outcomes, promote wellbeing and reduce health inequalities across an entire population. They stated that they see it as a broad overarching concept, encompassing but going beyond the NHS, public health and population health management. Crucially, it focuses on the wider determinants of health and the role of people and communities. Their vision for population health is that:

> *'Health outcomes and inequalities in health in England will be on a par with the best in the world. This will be achieved by a consistent and coherent focus on population health locally, regionally and nationally'* (Kings Fund, 2018, p. 18).

Equally that vision is based on the four interconnecting pillars as seen in Figure 2 below.

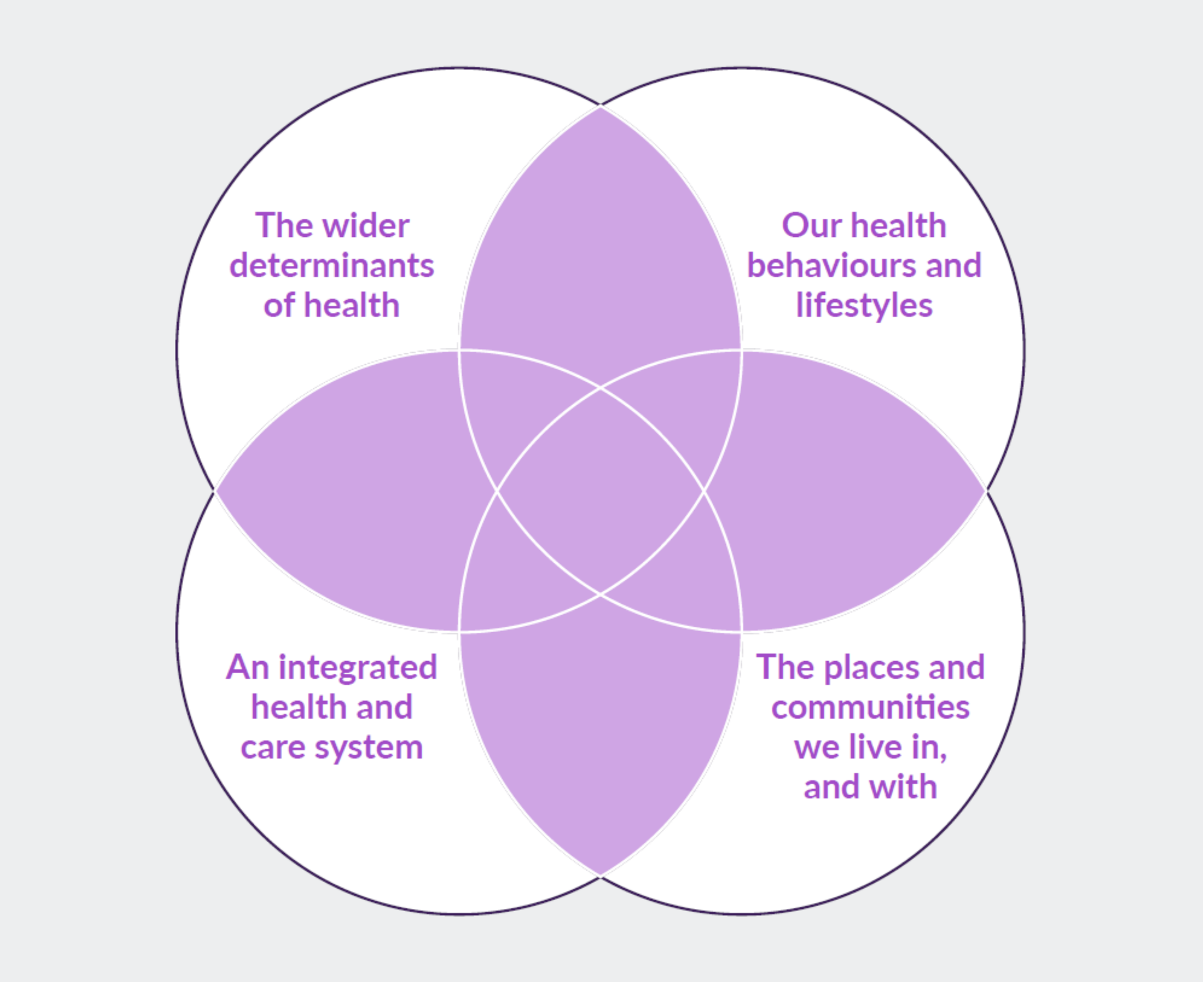


Figure 2: The four interconnecting pillars (Kings Fund, 2018 p35)

Those pillars have been defined as: "*the wider determinants of health, our health behaviours and lifestyles, the places and communities in which we live and an integrated health and care system"* (Kings Fund, 2018, p. 3).

It was suggested that in order to achieve their vision, action at national, regional and local levels would be required, hence drawing on the assets of people and communities. It was also proposed that Improving population health is a shared responsibility and progress also depends on supporting people to live healthier lives, (Kings Fund, 2018, p. 3).

Disparities in accessing and receiving mental health care is a worldwide phenomenon. In examining some statistics on the issue Herrman and Swartz, (2007), stated that every year up to 30% of the population worldwide has some form of mental disorder, and at least two-thirds of those people receive no treatment, even in countries with the most resources. In the USA, for example, 31% of people are affected by mental disorder every year, but 67% of them are not treated. In Europe, mental disorder affects 27% of people every year, 74% of whom receive no treatment. The proportions of people with mental disorder who are treated in low-income and middle-income countries are even lower than in the USA and UK; for example, a global survey reported that only 11·1% of severe cases of mental disorder in China had received any treatment in the previous 12 months. This survey also reported that, in low-income and middle-income countries, only a minority of treated people (as low as 10·4% in Nigeria) received adequate treatment, (Herrman and Swartz, 2007).

It is hoped that through the 17 Global Sustainable Development Goals that the above issues could be addressed as the United Nations (UN) have called for action by all countries–poor, rich and middle-income–to promote prosperity while protecting the planet. They recognise that ending poverty must go together with strategies that build economic growth and address a range of social needs including education, health, social protection, and job opportunities, while tackling climate change and environmental protection, (United Nations, 2019).

Almost a decade later from the WHO Europe 1999 strategy, Marmot et al. (2008), in reviewing social determinants of health and health equity found that the poor health of poor people, the social gradient in health within countries, and the substantial health inequities between countries are caused by the unequal distribution of power, income, goods, and services, globally and nationally. Likewise, the consequent unfairness in the immediate, visible circumstances of people's lives, their access to health care and education, their conditions of work and leisure, their homes, communities, towns, or cities and their chances of leading a flourishing life. Marmot *et al.* (2008) contended that this unequal distribution of health-damaging experiences is not in any sense a natural phenomenon but is the result of a combination of poor social policies and programmes, unfair economic arrangements, and bad politics. Together, the structural determinants and conditions of daily life constitute the social determinants of health and cause much of the health inequity between and within countries.

Marmot *et al.* (2008) analysis of their findings led to three principles for action: improve the conditions of daily life (that is the circumstances in which people are born), develop a workforce that is trained in the social determinants of health, and raise public awareness about these determinants. It could be argued that one of these social determinants is that of culture and diversity.

To this end, WHO (2013) put forward a further action plan termed: Mental Health Action Plan 2013–2030. The four major objectives of the action plan are to:

- Strengthen effective leadership and governance for mental health.
- Provide comprehensive, integrated and responsive mental health and social care services in community-based settings.
- Implement strategies for promotion and prevention in mental health.
- Strengthen information systems, evidence and research for mental health. (World Health Organisation, 2013)

Whilst the above action plan will help in the improvement in mental health care the recent Marmot review noted that:

- There is a strong relationship between deprivation measured at the small area level and healthy life expectancy at birth. The poorer the area, the worse the health.
- There is a social gradient in the proportion of life spent in ill health, with those in poorer areas spending more of their shorter lives in ill health.

- Healthy life expectancy has declined for women since 2010 and the percentage of life spent in ill health has increased for men and women (Marmot *et al.* 2020, p. 13).

2.2.5 Cultural Diversity

Cultural diversity has become the norm of the present day multi-cultural societies because of globalisation and migration for different reasons. Cultural competence is something that is now being demanded out of every health professional working in multi-cultural areas (Bhugra and Gupta, 2011 as cited in Kalra et al. 2011, p. 84). Negatively, cultural diversity is tinted with intended or unintended discrimination of the people who belong to a foreign culture (Kalra et al. 2011, p. 84). Cultural psychiatrists need more nuanced and sophisticated ideas of culture to discover how culture shapes symptom formation, in terms of pattern, form and content, and how the illness impact on outcomes (Dein and Bhui, 2013, p. 776). Kalra *et al.* (2011, p. 84) went on further to say that it is important to put across the message on being more forbearing and understanding of the dignity of people from diverse cultures. Building of policies that ensure an equitable treatment of people of all origins, cultures, and orientation is important.

Within the past decade or two cultural competence has become a popular term to use, however, good clinical practice has always been looking at individual patient's social, and cultural factors to understand their impact on the illness being experienced. Nevertheless, for migrants' mental health needs, cultural awareness becomes a very important aspect of assessment of their mental state and in planning any therapeutic interventions (Bhugra and Gupta, 2010, pp. 11-12). Campinha-Bacote (2002) defined cultural competence as,

> "*the on-going process in which the healthcare professional continuously strives to achieve the ability and availability to work effectively within the cultural context (individual, family, and community) of the patient" (*Campinha-Bacote, 2002, p.181).

Lo and Fung (2003) define cultural competence as an ability to perform and obtain positive clinical outcomes in cross-cultural encounters. Recognising the differences in the therapeutic encounter, being sensitive to the patients and their families concerns and displaying an awareness of strengths and weaknesses of the individuals and their cultures allow clinicians to engage patients from other cultures, thereby increasing therapeutic adherence.

Notwithstanding, Campinha-Bacotes (2002, p. 181) model of cultural competence in the delivery of healthcare services, serves as a conceptual framework to deliver patient-centred care amid cultural conflict. Patient-centred care is a model of care that respects the patient’s experience, values, needs and preferences in the planning, co-ordination and delivery of care. In patient-centered care, each patient should expect to receive the standard best care considered to be most suitable for his or her particular condition. Such care should be tailored to any unique elements of the personal profile that will create change in the patient's situation, (McGinnis, 2013, p. 91).

2.2.6 Cultural Skill

Cultural skill is the capability to collect pertinent cultural data regarding the patient's presenting problem (Campinha-Bacote, 2002, p.182). This process involves learning the skills of how to conduct a cultural assessment, an essential task in delivering patient-centred care. To this end achieving cultural competence in practice requires cultural awareness and cultural knowledge when completing appropriate cultural assessments. Alizadeh and Chavan (2015) conducted a systematic review to identify the most common cultural competence dimensions proposed in recent publications and to identify whether sufficient evidence exists regarding the efficacy of cultural competence in the healthcare context. They found that cultural awareness, cultural knowledge, and cultural skills/behaviour were suggested as the most important elements of cultural competence in many of the frameworks. Mostly that,

> *cultural awareness was defined as an individual’s awareness of her/his own views such as ethnocentric, biased and prejudiced beliefs towards other cultures, and cultural knowledge was pronounced as the continued acquisition of information about other cultures. Cultural skills or behaviour was described as the communication and behavioural ability to interact effectively with culturally different people* (Alizadeh and Chavan, 2015, p. 120).

Therefore, cultural competence in health care entails,

> *understanding the importance of social and cultural influences on patients' health beliefs and behaviours; considering how these factors interact at multiple levels of the health care delivery system (e.g., at the level of structural processes of care or clinical decision-making); and, finally, devising interventions that take these issues into account to assure quality health care delivery to diverse patient populations* (Betancourt *et al.* 2003, p. 291).

Equally, Papadopoulos (2006) defined cultural competence

> "*as the process one goes through in order to continually develop and refine one's capacity to provide effective healthcare, taking into consideration people's cultural beliefs, behaviours and needs"* (Papadopoulos, 2006, p. 11).

Similarly, the model put forward by Papadopoulos, Tilki and Taylor (1998) discusses four main concepts, *Cultural Awareness, Cultural Knowledge, Cultural Sensitivity* and *Cultural Competence*. The constructs in this model are suggestive of a notion of the need to understand the beliefs and values of people from diverse cultures to ensure true engagement and collaborative working with the service user. In examining the notion of cultural competence Papadopoulos *et al.* (2015) linked the concept of compassion to it and suggested that compassion varies from culture to culture.

They contended that specific areas such as the notions of time, being there, going the extra mile, defending and advocating and personalisation of care need to be taken into account when learning to provide culturally compassionate care, (Papadoulos *et al.* 2015, p. 290). Notwithstanding, the above notion links well with the caring values put forward by the Central Nursing Officer (CNO) for the NHS known as the 6Cs: Care, Compassion, Competence, Communication, Courage, and Commitment (Cummings and Bennett, 2012). Those values were in response to reports such as the Francis report 2013 which found appalling inadequacies in nursing care at Mid Staffordshire Hospital. Too many nurses were not showing compassion to patients and were not attending to their fundamental needs-to eat, to drink, to wash, to use the toilet. Francis argued that there was no excuse for this. What was required were *"changes in attitude, culture, values and behavior",* (Francis Report, 2013, p. 1499).

Hence the Compassion in Practice (Department of Health, 2012a) identified six action areas to help the NHS move into a more caring organisation:

- *Helping people stay independent, maximise well-being.*
- *Working with people to provide a positive experience.*
- *Delivering and measuring high quality care.*
- *Building and strengthening leadership.*
- *Ensuring we have the right staff with the right skills, in the right place.*
- *Supporting positive staff experience,* (Department of Health, 2012a, p. 3).

Those values found expression in the Nursing and Midwifery Code (2018), by suggesting that 'each nurse is required to embed care values into their practice which sits in the four domains; Prioritise people, Practise effectively, Preserve safety and Promote professionalism and trust'.

2.3 Summary of Chapter 2

This chapter incorporated the terms of reference and highlighted the aims and objectives of the study. A discussion was given using some key literature emphasising the needs of BME service users. The analysis of the literature discussed in the literature review showed that BME service users encountered barriers both in accessing and using mental health services. Those barriers were found not only in the UK but in other countries such as USA and Australia. The evidence suggested the BME service users were less likely to have visited their general practitioner GP and was more likely to be admitted compulsory under the Mental Health Act 1983/2007.

Concepts such as user involvement, health, need, cultural competence and cultural skill were explored. The evidence suggests that for areas where user involvement had been practised, better service outcomes were noted. The evidence showed that there were factors which determined our state of health with some suggestions of how to tackle inequalities in health. The concept of need was explored, and the findings stated that a need could be psychological, physical, social, financial, spiritual, and cultural. That needs could be met or not met depending on whether the service is able to meet presenting needs of individual service users. Equally, it was noted in this chapter that the repertoire of cultural competence and cultural skills were essential facets within health and social care practice. The next chapter will discuss and consider methodological approaches and will discuss the approach used in completing this research project.

2.4 Reflection on Chapter 2

It was interesting to note that the discussion on page 27 regarding the count me in census (which started in 2005 and ended in 2014) showed that the rates of admission were two times higher than average for BME service users. What is more concerning is that this trend has continued; a recent report by the department of health showed that BME service users are more likely to be subject to the Mental Health Act when compared to their white counterparts (Department of Health, 2018). Similar evidence has been found by the CQC (2018).

This study did not allow for comparisons to be made regarding admission and detention of service users from other ethnic groups as this was not the remit of the study. However, it was noted from the literature that the disparity which confronts the BME population is a worldwide phenomenon. The literature on page 29 showed that African and Caribbean people are more likely to be diagnosed with a serious mental illness. Efforts have been made to find out why this is the case. In their literature review, Codjoe, Barber, and Thornicroft (2019) highlighted the different reasons that have been put forward by previous authors as to why BME service users face inequalities. As the current discussion seemed dynamic and varying, I drew no clear consensus and found the topic to remain multifaceted.

Although, notable reasons found would include racism, socioeconomic disadvantages, and pathways to care. The literature indicated that over the past two decades, BME service users continue to face inequalities with higher rates of detention and admission to hospital under the Mental Health Act. It was also interesting to note that these trends were not only seen in the UK, but in other countries such as America and Australia. It was startling to see the figures highlighted by Davie (2014), on page 34 regarding BME service users' admission on secure psychiatric settings in Lambeth. Davie's findings would suggest that a number of socio-economic factors need to be addressed by the commission in order to unravel underlying causes.

Within mental health care there appears to be a need and desire to involve service users in their care, as service users are regarded as *experts through experience of mental illness*. However, one of the barriers to involvement is regarding risk and risk assessments. Mental health professionals have a professional and legal duty to protect the individual with mental illness as well as the wider society. Hence, user involvement presents a dichotomy. The concept of user involvement was discussed further in chapter 2. The literature suggested that user involvement had positive outcomes including patient satisfaction and improved self-esteem. This suggests that if mental health service users are satisfied with the service they receive, they are less likely to complain about their care.

The concept of disability and health was also discussed in chapter 2. In terms of service provision, if one was assessed as being disabled due to mental health difficulties, then that person would require and receive a service. However, this process also links to needs and whether they are met or not met. On page 40, Wing, Brewin, and Thornicroft (2001) provided various reasons why needs may be unmet. I am of the view that if needs remain unmet, inevitably one's health may be negatively impacted. The discussion on whether needs are met or unmet could be a broader political issue and questions whether mental health services are failing those who use them by not providing services that meet their needs.

A further highlight in the literature was to do with patients' perception about the causes of their illness and how it impacted on their belief and attitude towards treatment (Broadbent *et al.* 2008). If the views were negative, then it is unlikely that a service user would adhere to the care and treatment being offered.

Moreover, the Kings Fund (2018) highlighted that there were several determinants which impact on our health: including housing, transport, and lifestyle. Their outlined framework suggested that a community approach was necessary. As I reflect on the Marmot report of 2008 and the most recent Marmot report in February 2020, both highlighted determinants on health citing inequalities and poverty as social determinants on health. However, it was disheartening to observe that the population health had not improved for those living in poorer deprived areas in England. Hence furthering the health and wealth divide in the UK (Marmot *et al.* 2020).

The final focus of chapter 2 was to highlight the need for cultural competence among health professionals. The literature gave some insights suggesting that cultural skill is required to understand people’s belief, behaviours, and needs. I was pleased to note that on the subject of cultural competence it was suggested that good clinical practice was the key when working with people from different cultures. This means that mental health professionals need to be inclusive in the way they work to ensure they embrace these ideas. In examining the literature closely, there was also a link made between cultural competence and compassionate care. Compassionate care has been noted to be at the heart of the NHS (NMC, 2018; Francis Report, 2013; Cummings and Bennett, 2012).

3.0 Chapter 3: Project Design and Methodology

Chapter 3 will provide a discussion on research methodologies and put forward a view for following the qualitative research method. A discussion will also be given on the research design used to complete this study. It will show how as a researcher consideration was given to ethical and legal aspects when undertaking research. Each researcher approaches a research study with an underlying philosophical assumption. In this chapter I will highlight some of the common philosophical assumptions and give a rationale for the one chosen to conduct this study in order to answer the research question. Consideration will also be given to the role of insider researcher and how the data collected and analysed will be discussed.

3.1 Methodology

As the intention of this study was to find out the lived experience of the participants, I gave consideration as to what the most appropriate design would be. A chosen methodology allows the researcher to describe how, when and where data will be collected and analysed. For this reason, a qualitative research methodology would be more appropriate in this study. Parahoo (1997) confirmed that,

> *"in practice the selection of a design is largely dependent on the belief and values of the researcher (s/he may place particular value for example on the quantitative approach), the resources available (cost, time, expertise of the researcher), how accessible the respondents are and whether the research is ethically sound''* (Parahoo,1997, p.143).

However, authors such as Gullick and West (2012) and Miller (2010) have suggested that there is a closer fit between the practice of nursing and qualitative research than any other methodological approach. Moreover, qualitative research seeks to answer certain types of research questions only; not all research questions can be answered using this approach.

In keeping with Parahoo's suggestion above, I had to examine my belief and value about the research study. Having worked within mental health care for three decades I was acutely aware that to afford me the ability to gain an understanding of the service users experience it would be fitting to ask them. This was not dissimilar to Walliman (2006, p. 246) who asserted that qualitative and quantitative research have different characteristics and require different techniques for their analysis.

> *''By contrast, natural science has traditionally concentrated on 'hard' quantitative (positivist) analysis which was adopted by the human sciences until its shortcomings became evident''* (Walliman, 2011, p.197).

Holloway and Galvin (2016) and Forster (2001) felt that subjective human feelings and emotions were difficult (or impossible) to quantify, therefore qualitative (interpretivism) analytical methods, were evolved which demonstrated more of the 'soft' personal data, (Walliman, 2006, p. 132).

Equally the Department of Health's definition of research alluded to the fact that there are a range of research methods and methodologies. These are grouped under two paradigms: the quantitative (Positivism) and Qualitative (Interpretivism). Each paradigm is concerned with uncovering new knowledge; however, the knowledge produced and the way the researchers set out to uncovering this knowledge is different within each paradigm. Paradigms have been described as different scientific communities which share specific constellation of beliefs, values and techniques for deciding which questions are interesting, how one should breakdown an interesting question into small parts, and how to interpret the relationship of those parts to the answers (Smith, 1991).

This notion informed my rationale for the chosen methodology. Hence, qualitative research seeks to gain an in-depth investigation on human phenomena in order to understand the values and meanings these phenomena have for the individuals under study (Holloway and Galvin 2016; Forster, 2001). Consequently, this notion helped to gain an in-depth view from the participants of a Black Minority Ethnic (BME) background who agreed to take part in the study.

Holloway and Galvin (2016, p. 3) asserted that qualitative research is a form of social enquiry that emphases on the way people interpret and make sense of their experiences and the world in which they live. Bowling (2009, p.380) posited, that qualitative research aims to study people in their natural social setting and to collect naturally occurring data. Notwithstanding, Creswell and Creswell (2018) propound that conducting a research study:

> “*involves which approach should be used to study a topic. Informing this decision should be the philosophical assumptions the researcher brings to the study, procedures of inquiry (called research design); and specific research methods of data collection, analysis, and interpretation”* (Creswell and Creswell, 2018, p. 3).

Hence, it is reasonably to suggest that some researchers see reality as subjective and want a close interaction with informants, while others may want an objective stance using surveys or experimental instruments, or alternatively a mixed methods approach by those who hold both an objective and subjective view. This ideology supports the view that a descriptive phenomenological study, will seek to explore the BME service users' individual and personal experiences.

I also gave some thought to the purpose of this study and how it would inform practice. Whilst the outcome of a research study is the production of new knowledge it is essential that this knowledge is transferred back into practice. However, authors such as Winters and Echeverri (2012) and Sandelowski (1998) purported that one of the barriers to implementing evidence-based practice is the way in which research reports are written and suggested that reports need to be clear, intelligible, relevant and generate interest for the reader. Kneale and Santy (1999) supported this view and added, that likewise the reader needs to appreciate the language of research, the way in which such papers are written and be able to critique their value.

In further unpicking the qualitative research methodology I was cognisant of the fact that there are a number of approaches that could be followed. In view of this Kneale and Santy (1999) suggested that there are three main types of qualitative research which are commonly used in nursing: Ethnography, Grounded Theory and Phenomenology. Each of these approaches has a different philosophical stance and links to different methodologies. Ethnography is a research methodology developed from cultural anthropology. This strategy for inquiry provides a rich source of descriptive data about the contexts, activities or beliefs of the participants with a particular focus on the cultural context in which health care takes place (Morse and Field, 1996, p. 21). The study is usually small and geographically bound, for example, on one ward with the researcher returning repeatedly over a long period of time. The data is usually collected through participant or non-participant observation and recorded in field notes (Atkinson and Hammersley, 1994, p. 248).

Glaser and Strauss (1967) developed grounded theory in the 1960s. The methodology has been developed further over the past three decades (Strauss and Corbin,1998). This research strategy aims to understand and explain human behaviour and is based on the sociological theory of symbolic interactionism. This proposes that human behaviour be developed through interaction with others, through a continuous process of negotiation and renegotiation.

People construct their own reality from the symbols around them by interaction rather than because of static reaction to symbols. In order to generate a theory, data is collected and analysed through a process of systematic data collection and analysis. Data collection, sampling and data analysis occur simultaneously during the research process as the researcher is theoretically sensitised to the emerging theory (Morse and Field, 1996, p. 22) in order to understand the phenomena. The findings can lead to the development of relevant interventions in the social environment under consideration.

Alternatively, phenomenological research is about asking *'what is it like to have this experience'*. The essence of phenomenological research is to describe the world as experienced by the participants of the inquiry to discover the common meanings underpinning the different facets of particular phenomena (Barker, Wuest, and Stern, 1992). Hence by using semi structured interviews I was able to find out from the BME participants what their experience was when accessing care from the mental health service.

3.2 Philosophical Assumptions

It is suggested that worldviews form the type of questions one would ask and what their answers might look like. These views form the theoretical perspectives (philosophical stance) which inform the methodology of a study (Crotty, 1998). Therefore, it is reasonable to suggest that every research method embraces an underlying theoretical perspective for example Symbolic Interactionism, Pragmatism or Feminism (to name a few). Forster (2001) proposed that qualitative research seeks to gain an in-depth investigation on human phenomena, in order to understand the value and meanings these phenomena have for the individuals under study. Equally, Holloway, (1997), put forward the view that qualitative research is a form of social enquiry that focuses on the way people interpret and make sense of their experience and the world in which they live.

By contrast quantitative (positivist) research assume that reality is fixed, directly measurable, and knowable and that there is just one truth, one external reality (Rubin and Rubin, 2012, p.14). Scientific techniques that are likely to produce quantified and if possible, generalizable conclusions are used as measurements, (Bell, 1987). Similarly, Blaxter, Hughes, and Tight, (1996) suggested that quantitative research is concerned with the collection and analysis of data in numerical form. The above concept has been embraced by authors such as Burke and Onwuegbuzie (2004) who inferred that mixed methods research is where the researcher blends or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study.

Burke and Onwuegbuzie (2004), took a philosophical stance and suggested that mixed methods is a third research movement that has moved pass the paradigm wars by offering a logical and practical alternative. To this end, Sandelowski (1993) affirmed that the researcher does not always clearly state the philosophical stance on which the study is based; however this can be recognised by careful reading of the literature, the presentation of the problem and the methods used. This means that the reader needs to have a sound knowledge base to ascertain the philosophical assumptions of the researchers.

3.3 Theoretical Framework

Bearing the above thought in mind I further examined my own philosophical assumption regarding which methodological approach that has shaped my thinking to conduct this research. It is without doubt that in order for a research study to demonstrate rigour the philosophical assumption needs to complement the methodological approach. Hence my philosophical assumption has been shaped by the many years I have worked as a Mental Health Nurse (MHN). Apart from working as a clinician I also worked in a few senior management roles. However, what has remained constant in my role as a Mental Health Professional is the desire to ensure that the care and treatment of service users-for whom I am responsible, is given to a high standard. Equally, that I employed practices that are respectful to service users hence acting in a professional manner.

Smith, Flowers, and Larkin, (2009, p. 11) for example, define phenomenology as a philosophical approach to the study of experience that shares a particular interest in thinking about what the experience of being human is like, in all of its various aspects, but especially in terms of the things that matter to us and which constitute our lived world. Phenomenology as a concept has been described as the study of conscious experience and can be traced back to early 20th-century philosophers such as Husserl, Sartre, and Merleau-Ponty (1963). A number of the ideas that sit within the works of these early phenomenologists were later adopted in the behavioural and social sciences by notable scholars, such as psychologist Amedeo Giorgi (1970) and social scientist Alfred Schütz (1967).

Similarly, Sundler *et al.* (2019) theorised that,

> “*the philosophy of phenomenology is the study of a phenomenon, for example something as it is experienced (or lived) by a human being that means how things appear in our experiences”* (Sundler *et al.* 2019: p. 734).

Over many years now several researchers have embraced and used the phenomenological approach with some researchers giving guidance with regards to aspects such as interviewing and data analysis (Giorgi, 2009).

Although phenomenologists share this belief, they have developed more than one approach to gain understanding of human knowledge. Holloway and Wheeler (2002) suggested that some researchers follow Husserl (1859-1938) and his followers who advocate a descriptive phenomenology, others use the ideas of Heidegger (1927-1962) and his colleagues who believe that phenomenology is interpretive. Streubert and Carpenter (1999) interjected and felt that neither approach is wrong it merely means that the researchers approach the study of lived experience in different ways. Phenomenological researchers hope to gain an understanding of the essential truths (that is essences) of the lived experience. Phenomenologists believe that knowledge and understanding are embedded in our everyday world. In other words, they do not believe that knowledge can be quantified or reduced to numbers or statistics.

Phenomenologists believe that truth and understanding of life can emerge from people's life experiences (Brooks, 2015; Gelling, 2014). I have chosen to follow the descriptive phenomenological approach as stated earlier as it will help to discuss the lived experience of the service users from a BME background. Hence, as a phenomenological researcher my role is to describe the BME participants' experience in the way they experienced it, rather than from a solely theoretical standpoint.

Having held those views for many years I felt certain that through this descriptive phenomenological study much would be gained by seeking the view of service users from a BME background about their perception of their needs and whether they are being met in the mental health service. Qualitative research examines the lived experience in an attempt to understand and give meaning. This usually is done by systematically collecting and analysing narrative materials using methods that ensure credibility of both the data and the results.

Mason (2002) declared that the epistemological perspective of phenomenological approach is principally postmodern, in recognising that human experience is complex, is grounded in the world, which is experienced, intersubjective and has meaning. Hence, respondents are viewed as real, active, and interpreting, and will intend to find meaning in experience-including the research interview (Holstein and Gubrium, 1995; Eckartsberg, 1986). In phenomenological terms this is known as modes of appearing. Bevan (2014) posited that modes of appearing means that a thing experienced, such as a person, car, idea, emotion, or memory, is experienced in many ways from different perspectives, by one person or by many people. Therefore, the participants from a BME background were given an opportunity to say what their experience was through their mental health journey within the Mental Health Trust.

Having worked in the Mental Health Trust, I was cognisant of the fact that exercising sensitivity when communicating and caring for people with a diagnosed mental health problem was an essential part of practice. Hence, to learn about the experience of service users from a BME background, I had to choose a methodology that lends itself to an inquiry where the service users are able to express themselves and describe their lived experience.

To this end, a qualitative approach is one in which the inquirer often makes knowledge claims based primarily on constructivist perspectives (namely the multiple meanings of individual experiences, meanings socially and historically constructed, with an intent of developing a theory or pattern, or advocacy/participatory perspectives; political, issue-oriented, collaborative or change oriented or both. The qualitative approach also uses strategies of inquiry such as narratives, phenomenologies, ethnographies, grounded theory studies, or case studies (Creswell, 2003, p.18). The researcher collects open-ended, emerging data with the primary intent of developing themes from the data (Creswell, 2003, p.18).

This is opposite to quantitative research, which is an approach in which the investigator primarily uses post positivist claims for developing knowledge that is, cause and effect thinking, reduction to specific variables and hypotheses and questions, use of measurement and observation, and the test of theories, employs strategies of inquiry such as experiments and surveys, and collects data on predetermined instruments that yield statistical data (Creswell, 2003). Therefore, a qualitative research method would be best suited to this study due to the nature of the information I needed to obtain from the participants.

As compared to quantitative research, qualitative research is much more difficult to generalise especially case study-based research. However, Polit and Beck (2010) contended that in nursing and other applied health research, generalisations are critical to the awareness of applying the findings to people, situations, and times other than those in a study. The authors further suggested that without generalisations there would be no evidenced based practice: research evidence can be used only if it has some relevance to settings and people outside of the context studied (Polit and Beck, 2010).

Three models of generalisation have been proposed by Firestone (1993): classic sample-to-population (statistical) generalisation, analytic generalisation, and case-to-case transfer (transferability). Analytic generalisation in qualitative inquiry occurs most keenly at the point of analysis and interpretation. Through rigorous inductive analysis, together with the use of confirmatory strategies that address the credibility of the conclusions, qualitative researchers can arrive at insightful, inductive generalisations regarding the phenomenon under study (Polit and Beck, 2010).

3.4 Sampling strategy

A survey was carried out of the service users registered on the electronic database RIO which revealed that there were 17,020 service users from a diverse background with some groups being larger than others. For the purposes of this research project the participants were drawn from the black minority ethnic groups namely: Black African, Black Caribbean, Black British and Black Mixed Race.

The inclusion criteria used was that the BME service users needed to be in receipt of services from the NLMHT and have a Severe and Enduring Mental Illness (SMI). These service users would also need to have been cared for in the NLMHT for 1 year or more as an inpatient, or in the community and have been selected following discussion with their Care Co-ordinators (CC) on their suitability (due to their vulnerability) to take part in the study.

The sampling process spanned four months namely, June to September 2013. Firstly, I contacted Community Mental Health Team Managers to seek permission to access the participants. The managers liaised with the Care Coordinators (CC) in their teams to identify BME participants who might be willing to take part in the study. I then contacted the CCs and gave appropriate information including consent forms (Appendix 2), patient participant sheet (Appendix 3), patient letter (Appendix 4) which they gave to the service users who were willing to take part in the study. Subsequently, the CCs informed me of the service users who were willing to participate, a sample quota of 24 service users. I also collected their signed consent forms.

This method of purposive sampling according to Gerrish and Lathlean (2015, p.181) and Polit and Hungler (1999) is based on the belief that a researcher’s knowledge about the population can be used to select cases for the sample. Reed and Procter (1996) suggested that sample sizes in qualitative research are often small and the sampling is often purposive rather than focused on statistical principles such as randomisation. Whilst the findings of this study would be applicable to the above service users, consideration would need to be given to transferability when applied to other BME groups.

3.5 Data Collection

The data for the study was derived via the use of semi-structured interviews with 24 service users from a BME background in a local Mental Health Trust. In conducting this study, I have been acutely aware that data from this study needed to be reliable and valid. Silverman (2006, p.288) suggested that both reliability and validity are important matters in field research. Equally, the credibility of qualitative research studies rests not just on the reliability of their data and methods but on the validity of their findings (Silverman, 2006, p. 289). With those thoughts in mind, whilst there are a number of different approaches in qualitative research, I have chosen to use the phenomenological approach.

Giorgi (1997) inferred that,

> *"questions are generally broad and open ended so that the subject has sufficient opportunity to express his or her viewpoint extensively"* (Giorgi,1997, p. 245).

Nonetheless, Benner (1994) gave some practical advice to phenomenological researchers by recommending that questions be asked in the vocabulary and language of the individual being interviewed. In Benner's view this approach enabled access to the respondent's perspective unencumbered by theoretical terms. This would appear to imply a form of phenomenological reduction. Benner also advised the researcher to listen attentively, which should lead to areas for clarification and probing.

For this, the researcher requires good listening and questioning skills to afford the ability to collect rich data, without leading the interviewee along a specific path. The aim is to reveal the meaning of an event in order to understand the participant's experience of it, without the researcher's bias. This is achieved by the researcher *'bracketing'* (Bernard and Ryan, 2010), or being conscious of their own pre-conceptions, presupposition and assumptions about the phenomena under investigation and disengaging from them during the research. The resultant data will enable the researcher to describe and interpret the phenomena by generating categories of meaning derived from the participant's experience and not the researcher's perception of the events (Kneale and Santy, 1999).

In the world of research qualitative data is most often obtained through unstructured and semi-structured interviews and/or participant or non-participant observation. Qualitative researchers often say that it is the *'richness'* of this data that is important rather than its quantity. In such situations the researcher is seen to be *'reflexive'* as they can influence the data and are almost a research tool in themselves. The researcher's effect on the subjects under study and the data produced is recognised through a process of analysis during data collection.

The concept of gratitude comes to the fore as suggested by Gibbs (2009). The author contended that workplace learning is complex, explorative, social and creative, and because it is carried out in the socio-political domain of the workplace, it is potentially exploitative of all who contribute. Hence, reflexivity plays an important role when carrying out a research study.

Reflexivity conceptualises, in part, who the researchers are, what is going on in them, and how a sense of self-consciousness can be put to analytic use (Aamodt 1991: p. 48). Much literature recognises the contribution of the researcher to the data collected (Rudge, 1996, Bruni, 1995), and the term reflexivity suggests that researchers need to be conscious of their role as actors and their own internal state (Lipson, 1991: p. 75). These are important considerations to be taken into account when considering the trustworthiness of qualitative research. In any case I ensured that remarkable non-verbal communication such as laughter, smiles or pauses were documented throughout the interview process. In line with the thinking behind phronesis (Kinsella and Pitman, 2012), I am drawing on my lived experience from a professional and personal perspective.

3.6 Semi structured interviews

Bowling (2009, p. 285) suggested that interviews are data collection methods, achieved by talking to respondents (interviewees) and recording their responses. She explained that there were advantages and disadvantages to this method of data collection. The advantages of face to face interviewing is that interviewers can probe fully for responses and clarify any ambiguities. On the other hand, semi structured interviews can be expensive and time consuming and there is a potential for interviewer bias. Nonetheless, Bowling (2009) advocated that there are,

> *“techniques for reducing bias including good interviewing training in methods of establishing rapport with people, putting respondents at ease and appearing non-judgemental”* (Bowling, 2009, p. 286).

Qu and Dumay (2011), stated that the semi-structured interview involves a method of questioning guided by identified themes in a consistent and systematic manner, with probes designed to elicit more elaborate responses. Thus, the focus is on the interview guide incorporating a series of broad themes to be covered during the interview to help direct the conversation toward the topics and issues about which the interviewers want to learn. Generally, interview guides vary from highly scripted to relatively loose. However, the guides all serve the same purpose, which is to ensure the same thematic approach is applied during the interview. As a qualitative researcher I fully subscribe to the above notion. Therefore, below are the themes that made up the interview schedule (appendix 5) for the research study:

- Needs for individual Care Planning.
- Ethnicity and equality.
- Access to information.
- Meeting needs in a crisis.
- Needs for timely treatment and support with mental distress.
- Need for ordinary living and long-term support.
- Need for personal growth and development.

Additionally, Kvale and Brinkman (2009) purported that the semi-structured interview enjoys its popularity because it is flexible, accessible, intelligible and, more importantly, capable of disclosing significant and often hidden facets of human and organisational behaviour. Often, it is the most effective and convenient means of gathering information. This notion is supported by Qu and Dumay (2011) who suggested that this is because the qualitative method of data collection has its basis in human conversation as it allows the skilful interviewer to modify the style, pace and ordering of questions to evoke the fullest responses from the interviewee. Most importantly, it enables interviewees to provide responses in their own terms and in the way that they think and use language. It proves to be especially valuable if the researchers are to understand the way the interviewees perceive the social world under study.

Qu and Dumay (2011) also stated that a primary technique used in semi-structured interviews is the use of scheduled and unscheduled probes, providing the researcher with the resources to draw out more complete accounts from the interviewees, drilling down a particular topic. A scheduled probe would require the interviewee to expand on a stimulating or surprising answer just made. For example, the interviewer attempts to follow up instantly with a standard question, such as *"please tell me more about that''* when the interviewee suddenly reveals an area of great interest, (Qu and Dumay, 2011, p 247). I was able to use that technique while interviewing the BME participants for this research project and found it a beneficial way to clarify points that I may have misunderstood. Similarly, the BME participants also had the opportunity to ask me to rephrase a question if they did not understand when the question was asked.

Such a process lends itself to one component of triangulation known as respondent validation or member checks (Torrance, 2012; Lincoln and Guba, 1985). Respondent validation involves research participants responding either to forms of initial data, for example, transcripts of interviews, or observations of activities, in order to check them for accuracy, or to first drafts of interpretive reports to respond, again, to their accuracy, but also to the interpretive claims that are being made (Lincoln and Guba, 1985).

Denzin and Lincoln (1998) noted differences between structured and semi structured interviews. They suggested that because of the requirement of the interviewer to probe and follow up on questions, semi-structured interviews can produce different answers depending on the traits of the interviewers. Different interviewers will elicit different responses from the same interviewee according to the way questions are asked and probed. This however is different from the structured interview, which accepts that the same objective truth will be told no matter who conducts the interview so long as the right questions and the same structures are followed. Therefore, Qu and Dumay (2011) posited that:

> "*conducting semi-structured interviews requires a great deal of care and planning before, during and after the interviews with regard to the ways questions are asked and interpreted"* (Qu and Dumay, (2011: p 247).

Denzin and Lincoln (2000) purported that other quantitative researchers regard the empirical data produced by interpretive methods such as the interview as *"unreliable, impressionistic, and not objective*" (Denzin and Lincoln, 2000: p.12). To these researchers, interviews are regarded as nothing more than casual everyday conversations. However, in comparison to everyday conversations or philosophical dialogues, which usually place the participants on an equal footing, the research interview can be characterised by an asymmetry of power in which the researcher is in charge of questioning a more or less voluntary and sometimes naïve interviewee. Although it may seem that everyone can simply ask questions, interviews conducted in a casual manner with little preparation could lead to unsatisfactory results, such as a wasted opportunity (Hannabuss, 1996).

Therefore, Doyle (2004) asserted that conducting qualitative research interviews is not a minor initiative. It requires not only the use of several skills, such as thorough listening and note taking, but also careful planning and enough preparation. To collect interview data useful for research purposes, it is necessary for the researchers to develop as much expertise in relevant topic areas as possible so they can ask informed questions. In terms of the interview design process, there are many decisions that must be considered wisely, such as who to interview, how many interviewees will be needed, what type of interview to conduct, and how the interview data will be analysed (Doyle, 2004). Giving further insights on the matter Rubin and Rubin (1995) highlighted that Interviewing requires,

> *"a respect for and curiosity about what people say, and a systematic effort to really hear and understand what people tell you"* (Rubin and Rubin, 1995: p.17).

Through the interview process I had an opportunity to hear the authentic voice of the BME participants under study.

3.7 Data Analysis

Data analysis in qualitative research is said to be a complex but rewarding process for the qualitative researcher. The aim of data analysis is to extract themes from the data collected. Holloway and Wheeler, (2010, 2002, p. 235), supported this by suggesting that qualitative data analysis is a complex, time consuming and iterative activity. Equally, Parahoo, (1997, p. 354) suggested that in qualitative research the process of data analysis start during data collection and continues after the field notes and /or tapes have been transcribed. I used the systematic method developed by Giorgi (2009, 1985) to aid the analysis of the data. Giorgi (ibid) prescribed the following steps for analysing data:

1. The entire description is read to get a sense of the whole. This is important as Phenomenology is holistic and focuses initially on the *'Gestalt'*, that is the whole.

2. Once the Gestalt has been grasped, researchers attempt to constitute the parts of the description, make and differentiate between *'meaning units'*–as the parts are labelled (these parts have to be relevant)–and centre on the phenomenon under study. It is important that these units are not theory-laden, but the language of everyday life is used.

3. When the meaning units have been illuminated, the researcher actively transforms the original data and expresses the insight that is contained in them and highlights common themes which are illustrated by quotes from participants

4. Making the implicit explicit in that the researcher integrates the transformed meaning units into a consistent statement about the participants' experience across individual sources. This is called the '*structure'* of experience. In other words, it is the essence of the experience.

Researchers usually approach people to find out about them to collect rich and in-depth data that may become the basis for theorising (Holloway, 1997). However, my thoughts about the study was not to generate a theory rather it was to gain an in-depth understanding of the BME participants experience regarding their needs while being cared for in the Trust. Each of the tape recordings was listened to in their entirety. I then listened to the tapes again to ensure that I captured the essence of what the participant had said. Listening to the tapes was quite refreshing as it allowed me to reflect and connect with each of the individual participants. I then started the arduous process of transcribing the tape recordings. The process of verbatim transcription of the recordings took several weeks. To ensure that I maintained accuracy of what the BME participants had said I had to replay the tapes at certain points. Whilst this process was a lengthy, I felt that in order to do justice in this study, it was necessary that the participants were able to tell their story.

In taking careful guidance from Giorgi (2009, 1985) the transcribed interviews notes were read to make sense of the data. At that point words and phrases were being highlighted with the premise to group similar words and phrases to begin the process of identifying emerging themes (appendix 12). According to Braun and Clarke (2006: p 82) thematic analysis requires researchers to ask themselves a variety of questions, normally surrounding *"What is a theme?"*. They argue that a theme captures a relevant aspect of the data in a patterned way, regardless of whether that theme captures the majority experience (Braun and Clarke, 2006). Whilst I used Giorgi (2009, 1985) systematic method to analyse the data I noted similarities to the 6-stage approach proposed by Braun and Clarke (2006), with regards to reflecting and coding of the data.

Reflecting on the BME participants' presentation in terms of their expression was evident during the transcription of the data. For example, one of the participants who at the start of the interview was fixed on the view that medication had not helped him. He was troubled by evil spirits. As he was explaining that those negative thoughts had not happened for some time, which seem to coincide with when he started taking prescribed medication, I could see the changes in his facial expression (smiling) and he then alluded to the fact that it could be the medication that has helped him. It was as if something illuminated in him that the medication had played a part in getting rid of the thoughts of evil spirits.

Immersing oneself in the data has been one of the hallmarks of qualitative research, (Gerrish and Lathlean, 2015, P. 481). Having gone through that process I would say it allows the researcher to form a deeper understanding of the subjects under study also it enables the researcher to produce a structured, coherent report. As I read through the transcripts, I noticed that the BME participants talked about the support they received from CCs, support from doctor/psychiatrist and support from the mental health service. I proceeded to highlight those areas of text and group them together. Those areas of text have been described as codes (Saks and Allsop, 2013, p. 94), inductively coming from the data. To this end, Saldana (2009, p.15) stated that a code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence–capturing and/or evocative attribute for a portion of visual data. Once the first theme emerged from the data, I proceeded to read through the transcripts highlighting and group similar words and phrases together. As this processing was taking place, I was reflecting on what messages I was getting from the data and kept referring back to the data for accuracy in my thinking.

The next stage of the analysis was to identify sub-themes and then linking them to major themes identified. The following is a sample of text from the transcribed tape recording for Grace (pseudonym). Figure 3 on page 72 gives a breakdown of how the coded text were grouped together to form the major theme–BME services users require support from Mental Health Services.

> Researcher: You have been receiving a service from North London Mental Health NHS Trust, what would you say your main needs are?
>
> Grace: In general my mental health but because over the years I have had a lot of side effects from the medications like mood and sometimes I do still get depressed I get support from my care coordinator you know, encouraging me and I have had issues in the past that produce negative feelings in me so now I am getting extra therapy from psychology I started a few months ago.
>
> Researcher: -You mentioned that you had mood swings is there a diagnosis that you have been given?
>
> Grace: Well I had a psychotic episode 12 years ago and I was hospitalised for nine months but since then I have suffered from depression from time to time, so I have to be on medication since then.

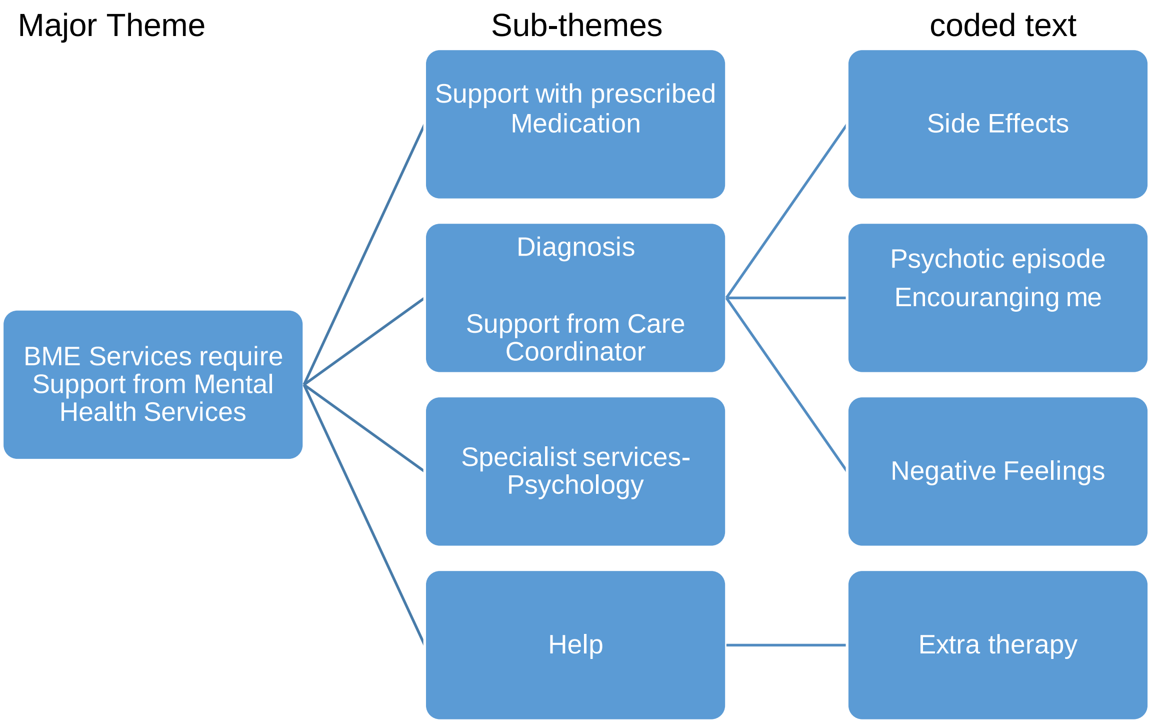


Figure 3: Breakdown of coded text

3.8 Addressing Rigour in this study

Morse *et al.* (2002) contended, that without rigour, research is worthless, becomes fiction, and loses its value. Therefore, a great deal of attention is applied to reliability and validity in all research methods. Guba and Lincoln (1981) emphasised that while all research must have *"truth value", "applicability", "consistency",* and *"neutrality"* in order to be considered worthwhile, the nature of knowledge within the rationalistic (or quantitative) paradigm is different from the knowledge in naturalistic (qualitative) paradigm.

Consequently, each paradigm requires paradigm-specific criteria for addressing *"rigour"* (the term most often used in the rationalistic paradigm) or *"trustworthiness*"; their parallel term for qualitative *"rigour".* They noted that, within the rationalistic paradigm, the criteria to reach the goal of rigour are internal validity, external validity, reliability, and objectivity. On the other hand, they proposed that the criteria in the qualitative paradigm to ensure *"trustworthiness*" are credibility, fittingness, auditability, and confirmability (Guba and Lincoln, 1981). These criteria were quickly refined to credibility, transferability, dependability, and confirmability (Lincoln and Guba, 1985).

Morse (2015, p.1213) suggested *that "rigour as a concept is an important goal, and rigour is the concern of external evaluators who ultimately determine the worth of qualitative research".*

The strategies for ensuring validity are:

> *"prolonged engagement, persistent observation, and thick, rich description; negative case analysis; peer review or debriefing; clarifying researcher bias; member checking; external audits; and triangulation"* (ibid, p. 1214).

I would suggest that in addressing rigour in this study the data obtained was done through semi structured interviews. Through those engagements it allowed the BME participants to build an element of trust in me and hence they were able to talk about their needs in an open and honest manner.

Gelling (2014) inferred that probably the most used approach is based on the idea that qualitative research should be trustworthy (Lincoln and Guba, 1985). They argue that trustworthiness can be demonstrated by considering the following:

- Credibility–demonstrating to readers why they can have confidence in the research findings.
- Transferability–demonstrating to readers how the findings might be transferred to another setting.
- Dependability–demonstrating to readers that the findings are consistent and repeatable.
- Confirmability–demonstrating to readers that the findings have emerged from the experiences of participants and have not, as far as possible, been influenced by the researcher (Lincoln and Guba, 1985, p 290).

A technique used to determine the credibility of qualitative research is triangulation which refers to the use of multiple referents to draw conclusions about what constitutes the truth. Patton (1999) and Denzin (1989) put forward four types of triangulation namely data triangulation, investigator triangulation, theory triangulation and method triangulation. Carter *et al*. (2014) further explained that data source triangulation involves the collection of data from different types of people, including individuals, groups, families, and communities, to gain multiple perspectives and validation of data.

In this study I used data triangulation to ensure credibility of the research through the semi structured interviews with 24 BME participants. A summary of the findings was distributed to the identified CCs to discuss with the participants in this study. To date no comment had been received. To further support this study, theory triangulation was done in that I was able to appraise other research that had been conducted regarding BME service users. Equally, method triangulation was completed by comparing the transcripts with the audio tapes and information gathered from field notes to ensure accuracy. This also ensured confirmability (Thomas and Magilvy, 2011), in the research processes. Thomas and Magilvy (2011) suggested that reflective research allows a big picture view with interpretations that produce new insights, allowing for developing confirmability of the research and, overall, leading the reader or consumer of the research to have a sense of trust in the conduct credibility of findings and applicability of the study.

A further aspect of credibility has been referred to as researcher credibility. Patton (1990) suggested that it is the faith that can be put in the researcher. In that qualitative researchers are the data collecting instrument as well as the creator of the analytical process, hence researchers training, qualification and experience are important in establishing confidence in the data. A further issue is that of dependability, the stability of the data over time and conditions.

Another assessment of qualitative research is that of conformability which refers to the objectivity or neutrality of the agreement between two or more independent people about the data's relevance or meanings. I would need to ensure that I maintained research credibility through accurate data collection and analysis of the data. It could be said that this study demonstrated transferability as I have detailed aspects such as the inclusion criteria, where the research was carried out, who took part and data collection and analysis. It could be assumed that given that information similar studies can be transferred to other settings and population.

The new information generated could be used to informed better practice when caring for people from a BME background in mainstream health care and mental health care. This would help promote parity of esteem that in the long term would help address the gaps in the service. Hence, the results in this study will help to contribute to and build a theory in care for people from a BME background. For example, Grace (pseudonym) and Luke (pseudonym) who both had gained weight while on psychotropic medication gave a view on what they required to maintain a healthy weight.

3.9 Reflexivity during the analytic process

Reflexivity is a critical reflection on what has been thought and done in a qualitative research project. Finlay (2002, p. 531) names reflexivity as the process whereby researchers engage in explicit self-aware analysis of their own role. It is a conscious attempt by researchers to acknowledge, their own involvement in the study- a form of self-monitoring in relation to research that is being carried out (Holloway and Galvin, 2016, p. 9).

Kempny (2012) highlighted the need for researchers to have reflective awareness to address their personal biases and examine how these affect the production of knowledge (Insider researcher). When I started the Doctorate in Professional Studies (DProf) programme in 2008 there was much discussion about how BME populations were experiencing difficulties in accessing and using mental health services. There was also a commitment in the Trust to address the inequality in care and meet the requirements of the Race Equality Scheme.

In 2002 I completed a master's programme where I undertook a project looking at service users' involvement in their care and treatment plan. Since then I had the desire to follow-up in a different study with a specific group in terms of race and culture. Hence my assumption was to carry out a study looking at the experience of BME service users.

Through the interviews the BME participants reported that their experience of using the mental health service was generally good. I started thinking whether they were telling me what they thought I wanted to hear as they will have associated me with the *'system'*. I then had to bracket (Bernard and Ryan, 2010) those thoughts and accept that the participants are recounting their experience and as the researcher I should not try and influence what is being said.

Another issue arose for me was while reading one of the participant's transcript I noted that in talking about the support he got from the psychologist he stated that it allowed him to talk about things *"people passing and that".* I felt a sense of unease that I did not probe a bit more when he made that statement. I had to resolve in my mind that my role was that of researcher and at that time he was getting the help from the psychologist. I suppose as a mental health professional one learns to listen to what was said and what was not said.

3.10 Ethical, Moral and Legal Issues

The Department of Health (2005a) posited that there has been a lack of research on the effects of the mental health system in meeting the needs of black and ethnic minority people. The Equality Act (2010), gives organisations a legal duty to ensure that every service or policy that is developed must be subject to an Equality Impact Assessment. The aim of this is to ensure that BME groups will receive a service that is equitable and fair.

In conducting a research project, the rights of the participants must be valued. Couchman and Dawson (1995) specified that the rights of individuals are that they are not to be harmed (beneficence), that they give their consent on the basis of information and knowledge about the research, their participation is voluntary and that the researcher follows the rules of confidentiality and anonymity. Similarly, Seale *et al.* (2004) stated that research subjects have the right to know that they are being researched, the right to be informed about the nature of the research and the right to withdraw at any time (respect for their autonomy); also the National Commission for the protection of human subjects of Biomedical and Behavioural research (1978) articulated beneficence, respect for human dignity and justice as ethical principles in research.

Arguably, Seale *et al.* (2004) suggested that there is no international agreement or regulations of ethical standards in research. However, the three main issues frequently raised in western ethical discourse are codes and consent, confidentiality, and trust. Consequently, following presentation at the programme plan at Middlesex University (MU) the proposal was sent to the North Central London Research Consortium (NoCLoR for peer review. Ethical clearance was obtained at National Research Ethics Service (NRES). I wrote to senior managers of the inpatient and community services to gain access to the participants. Once permission was granted (appendix 6) I approached the CCs via Community Mental Health Managers to agree the suitability of the service users due to their vulnerability.

From an ethical standpoint one could argue, how can a service user fully consent to a procedure or even take part in a research study if they don’t understand the verbal or written information that is presented to them. Polit and Hungler (1999) suggested that informed consent is when participants have adequate information regarding the research, and can comprehend the information, enabling them to consent or decline participation in the research voluntarily. One of the problems with informed consent is that at times the information about what will be done in the experiment is given in a language that is not clearly understood by the prospective participant. Another problem is that the researcher is not able to know everything about the research at the beginning, due to the exploratory nature of qualitative research thus the subjects cannot give a consent that is fully informed (Holloway, 1997).

Hence, in conducting this research study I was mindful that I use language that the service users understood also during the interviews I was able to give points of clarification where it was needed. Due regard was also given to the BME participants when conducting the interviews, in that I approach and maintained a respectful manner throughout the encounter with each participant. I was careful to ensure that the CC of the BME participants discussed the research with them after which the BME participants gave their consent to take part in the research. The consent forms detailed the aim of the research study. It further outlined details of the research and emphasised that it would be strictly confidential. Researchers need to be aware of the vulnerable nature of a person who has a diagnosed mental illness. Therefore, it was incumbent upon me to ensure that I inform the participants that their participation was completely voluntary, they have the right to withdraw from the research at any time.

The ethical issue of confidentiality meant that I informed the BME participants that their names will not be used (anonymity) and that the tape recordings once transcribed will be destroyed on completion of the research project. By giving those details to the participants enabled an atmosphere of trust which lends itself to the principle of veracity. In so doing I considered my professional accountability with regards to the BME participants (service users) in the research study.

In the light of Mason (2002, p. 21) who stated that the researcher will establish whether the purpose of the research concerns her personal gain such as achievement, a higher degree, a promotion; or is it about the advancement of knowledge and understanding? Consideration was given to the moral reason I embarked on this research study. However, my moral stance is that I am aware that several authors have discussed the inequalities that exist in meeting the needs of BME service users. My moral reason was to follow those lines of inquiry and to add to the body of knowledge that already exists.

From a legal standpoint the civil and criminal law place certain prescriptions on my profession concerning issues such as negligence, confidentiality and contractual obligation relating to my employment. Therefore, it would be obligatory that the rights, privacy and dignity of participants was maintained by treating them with respect. Hence, I exercised sensitivity throughout the whole process of the research, from initial contact with the participants through to dissemination of the finished project. Equally, I was mindful that identifiable names such as the name of the organisation have been anonymised to further protect confidentiality of the participants under study.

In the UK the rights of individuals who have a diagnosed mental illness have been protected by many laws within the legal system. These include the Mental Health Act 1983 (Department of Health, 1983) amended November 2007 (for those with a diagnosed mental illness), the Human Rights Act (1998) and the Data Protection Act (2018) to ensure that the rights of those individuals are respected. In addition, participants were reimbursed for monies spent on their travel to and from the interview and for taking part in the interviews. This was done according to Trust policy for their involvement in the study, thus avoiding civil action for malpractice and upholding the principle of beneficence.

3.11 Work base Insider Researcher - advantages and disadvantages

Floyd and Arthur (2012) inferred that Insider position may give privileged access and information, but the researcher's role in an organisation may also act as a constraint. This view was held by Mercer (2007) who concluded that on the one hand, insider researchers have freer access, stronger rapport and a deeper, more readily-accessible frame of shared reference with which to interpret the data they collect; conversely , they have to deal with their own pre-conceptions, and those their informants have fashioned about them as a result of their shared history, (Mercer, 2007, p. 13).

Floyd and Arthur (2012), put forward the view that external ethical engagement is,

> *"the superficial, easily identifiable ethical issues, such as informed consent and anonymity, which insider researchers attend to by submitting their application for ethical approval to their institution's internal review board"* (Floyd and Arthur, 2012, p. 5).

While in contrast, internal ethical engagement relates to the deeper level of ethical and moral dilemmas that insider researchers have to deal with once '*in the field'*. For example, the below-surface, murky issues that arise during and after the research process, linked to ongoing personal and professional relationships with participants, insider knowledge, conflicting professional and researcher roles, and anonymity, (Floyd and Arthur, ibid).

Consequently, one could argue that there are advantages and disadvantages of being an insider researcher. One example is that the participants could view you as an employee of the organisation rather than a researcher. After completing the interview with one participant he asked, '*will I be seeing you next week?'* I then had to explain that my role was purely to do with the research and that he would continue to see his current CC. The above scenario resembles the campaign '#hellomynameis' that urges NHS staff to introduce themselves properly to patients and visitors (Granger, 2015). Notwithstanding, I was able to clarify what my role was to the participants in this study.

In discussing the comprehensive nature of applications for ethical approval Floyd and Arthur (2012) contended that this increasingly bureaucratic approach could lead to novice insider researchers avoiding, or not engaging fully with, what has been termed the *'ethic of care,'* (Gibbs and Costley, 2006, p. 244). Gibbs and Costley (2006, p. 247) suggested that once the researchers are *'in the field'*, because they may feel that by gaining ethical approval at the start of their project, they do not need to be concerned about such issues any further. While it could be argued that these more robust procedures are appropriate to safeguard participants' interests, they felt that an over-emphasis on box-ticking for researchers may, at times, be at the expense of engagement with deeper ethical issues. However, throughout this research process I have consciously made efforts to ensure that the rights of the BME participants were respected and that confidentiality have been maintained with regards to managing and securing the data collected.

Tuffour (2018) discussed how while conducting a research study as part of his doctoral thesis he struggled to separate his identity as a black African and as a researcher due to connection that was being made between him and the participants in the study. He stated that:

> *“the effort to remain neutral was emotionally draining. The struggle to separate my black African identity from my position as a researcher was challenging”* (Tuffour, 2018, p. 3).

He was however able to bracket his feelings as suggested by Smith, Flowers and Larkin (2009). I had to employ similar strategies especially when one of the participants was from the same island as where my parents were from.

3.12 Summary of Chapter 3

In this chapter research methodologies were discussed, and a rationale was given for following the qualitative research method. Chapter 3 highlighted the differences between the two research paradigms. The chapter also highlighted that, apart from qualitative and quantitative research, mixed methods have been viewed as a third research methodology where qualitative and quantitative methods are used in a study. Some of the common philosophical assumptions were highlighted and rationale was given for the one chosen to conduct this study in order to answer the research question. This led to a discussion on the phenomenological approach, its origins and its relevance to qualitative research and particularly in nursing research.

This chapter highlighted the sampling strategy noting the inclusion criteria that was used. Notably, the concept of data collection was discussed followed by a discussion on semi structured interviews which was the data collection method in this study. In this section the differences between structured and semi structured interviews were also noted.

What followed next in this chapter was how the data collected was transcribed and analysed. In doing so the systematic method proposed by Giorgi, (2009, 1985) was used to identify themes and subthemes. A sample of coded text was given in figure 3 on page 72 as a visual example of a theme and subsequent subtheme. This chapter also highlighted that rigour in qualitative research is of absolute importance to ensure credibility of the work that has been done. Triangulation as a method to determine credibility was highlighted and the different types of triangulation was discussed. What followed next was the concept of reflexivity and how researches need to address their personal biases. I was able to reflect on my role as a researcher and how it impacted in this study.

In this chapter consideration was given to ethical and legal aspects when undertaking research. I was able to discuss the process followed in obtaining ethical approval to conduct this research study. This section highlighted the importance of consent, confidentiality, trust and how the rights of participants would be respected and valued. A discussion ensued on the role of insider researcher highlighting advantages and disadvantages of being an insider researcher. The next chapter will give a discussion on the project activity, describing each steps of the process in this study. How and what was done including highlights of any challenges faced during that process.

3.13 Reflection on Chapter 3

Chapter 3 began by discussing methodological approaches used in research. In deciphering differences between qualitative and quantitative research some authors have suggested that there is a better fit between qualitative research and nursing rather than quantitative research (Gullick and West, 2012; Millier, 2010). Whilst I would agree with those views as patients often talk about their experience of care, there are times when quantitative research is necessary in nursing. For example, if a team manager wants to know about service users attendance at different therapy groups, a survey could be conducted. The results will show which groups are well attended and those where the attendance is less. A qualitative study could then follow to find out what are the benefits experienced by the service users.

This is suggestive of the third research methodology termed mixed methods. So, in reflecting on my example given above the team manager could have decided at the outset that s/he would follow a mixed methods approach. A decision can be made whether to continue with the groups where the attendance is poor, taking into consideration resources available to run and manage said groups.

Whilst there are different types of qualitative research used in nursing including Ethnography, grounded theory and phenomenological, I chose to use the phenomenological approach in this study. The choice was based on my own philosophical assumption and the type of information that would need to be elicited from the participants. The purposive method of sampling was used in this study. It seemed to be the most appropriate sampling method for the target group within which the sample was drawn. As I reflect on the participants who took part in the study, it struck me that an alternative sampling method (random sampling) may well have been applicable. It would however be more time consuming.

With regards to data collection the literature suggested that a researcher should use vocabulary and language that the participant understands and should practice active listening (Benner, 1994). I am in agreement with the advice given by Benner as it resonates well within mental health. One of the core features of working with service users who have mental health problems is about the use of language and the ability to actively listen to what the service users have to say. Hence, in either building a therapeutic relationship or in conversing with a service user, mental health professionals should use language that the service user understands. This may let service users know that the professionals take a non-judgmental approach when caring for them.

The notion of 'bracketing' came to the fore as I embarked on a literature review prior to the data collection process, which suggested that inequalities exist within mental health for BME service users in accessing and using mental health services. Therefore, during the data collection process I had to bracket those views and accept what the participants were saying, as they expressed that were happy about the care they received within the Mental Health Trust.

The method within which the data was collected was via the use of semi structured interviews. I believe that this method worked well as each participant was given individual time which allowed them to relate to me as a researcher in a positive way. If I had used, for example, focus groups, it is highly likely that some participants would not participate readily which would have impacted on the data collection.

The data analysis was conducted in a systematic manner. The process was long and arduous but necessary. An important aspect of qualitative research is about how the researcher addresses rigour in the research study. I believe that I was able to demonstrate trustworthiness by using methods such as triangulation. Although I was keen to hear the authentic voice of the participants, I was mindful of the fact that I had to implement ethical principles in particular consent. This was extremely important as the participants had a diagnosed mental illness and it would be wrong if I interviewed a participant who had not consented.

Bowling (2009) highlighted techniques for reducing bias including good interviewing training in methods of establishing rapport with people, putting respondents at ease and appearing non-judgemental. I identified very much with this statement as it resonates well with me as a mental health nurse and as a researcher. I say that because the concept put forward by Bowling (2009) is the approach that is taken when working with service users with a diagnosed mental health problem. This is because it is incumbent on the mental health professional to help raise a service user's self-esteem and self-image. Therefore, throughout the interviews I ensured that the participants felt at ease and remained respectful throughout the interview.

During the interview with one of the participants, he asked if I would be seeing him next week. As I reflected on his question, I wondered about the concept of insider researcher and the challenges it presents when undertaking a research study. It could also be that the participant was at ease during the interview which suggest that the efforts I made to observe ethical practice worked well.

4.0 Chapter 4: Project Activity

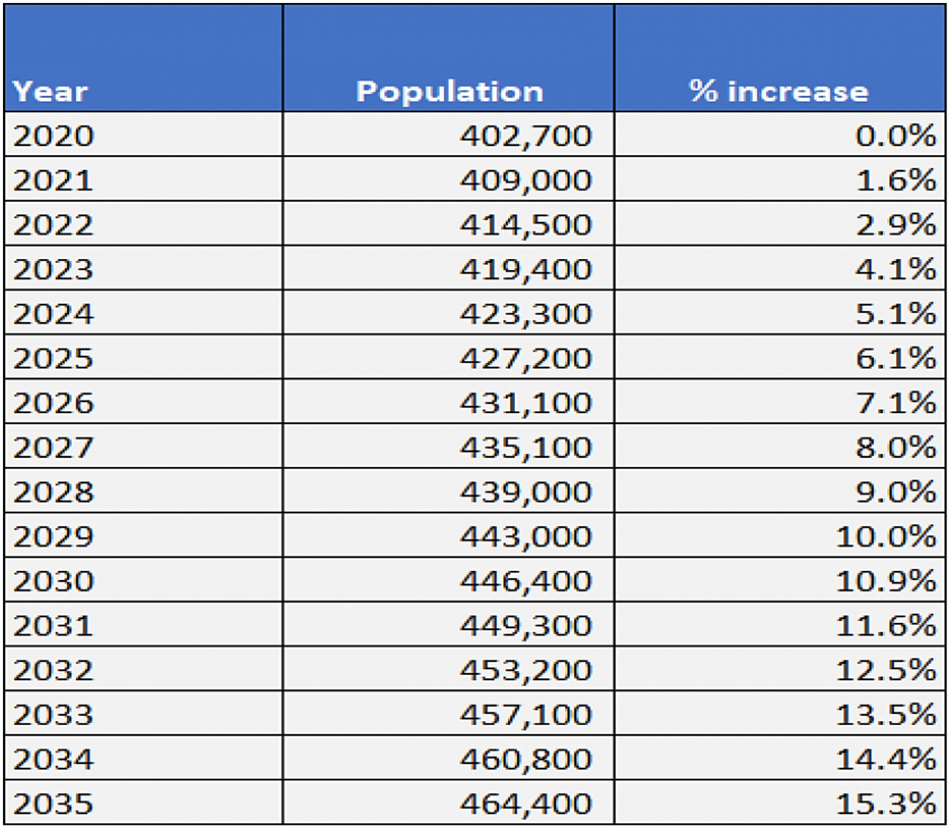
4.1 Research Activity

In this chapter an account will be given on the method used in conducting this study. I will detail the process of obtaining ethical approval and how participants were selected for the study. A rationale will be given for the use of semi-structured interviews. I will discuss the steps taken in the analysis of the data leading to the themes as discussed in chapters 5 and 6. The chapter will end with a critical and detailed reflection of the methods and limitations regarding participants and data collection, including gender equality and difference**.** I will first highlight the research location which is aligned to the NLMHT.

4.2 North London Borough 1

For 2020, the population of North London Borough 1 (NLB1) was estimated to be 402,700, which is the largest of all the London boroughs. The borough's overall population is projected to increase by around 10.9% between 2020 and 2030, taking the number of residents to about 446,400 and to 464,400 in 2035 as seen in table 2 below.

Table 2: Growth in NLB1 population between 2020 and 2035



Year	Population	% increase
2020	402,700	0.0%
2021	409,000	1.6%
2022	414,500	2.9%
2023	419,400	4.1%
2024	423,300	5.1%
2025	427,200	6.1%
2026	431,100	7.1%
2027	435,100	8.0%
2028	439,000	9.0%
2029	443,000	10.0%
2030	446,400	10.9%
2031	449,300	11.6%
2032	453,200	12.5%
2033	457,100	13.5%
2034	460,800	14.4%
2035	464,400	15.3%

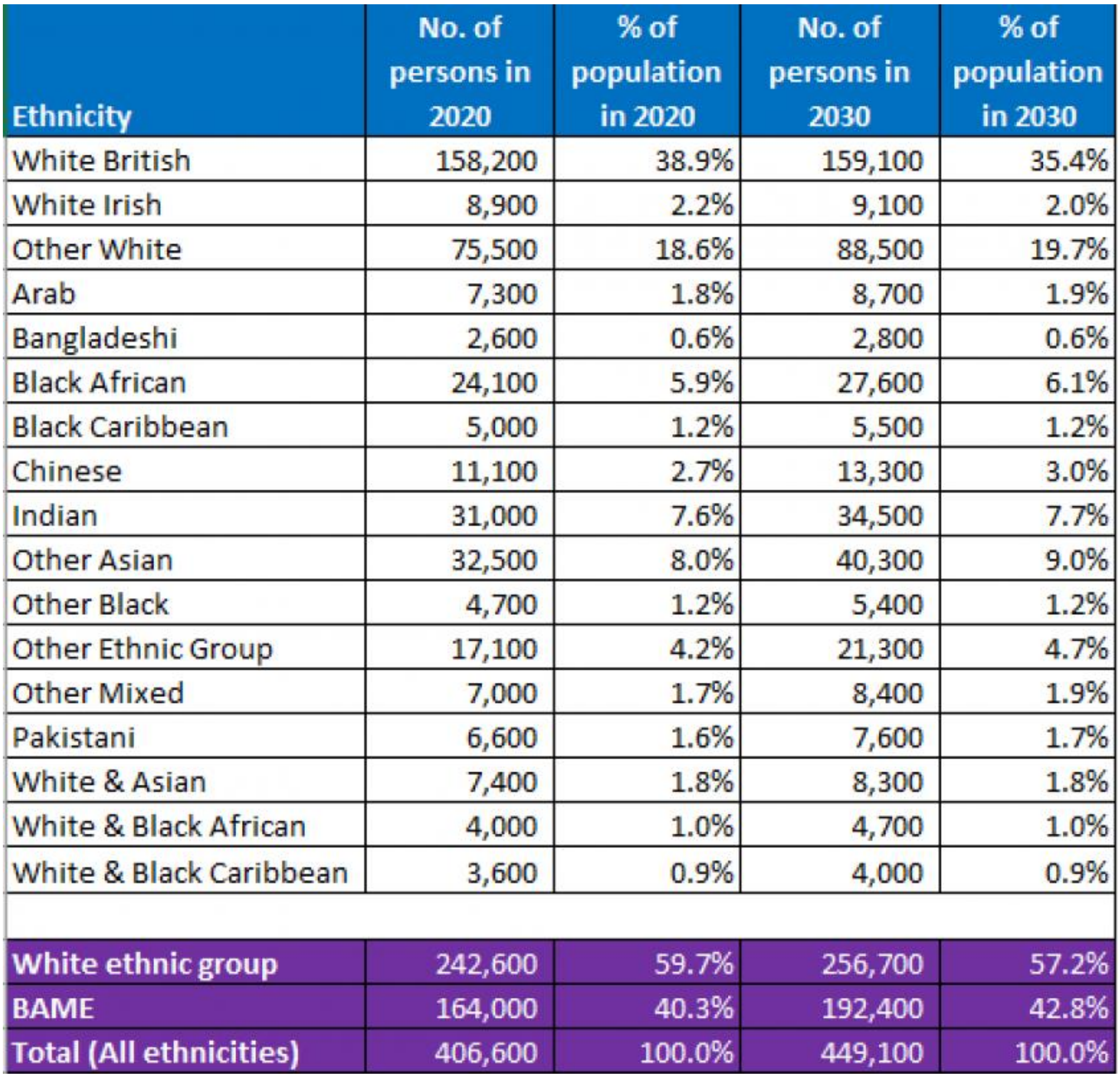
Source: Greater London Authority (GLA, 2019). Borough Preferred Option (BPO). [Population estimates have been rounded to the nearest 100.]

The number of people aged 65 and over is projected to increase by 29.8% between 2020 and 2030, compared with a 4.9% increase in the 0-19 age group and a 9.4% increase for working age adults aged 16-64 (NLB1, 2020).

In 2020, the White ethnic group (composed of “White British,” “White Irish” and “Other White”) makes up 59.7% of the borough’s population. However, by 2030, this segment of the NLB1 population is predicted to fall to 57.2% of the total. The largest ethnic category in NLB1 during 2020 is “White British,” accounting for 38.9% of the borough population. However, by 2030, this proportion is predicted to shrink to 35.4% as seen in table 3 on page 86, (NLB1, 2020).

In contrast, the proportion of Black, Asian and Minority Ethnic (BAME) people in the borough is projected to rise from 40.3% in 2020 to 42.8% in 2030. Whilst there is estimated to be an overall increase in the proportion of the NLB1 population within the BAME communities, different ethnic groups within the BAME category will experience varying changes during the period 2020-2030, (NLB1, 2020). According to the 2011 census, by religion, Christianity is the largest faith in NLB1 accounting for 41.2% of the total population. The next most common religions are Judaism (15.2%), Islam (10.3%), Hinduism (6.2%) and Buddhism (1.3%), (NLB1, 2020).

Table 3: Population counts and percentages for ethnic groups in NLB1, persons, 2020 and 2030.



Ethnicity	No. of persons in 2020	% of population in 2020	No. of persons in 2030	% of population in 2030
White British	158,200	38.9%	159,100	35.4%
White Irish	8,900	2.2%	9,100	2.0%
Other White	75,500	18.6%	88,500	19.7%
Arab	7,300	1.8%	8,700	1.9%
Bangladeshi	2,600	0.6%	2,800	0.6%
Black African	24,100	5.9%	27,600	6.1%
Black Caribbean	5,000	1.2%	5,500	1.2%
Chinese	11,100	2.7%	13,300	3.0%
Indian	31,000	7.6%	34,500	7.7%
Other Asian	32,500	8.0%	40,300	9.0%
Other Black	4,700	1.2%	5,400	1.2%
Other Ethnic Group	17,100	4.2%	21,300	4.7%
Other Mixed	7,000	1.7%	8,400	1.9%
Pakistani	6,600	1.6%	7,600	1.7%
White & Asian	7,400	1.8%	8,300	1.8%
White & Black African	4,000	1.0%	4,700	1.0%
White & Black Caribbean	3,600	0.9%	4,000	0.9%
White ethnic group	242,600	59.7%	256,700	57.2%
BAME	164,000	40.3%	192,400	42.8%
Total (All ethnicities)	406,600	100.0%	449,100	100.0%

Source: GLA (2016a): 2016-based central trend ethnic group projections. [Population counts are rounded to the nearest 100].

NLB1 has a great collection of parks and open spaces and these are a significant part of what makes NLB1 a green and family friendly borough. People who live and work in NLB1 enjoy access to formal parks and gardens, wild landscapes, extensive areas of greenbelt and leafy river valleys (NLB1, 2016).

4.3 North London Borough 2

One of the most striking demographic characteristics of NLB2 is its rich ethnic diversity. Table 4 below give a breakdown of the ethnic mix within the borough. Based on the 2019 NLB2 Ethnicity estimates, residents from White British backgrounds make up 35.32% of NLB2's inhabitants with White Irish at 2.18% and other White groups at 25.13%. Other Ethnic Groups represent 5.25% of the population, Mixed Groups at 5.48%, Asian Groups at 10.97% and Black groups at 17.89%%. The population was estimated to be 333 794 in mid-2019. Over the next decade, this figure is expected to steadily increase, reaching around 340,000 by 2032 (NLB2, 2020).

Table 4: 2019 NLB2 Ethnicity Estimates

Ethnicity Estimate	Grand Total	%
Black African	24,763	7.38%
Bangladeshi	6,432	1.92%
Black Caribbean	17,725	5.28%
Chinese	2,732	0.81%
Greek	4,549	1.36%
Greek Cypriot	16,302	4.86%
Indian	11,937	3.56%
Kurdish	4,264	1.27%
Other Asian	12,852	3.83%
Other Black	8,357	2.49%
Other Ethnic Group	13,354	3.98%
Other mixed	6,890	2.05%
Pakistani	2,829	0.84%
Somali	9,157	2.73%
Turkish	24,209	7.22%
Turkish Cypriot	6,432	1.92%
White and Black Caribbean	4,664	1.39%
White and Asian	4,348	1.30%
White and Black African	2,471	0.74%
White British	118,466	35.32%
White Irish	7,309	2.18%
White Other	25,381	7.57%
Grand Total	335,423	100.00%

Source: (NLB2, 2020).

NLB2 is the 5th largest borough amongst the 33 London boroughs, based on their mid-year population estimate, with NLB1 being the largest borough in London (ONS mid-year Population Estimates, 2018). 23% of the population are under 16 (London average 20.5%), 13% of the population are 65 and over (London average 11.5%) and 35% of residents were born overseas. 178 languages or dialects are spoken in the borough including Turkish, Somali, Polish, Bengali, Albanian and Greek. NLB2 is 5th most deprived borough in London with 10 out of 21 wards among the 20% most deprived in England. 22% of children under 20 live in low-income households (NLB2, 2018).

NLB2 is the 7th least populated borough in London, as a result about 40% of the Borough’s area is designated as Green Belt with several sizeable parks within the built-up area. The Council has developed additional town twinning arrangements with Turkey and Greece in response to the large Greek and Turkish speaking communities that live in the Borough (NLB2, 2020).

A review by the Trust for London showed North London Borough 2 has the highest eviction rate in the capital by a wide margin, with 34 evictions per every 1,000 renting households (compared to 28 per 1,000 in the second highest borough: Brent). Those figures suggest that North London Borough 2 has one of London's largest private rented sectors. While the unemployment rate in North London Borough 2 is 4% lower than the London average, 29% of workers do not earn a living wage. This amounts to 8 percentage points higher than the London average. The figure has gone up 3.2% since 2013, one of the highest increases in London. However, 69.5% of working-age people are in employment (NLB2, 2018).

4.4 North London Borough 3

North London Borough 3 (NLB3) has been described as an exceptionally diverse and fast-changing borough. NLB3 has a population of 282,904 residents. By 2025, NLB3’s population is estimated to reach 300,600, an increase of 10.9% from 2015. Population growth locally is due to higher annual births than annual deaths, and net migration gain driven by high annual international migration.

Sixty three percent of the NLB3 population are from a BME group or Other White ethnic groups as seen in figure 4 on page 89 compared to 58% in London. Around 15% of residents in NLB3 are from Black ethnic groups and just under one in ten are Asian (9%). Of those whose main language is not English in NLB3, one in four (24%) either do not speak English well or do not speak it at all. This is the third largest proportion of all London boroughs, and is above the statistical neighbour and London levels. The proportion of NLB3 residents who say they are Christian (45%)

is in line with statistical neighbour boroughs (46%) and is slightly below London (48%) (NLB3, 2019).

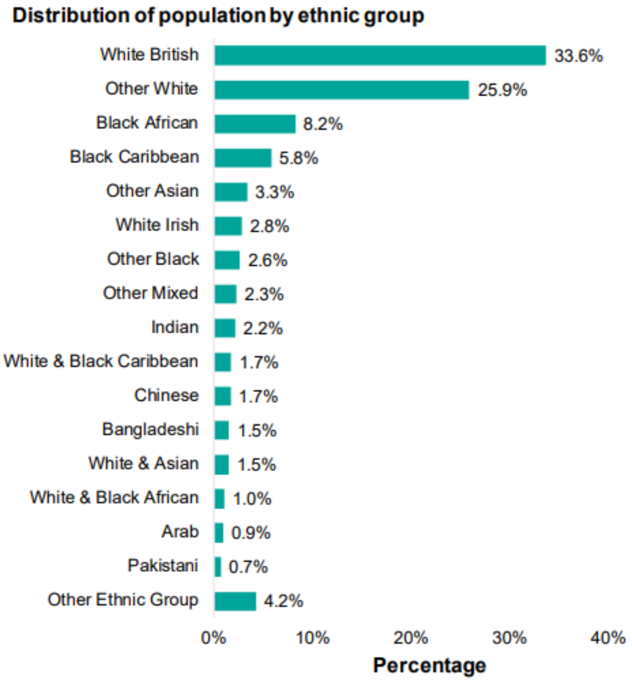


Figure 4: Distribution of population by ethnic group

Source: NLB3, 2019.

Almost two-thirds of the population, and over 70% of the young people, are from ethnic minority backgrounds. There are over 100 languages spoken in the borough. NLB3's population is the fifth most ethnically diverse in the country. The borough ranks among the most deprived in the country with pockets of extreme deprivation in the east, (NLB3, 2019).

By 2028, the ethnic groups with the highest projected growth are expected to be the Other ethnic group and Other White, growing by 10% each, while Black Caribbean and Bangladeshi groups are expected to decrease by 12% and 8% respectively. The White British group will remain the largest population overall, followed by Other White and Black African. The highest expected growth is in the older age groups. The 85+ age group will rise from 3,136 to 4,209. The 65-84 group will rise from 24,054 to 31,103 people. The working age population will remain the largest population overall, (NLB3, 2019).

NLB3 is ranked 49 out of the 317 local authorities in England with respect to deprivation and is the 3rd most deprived in London as measured by the IMD score

2019 (where 1 = most deprived). The Index considers a range of deprivation types, including income, employment, education, health, crime, barriers to housing and services and living environment, (NLB3, 2019).

In NLB3, it is estimated that 34,500 adults have a common mental health problem. About half will seek help from primary care (e.g. a GP), with only half of these having their illness recognised and diagnosed as a mental illness. This suggests that many residents are experiencing anxiety and depression without help or support from health professionals. Seventeen point seven percent of adults in NLB3 are smokers, an increase from 2017 (15.6%). Those with depression, schizophrenia and who are homeless are significantly more likely to be smokers, compared to the general population. Although there has been a decrease in overall smoking prevalence, it is higher in more deprived parts of the borough (24.2%), (NLB3, 2019). Notably, it has been found that smoking is more common in people with poor mental health than in the general population (Ross, 2020). In the UK, >40% of adults who have a serious mental illness also smoke while in the general population, the proportion of smokers is nearly 15%, (Action on Smoking and Health, 2019a).

Just over a quarter (27.8%) of NLB3 is made up of open space. Although below the borough average for London (33%), NLB3 has many public parks and open spaces. NLB3's current unemployment level (in the 12 months to June 2019) was 4.5%, in line with SN's (4.9%) and London (4.7%). Unemployment levels in NLB3 have fallen at the same rate as statistical neighbours and London and are currently in line with SN and London averages. NLB3 has however, a larger than average number of Jobseeker's Allowance (JSA) and Employment Support Allowance (ESA) claimants (NLB3, 2019).

The Indices of Deprivation (2019) are the Government's primary measure of deprivation for small areas (known as LSOAs) in England. NLB1 has been described as the twenty-seventh most deprived borough. NLB2 is the fifth deprived borough and NLB3 is the third deprived borough, (London Datastore, 2019). Those figures are significant as levels of deprivation can have an impact on one's mental health.

4.5 Reflection on the individual process

The initial part of the project was to develop a project plan which was presented at Middlesex University (MU) for approval in October 2009. Following approval by MU (appendix 1) the next stage was to begin the process of seeking NHSREC approval. Before approaching the ethics committee, I had to develop a patient letter (appendix 4) Patient Information Sheet (PIS) (appendix 3) and a semi structured interview schedule (appendix 5). I was mindful of the fact that I needed to gain service user experience of using the mental health service therefore the questions needed to be structured to elicit that information. Equally, a service user's journey within mental health is also part of their recovery, hence questions needed to be centred around those aspects as well. Using some guidance from the Mental Health Foundation on aspects of the service user care I was able to structure the interview schedule under the following headings adopted from the Mental Health Foundation 2011:

- Needs for individual Care Planning.
- Ethnicity.
- Access to information.
- Meeting needs in a crisis.
- Needs for treatment and support with mental distress.
- Need for ordinary living and long-term support.
- Need for personal growth and development. (Mental Health Foundation, 2011).

Piloting the research instruments

Once I had formulated the interview schedule, I sent it to the manager of one of the local service user groups to give her comment. I also sent the schedule to the Lead Nurse for the acute service for her comment. Both reported that the structure and the questions in the interview schedule were appropriate. When the paperwork I needed to present for ethical approval was ready, they were sent to North Central London Research Consortium (NoCLoR) in March 2011 for peer review. Peer review is an important part of the development of the project in that it gives objectivity on a way forward prior to commencing a research study: A critical eye to guide the researcher. Following peer review at NoCLoR a request was made for clarification on two points in the proposal. The points of clarification were made and submitted to NoCLoR. For example, the peer reviewers suggested that I changed my focus on accessing service users from ethnic groups as the focus of the project would be too broad. Instead I should focus on black African, black Caribbean and black British. This was a helpful insight. A letter agreeing to the points that had been addressed and clarified was received from the peer review panel NoCLoR (appendix 7). In August 2012 a confirmation of sponsorship letter was received from MU (appendix 8).

All the appropriate paperwork was sent to the National Research Ethics Service (NRES) in October 2011 to seek approval to conduct this research study. Following presentation at the Ethics Committee, ethical approval was not granted as a few points were highlighted and needed to be addressed. Those changes were made and sent to the Ethics Committee in September 2012 (appendix 9). In October 2012 a response letter was received from NRES requesting further information. The areas raised were addressed and a final approval letter was received in January 2013 (appendix 10). Following ethical approval, I then had to make an application to the research and development committee (R&D) to ensure that the project is registered and that it has been agreed by the organisation I worked for. A letter of approval (appendix 11) was receive April in 2013 from the research and development committee. The final process was to ensure that the project was registered at Middlesex University hence, the NRES ethics approval letter was sent to MU Ethics in March 2013 as part of the registration process as shown in figure 5 on page 93.

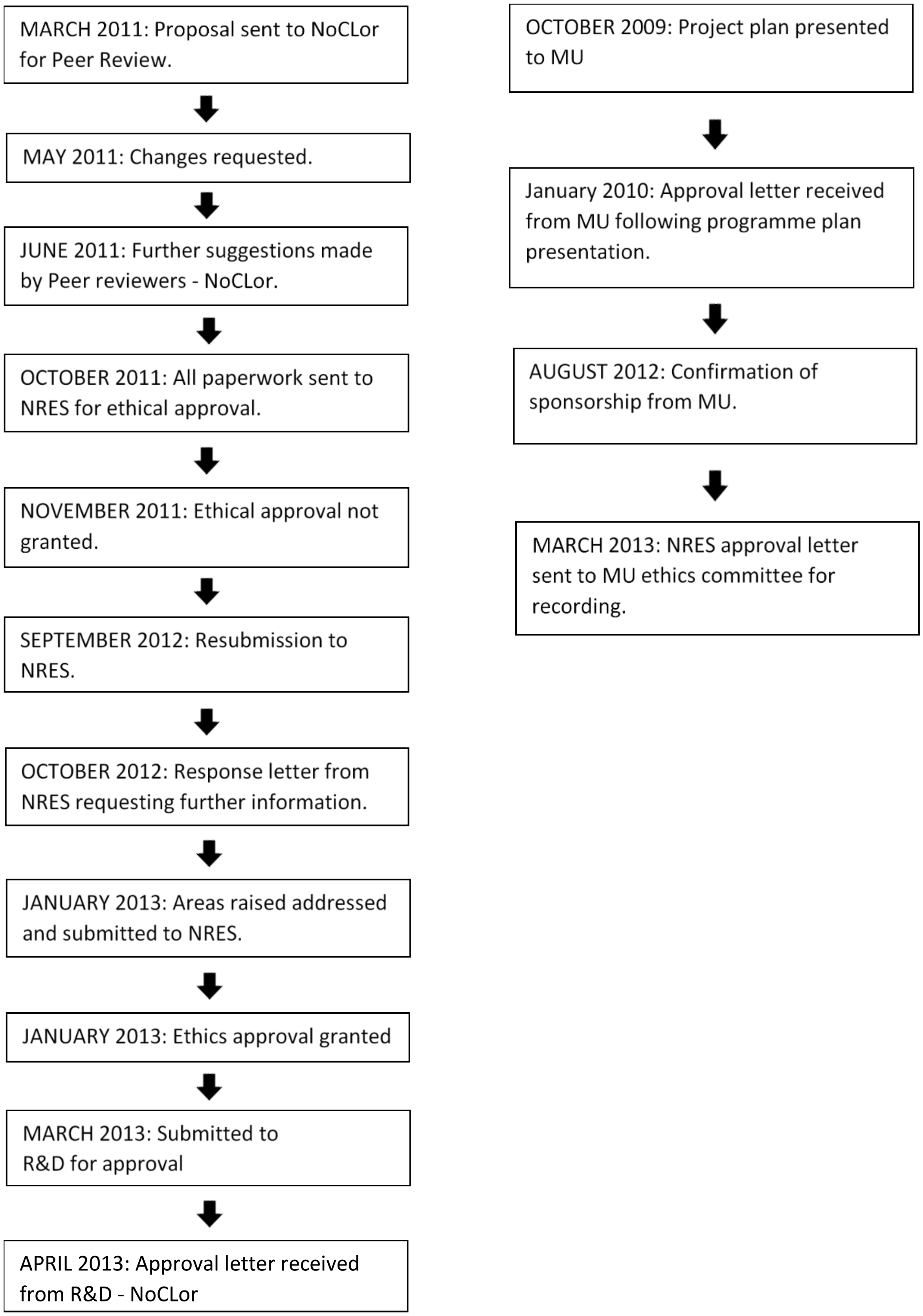


Figure 5: Process of seeking ethical approval

4.6 Seek Approval from Trust

My initial plan of accessing the participants was that after identifying those service users who met the research criteria and after appropriate sampling I would send an introductory letter to the service users informing them of my intentions to conduct this study and seek their consent to take part in the study. I was unable to go forward with this plan following presentation at the ethics committee. It was suggested that I needed to gain permission from the manager of the respective service where the service users were accessing mental health support. Therefore, I approached the Assistant Director for the service within which I intended to interview the service users. Permission was granted via an approval letter (Appendix 6). The Assistant Director acts as a gate keeper for the Trust and so I would not be able to proceed if their approval was not granted.

4.7 Ethical Consideration

Gerrish and Lacey (2009) in discussing the importance of the ethics in research highlighted that nurse researchers paid scant attention to ethics. Nurses were presumed to be professionals with integrity and a vocation in which putting patients' interest before their own could be assumed. However, with increasing public concern regarding the unethical behaviour of some professionals when conducting research ethical procedures exist. Robson (2002) referred to this as questionable practice and felt that it arises from the question's researchers ask, and the methods used to seek answers. Hence, when conducting research, researchers need to ensure that they respect the rights of participants. Researchers need to gain consent, maintain confidentiality, and ensure that the needs of vulnerable people and groups are respected. This means as a researcher I needed to take all necessary steps to ensure that the BME participants came to no harm.

I would say that I found the process of seeking ethical approval quite rigorous as following my application to the NRES I was invited to attend the panel where my application was discussed. This was a first experience for me as although I have studied at masters' level, I was not required to attend an ethics panel to present my project plan. In any case, a few questions were asked by the ethics panel members after which I was advised that a decision will be given to me in writing. I then received a letter which advised that ethical approval was not granted, and some suggestions was given as to which areas should be improved. Whilst it was disappointing, I took on board their suggestions.

For example, one of the questions I was asked at the ethics committee was *how would the participants know if their needs are being met if they don't know what their needs are?* To afford me the ability to answer that question, I had to revisit the interview schedule and include an opening question which asked the participants to describe what their needs were when being cared for in the Mental Health Trust. A further area that needed to be clarified was how I would maintain participant confidentiality during the research study. I had to ensure that I stated clearly that all the information collected about the participants during the course of the research will be confidential. Any information that might identify the participants will be changed or made anonymous and that the information they give will be used only for the study. I also had to show how I would let the participants know that the confidential information that they give may be shared with their CC in certain circumstances. For example, if the participant indicated that they were unwell and the support that they required was not within the research, contact would need to be made with their CC.

Equally, confidential information given by the participant may be shared without their agreement if there were issues around child protection, where there are signs of significant distress, where there are signs of relapse, and where there is clear evidence the participant posed a risk to themselves or others.

On refection this part of the process of seeking ethical approval was extremely important as it allowed me to focus more deeply on the ethical principles as described above. I then resubmitted the papers six months later to the ethics committee. On this occasion I received a letter from the ethics panel asking for some further changes to the interview schedule. The changes were made and a letter detailing the changes with a revised interview schedule were sent to the ethic committee. I then received a letter from the ethics committee informing me that I have been granted approval to conduct the research project. I would say that going through this process has given me a deeper appreciation of the ethical procedures and an assurance that much is being done to protect the rights of vulnerable people when conducting a research study.

Holloway and Wheeler (2002) proposed that researchers negotiate with *'gatekeepers'* who are the people who have the power to grant or withhold access to the settings and they are based at different places in the hierarchy of the organisation. The authors identified people such as managers, clinicians, consultants, GPs as gatekeepers. Whilst gatekeepers are necessary to protect vulnerable people in their care, Holloway and Wheeler (2002) noted that gatekeepers may make demands that the researches cannot fulfil and may guide in a path or deny them access to some individuals.

The above process resembles the steps I had to take in terms of seeking permission to gain access to the service users. Following a favourable answer, the Assistant Director requested that I contacted the three Service Managers, one from each borough to ask their permission to access the service users. The next step was to contact the Community Mental Health Team Managers who then agreed that I could contact the CCs. The role of the CCs was to go through their caseload first to establish which service users met the criteria and then approaching them to find out if they would be interested in taking part in the research study. This meant that the CCs were pivotal in access to the service users as even if I was an employee of the Trust, I had to maintain integrity in the way I conducted this study. In that, I could not approach the service users myself as agreed in my ethics application and approval.

As a MHN I have to work within the realms of a professional code of conduct (NMC, 2018). Hence it was incumbent upon me to differentiate my role from an employee to that of a researcher. Equally, within healthcare practice I am aware that the four ethical principles put forward by Beauchamp and Childress (2001) beneficence - to do good, non-maleficence-to do no harm, justice and autonomy, informed consent should be at the forefront on my practice irrespective of which role I undertook at a given time.

4.8 Sampling Strategy

The sample frame for this research study were service users from a BME background who were currently in receipt of services from a NLMHT and have a diagnosed mental illness. The criteria for the study was that the participants would need to have been cared for in the NLMHT for 1 year or more as an inpatient or in the community and have been selected following discussion with their CCs on their suitability (due to their vulnerability) to take part in the study. They needed to be either Black British, Black African, Black Mixed race or Black Caribbean. The CCs from 6 Community Mental Health Teams (CMHTs) identified participants from their caseload who met the criteria. Those service users were asked by their CCs if they were willing to take part in the study.

One of the crucial tasks in designing a research project is to decide on the number and characteristics of the respondents who will be invited to take part in the study, (Bowling 2009: p.187; Parahoo,1997, p.218). A carefully selected sample can provide data representative of the population from which the sample is drawn. Additionally, Bernard and Ryan, (2010), felt that 20-60 knowledgeable people are enough to uncover core categories of lived experience of a defined group.

Additionally, as the researcher I had decided that 24 participants would be adequate for the study. Consequently, the non-probability sample method-purposive sampling in which an explicit inclusion criterion was used, (Patton, 2002). The data was collected using a semi structured interview schedule. The duration of the interviews were 30 to 45 minutes and occurred in a room within the CMHT bases; however, 3 participants were not able to attend at the CMHT base therefore I arranged and conduct the interview at their home.

4.9 Semi structured interviews

Qu and Dumay (2011) suggested that interviews offer a valuable way for researchers to obtain information about the world of others, though real understanding may sometimes be elusive. Even when the interviewer and the interviewee seem to be speaking the same language, their words may have totally different cultural meanings. Thus, communicating may become problematic when people have different worldviews. However, done with care, a well-planned interview approach can provide a rich amount of data, (Qu and Dumay, 2011, p. 239).

It has been said that qualitative research can be subjective in nature as different researchers could interpret data from their perspective. Hence, the concept of reflexivity comes into play. Holloway and Wheeler, (2002), stated that human beings are self-reflective persons who are based in everyday life and personal relationships and experience in a temporal and historical context and their position in the world. Preconceptions and provisional knowledge are always revised in the light of previous experience and reflection. The text is always open to multiple interpretations because researchers are reflective persons who are involved in their own relationships with the world and others. The art of reflection (Johns 1994; Gibbs, 1988) has been imbedded in nursing practice over many years as it has been a vehicle through which nurses develop and learn.

Gerrish and Lacey (2009) supported this view and stated that reflexivity has some similarities and uses process like those used in reflective practice. Similarly, Somerville and keeling (2004) proposed that reflection is an examination of personal thoughts and actions. However, Gerrish and Lacey (2009) noted that there was a paradox in the above thoughts about reflexivity. This is because on one hand qualitative researchers are advised to be involved and immerse themselves in the data and on the other hand, they must produce a report that is free from bias. However, as a qualitative researcher it gives me comfort to know that there are a range of approaches to aid in the process of ensuring that the research is trustworthy.

4.10 Contact Care Coordinators

Once permission was granted by the service managers, I contacted the four Community Mental Team Managers where I had intended to conduct the research. My reason for contacting the managers was to seek permission to access participants who wanted to take part in the study. Equally, I needed to arrange to meet with CCs to discuss the project and seek their support in accessing participants for the study. Accessing participants to be involved in the study was of concern as in order for them to give their consent it would need to be established that they have the capacity to do so. The Mental Capacity Act 2005 (Department of Health, 2005c) requires that before any treatment or intervention is carried out with a service user diagnosed with a mental health problem it would need to be established that they have the capacity to consent to that treatment or intervention.

Furthermore, according to Beauchamp and Childress (2001) the four principles of ethics need to apply when dealing with service users. Hence, I would need to ensure that I exercise beneficence throughout the research process, demonstrate non-maleficence, treat each participant fairly and maintain integrity and justice throughout the process.

The team managers agreed that I can contact the CCs within the team. In addition, the team managers suggested I forwarded the paperwork including the patient letter, PIS, consent form to them and they will ensure that the CCs receive the paperwork. The CCs will approach those service users who met the inclusion criteria as discussed on page 63 in chapter 3. Whilst I had planned to have a meeting with each team, to save time I carried out telephone conversations with the managers who in turn were able to discuss with their staff what I required of them. From then the CCs approached the service users who met the criteria and were willing to take part in the study. I was then informed of the name of the participants after which I arranged to conduct the interviews.

The patient information sheet was given to the service users by their CCs and the CCs went through the consent forms with the service user who subsequently signed indicating that they were consenting to take part in the research study. As mentioned earlier the CCs ensured that the service users were approached and put forward for this study understood what they were being asked to do. Once the consent forms were signed, I collected them from the CCs following which dates were set to conduct the interviews. On the day of the interview I explained to the BME participants what the study was about and checked if they still would like to take part in the study. As a researcher I was maintaining transparency in the way that I conducted the study which would meet the requirements of ethical practice.

In order to ensure that a researcher acts in an ethical manner, all research that involves human subjects must have ethical approval. This is because the researcher has a social responsibility in ensuring that they respect the needs of the participants. In considering each of the four ethical principles I had to demonstrate to the ethics panel's how I would address each of those ethical principles. This was even more important as the service users have a diagnosed mental health problem and in safeguarding terms are individuals who are at risk of abuse. As a researcher, I was careful in the manner in which service users were approached and consented ensuring they were given adequate information about the research study also ensuring that they understood that it was their right if they did not want to participate. This information was conveyed to the participants both verbally and in writing using the patient information sheet. A statement to that effect was also written in the consent form.

At the end of each interview I thanked the BME participants for their time and asked if they had any questions, they wanted to ask me. Arrangements were made to ensure that each participant received reimbursement to cover their time spent in the interview at a rate of £10.00 per hour. This is in keeping with government policy when conducting research (INVOLVE, 2020). Travel cost was also reimbursed. The tapes were then listened to and transcribed. I completed the interviews in December 2013 and due to work commitments, I was not able to transcribe the tapes until July 2014. I felt slightly disappointed by that as it meant that I had to keep changing my timetable on when I would be able submit drafts of my work. In any case there were lessons to be learnt in completing a programme such as this in that with enthusiasm, time and the drive and desire to learn and develop, keeps the researcher focused on the task to be done. Once transcribed each of the notes was read through and key words and themes were drawn out as suggested by (Giorgio, 2009, 1985).

Whilst chapter 5 will go into more detail of the analysis of the data, it was essential to ensure that all precautions were taken to make sure the data was kept securely at all times and that was from tape recordings through to writing up this report. As agreed, the names of the BME participants were not used to maintain anonymity. However, pseudonyms and demographic information by participant (appendix 13 and 14) were used to bring live meaning to each BME participant.

4.12 Write-Up Project

The final stage in the research activity is to pull all the strands together via the writing up phase. Through the writing up I would be able to expand and explore the information elicited from the interview tapes that have been transcribed. That said, I began the process of writing up in 2014. I faced a few challenging issues in that I had started a new job as a Senior Lecturer in Mental Health Nursing in February 2014. At that time trying to balance the requirement of a new job and writing up was proving a bit difficult. My situation was further compounded in October 2015 after I had an unfavourable diagnosis regarding my health and had to interrupt my studies until November 2018. However, the writing up process has been insightful and a further learning curve in completion of this research study.

4.11 Transcription and analysis of data

Following transcription of the 24 tape recordings I used a content analysis as described by Giorgi, (2009, 1985), method to analyse the data. That involved reading and rereading the transcripts. I then used a coding framework to draw out themes and subthemes. An example of an analysis of a small anonymised section of transcript data can be seen on page 71 in chapter 3. In order to address rigour in this study Lincoln and Guba's (1985) approach was used to determine credibility, transferability, dependability and confirmability of this study. Other methods such as triangulation including data, investigator, theory and method triangulation were used (Denzin, 1989).

4.13 Summary of Chapter 4

Chapter 4 began by highlighting the research location within which the study was conducted. The findings showed that the population in NLB1 will continue to increase and is projected to reach 417,573 in 2030. Hence, suggesting a further increase in the BME population. NLB2 has been described as a hugely diverse population with 154 languages spoken in the borough. The evidence also suggests, that NLB3 is exceptionally diverse borough with over 100 languages spoken the borough.

What followed next was a reflection on the processes followed in the management of this research study. The process of obtaining ethical approval and how participants were selected for the study was discussed. A rationale was given for the use of semi-structured interviews. The next chapter will give details of the findings in this study supported by quotes from the BME participants who took part in this study.

4.14 Critical and detailed reflection and account of the methods and limitations regarding participants and data collection, including gender equality and difference.

Reflexivity was noted by Gerrish and Lacey (2009) as presenting a paradox for qualitative researchers. They suggested that on one hand qualitative researchers are advised to be involved and immerse themselves in the data and on the other hand, they must produce a report that is free from bias. I accept the authors views on reflexivity, and I am further reassured by the processes available to ensure trustworthiness in a research study.

In this study 24 BME participants were interviewed; 17 were male and 7 were female. On reflection this could be a limitation as having the views of an equal number of male and female participants may have elicited further insights into the needs of the BME participants. However, for the participants who took part in the study, gender specific issues did not arise as the participants talked about their health and social care needs.

A further issue regarding the sample was the method in which they were recruited to take part in the study. Once the CCs identified the participants who met the criteria and were willing to take part in the study, they informed me the names of each participant. It became clear that once the sampling quota of 24 was reached, I had to advise the CCs that I have reached the identified 24 participants to take part in the study. On reflection for equity with regards to gender, it is worth selecting an equal number of females and males until the desired number is reached.

A further observation following reflection of the process was a breakdown of the participants by borough and by gender. Hence, for impartiality, further insights could have been added if there were eight participants from each borough with an equal breakdown of four females and four males. However, the themes and subthemes identified in this study were drawn from the analysis of the data collected from the twenty-four BME participants. Equally, as seen in table 6 on pages 106-107 in chapter 5 the pseudonyms of each participants were linked to the identified theme or subtheme. This method showed that the views and experience of all the BME participants were represented.

The payment of public involvement including patients, service users and carers in research has been given consideration and discourse over the past two decades (INVOLVE, 2020; Patterson, Trite, and Weaver, 2014; Trivedi and Wykes, 2002). INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research to support active public participation in NHS, public health and social care research. It is one of the limited government-funded programmes of its kind in the world (INVOLVE, 2020).

More recent work of INVOLVE has been the development and formulation of a set of standards and indicators issued in 2018 for public involvement/engagement in research. The new national standards for public involvement in research provide a framework for reflecting on and improving the purpose, quality, and consistency of public involvement/engagement. They describe the building blocks for good public involvement/engagement and provide a baseline of expectations.

Likewise, in discussing how research partnerships with users will be formalised Trivedi and Wykes (2002) stated that it is necessary that clinical researchers need an explicit agreement about how they will work together; addressing issues such as when and how users will be involved in the research, payment of users, acknowledgement of users' contributions, and issues of confidentiality. Trivedi and Wykes (2002) used a research contract which was developed some years earlier within the institution where they worked.

To this end, a study conducted by Patterson, Trite, and Weaver (2014, p. 73) found that service user representatives were more frequently worried about their inability to access training and practical difficulties. For example, access to essential technology, travelling to meetings held in inconvenient locations and out-of-pocket expenses. Barnes and Cotterell (2011) suggested that if user involvement is to be effective, healthcare organisations and their staff need the skills, support, and knowledge to enable this to happen. The authors contended that:

> *the extra considerations that come with genuine user involvement, such as ongoing support and development, supervision, communication, cost, payment for travel expenses and payment for training delivered are often overlooked. All this needs to be factored in when implementing service user initiatives if they are to be supported and sustained appropriately,* (Barnes and Cotterell, 2011, p.119).

Notwithstanding, the policy in the NLMHT is that service users are reimbursed for travel and time spent in attending and being involved in service development activities. As this study is about enhancing care and practice it was incumbent upon me to ensure that the participants were reimbursed.

5.0 Chapter 5: Project Findings and Analysis

Chapter five will give an outline of the findings from the semi structured interviews held with 24 participants from a black minority ethnic background (BME). A Content analysis was first carried out followed by a thematic analysis using the framework developed by Giorgi (2009, 1985) as seen in table 5 below, to identify key themes. The process involved reading the transcripts twice. The first time was to familiarise myself with the transcripts. Then the second reading allowed me to allocate codes in order to group similar words together. The allocated codes resulted in six major themes and subsequent sub-themes.

Table 5: Thematic Analysis

Framework in practice	What I did
1. The entire description is read to get a sense of the whole. This is important as Phenomenology is holistic and focuses initially on the 'Gestalt', that is the whole.	The first time was to familiarise myself with the transcripts to get an overall sense of the participants' lived experiences.
2. Once the Gestalt has been grasped, researchers attempt to constitute the parts of the description, make and differentiate between 'meaning units' – as the parts are labelled (these parts have to be relevant) – and centre on the phenomenon under study. It is important that these units are not theory-laden, but the language of everyday life is used.	I read the data again which allowed me to highlight similar words and phrases.
3. When the meaning units have been illuminated, the researcher actively transforms the original data	Similar words and phrases were grouped together in order to form themes.

and expresses the insight that is contained in them and highlights common themes which are illustrated by quotes from participants.	These were significant statements or quotes that provided an understanding of how the participants experienced the Phenomenon under study.
4. Making the implicit explicit in that the researcher integrates the transformed meaning units into a consistent statement about the participants' experience across individual sources. This is called the structure of experience. In other words, it is the essence of the experience.	Six themes and subsequent sub-themes identified as seen in table 6 on pages 106-107.

Giorgi (2009, 1985)

The key themes identified from the analysis of the data will be highlighted followed by any identified sub themes. Not all the data generated in this study would be used. Participant quotes was used to support the themes and sub themes identified. Each participant was given a pseudonym to ensure that anonymity was maintained. Equally, the use of pseudonyms will aid in telling the participants stories. Some of the participants' demographic details will be presented in this chapter however further demographic details will be found in appendix 13 and 14.

Table 6 on page 106 – 107 gives a breakdown of the major themes and subthemes identified following the data analysis. The names (pseudonyms) of the BME participants have been added to the individual themes/subthemes to indicate that the data from each participant have been added and discussed. Appendix 12 will give an example of data and how it was analysed showing the development of themes and sub-themes.

Table 6: Breakdown of major themes and sub-themes following data analysis.

Themes	Subthemes
1. BME Service users require support from mental health services	**1.1 The need for suitable housing.** Nathan, Mary, Robert, Paula, Ali, Charles, Dominic, Peter, George. **1.2 The need for specialist services** Andrew, Jacob, Thomas, Grace. 1.3 **BME Participants had to wait for varying periods of time before accessing specialist services-Timelines.** Grace, Thomas, Luke. **1.4 Involvement in care plan:** Gloria, Harry, Mary, Grace. Paula, Charles, Robert. **1.5 Support from the Care Coordinator and/or the Mental Health Team.** Grace, Peter, George, Paula, Grace, Roger, Ali, Gloria, Emma, Rose, Ryan. **1.6 Information about illness and treatment options:** Paula, Thomas, Paul, Luke, Grace, Gloria, Charles, Nathan.
2. Participants from a BME background would like to find gainful employment	**2.1 BME participants experienced being stigmatised in their attempts to find work.** Gloria, Paula, Paul. **2.2 BME participants require extra support in returning to work.** Ryan, Nathan, Grace, Luke, Andrew.
3. Recognising signs of relapse	**3.1 BME participants established some trigger factors that can cause them to relapse.** Andrew, Paul, Guy, Charles, Roger, Ryan.

	3.2 Learning from previous experience of being unwell. Jacob, Andrew, Charles, Paul.
4. The need for help with taking medication and medication concordance	**4.1 BME participants link taking medication as a major part of their recovery.** Paula, Paul, Mary, Jacob, Nathan, Leo. **4.2 BME participants highlighted the negative effects of prescribed medication.** Paul, Paula, Harry, Rose, Dominic, Gloria, Peter, Luke, Robert. **4.3 Some BME participants experience weight gain as a side effect of medication.** Luke, Grace.
5. Service users from a BME background experience stigma	**5.1 Some BME participants linked the stigma they experienced as coming from the wider society.** Paula, Luke, Ali, Gloria.
6. Hope	**6.1 Service users from a BME background demonstrate resilience.** Paul, Ryan, Charles, Grace, Leo, Emma, Andrew, Peter, Harry, Mary, Jacob. **6.2 Spirituality** Roger, Paula, Ali, Thomas, Hannah, George, Luke.

5.1 Profile of Research Population

Table 7 on page 108 is a representation of the participants in the research study. 17 of the participants were male and 7 participants were female. Although more females were approached by their CC regarding taking part in the study 7 females agreed to take part. 5 of the participants were between the ages of 18-30. 7 participants were between the ages of 31-40. 8 of the participants were between the ages of 41-50 and 3 participants were between the ages of 51-65 as seen in the demographic information shown in appendix 14.

Table 7: Demographics of research participants

Gender	Number of participants
Male	**17**
Female	**7**
Age	
18-30	**5**
31-40	**7**
41-50	**9**
51-65	**3**

Figure 6 below reflects the type of mental health diagnosis and the number of participants per diagnosis. 15 participants had a diagnosis of Schizophrenia, 5 participants were diagnosed as Paranoid Schizophrenia. 1 participant was diagnosed as Paranoia, 2 participants were diagnosed as Schizo-Affective Disorder and 1 participant was diagnosed as Bipolar Affective Disorder.

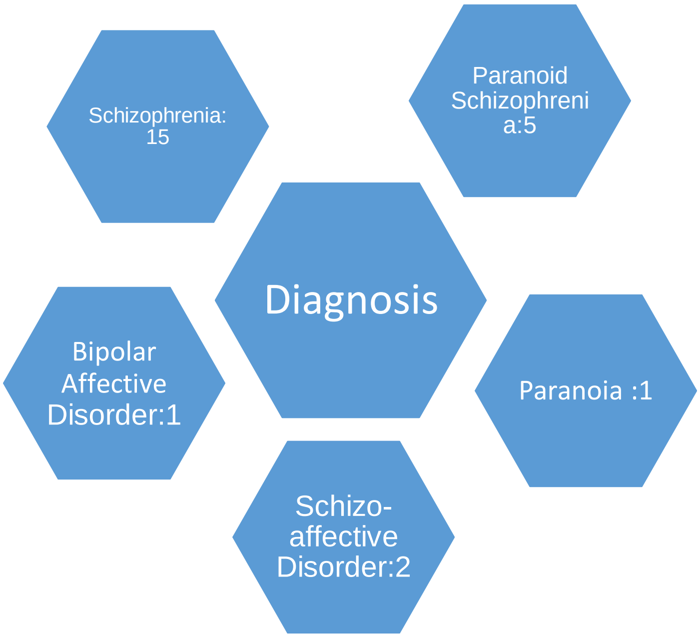


Figure 6: Participant diagnosis

5.2 Themes identified following the Semi Structured Interviews with participants from a BME background

Twenty-four participants from a BME background were interviewed using a semi structured interviewed schedule. There were seventeen males and seven females of an age range between eighteen and sixty-five years old; age range 23 to 61 years. Six themes and any subsequent subthemes are presented in this chapter and these were as a result of reading the data in a literal, interpretive and reflective sense. The use of direct participant quotes will be incorporated to form an integrated description of the phenomena in question which allowed for the organisation of themes.

5.2.1 Theme One: BME Service Users require support from mental health services

When an individual has been referred to the mental health service, the initial task of the mental health team is to conduct an assessment to establish what it is the service user needs. In this study when the participants were asked about their main need several the participants had a resounding response-*'support'.* Notwithstanding, whilst the term '*support*' could be quite broad in the range of ways it can be executed, each of the participants were specific in the type of support they required. Whilst the main theme is clear what follows next are the subthemes which correlate with the main theme.

5.2.1.1 The Need for Housing

Housing and benefits play a major role in the support service users receive from mental health services. Adequate housing is necessary for service users to live a more fulfilling life. When asked about their main needs some of the participants cited housing as one of their main needs. Nathan stated:

> *"I used to live in supported accommodation but now I have got my own flat, so I don't need to get that much support anymore. I just come for blood test and stick to appointments that's it really"* (Nathan, 29yrs, male, Schizo Affective Disorder).

Mary had a similar view and cited housing and benefits as her main needs. Mary said:

> *"Just things like housing and benefits just things like housing and benefits really."* (Mary, 29yrs, female, Schizophrenia).

Professionals who work in mental health services take on the role of advocate. For service users who are unable to articulate their needs specifically due to the difficulties they might be experiencing or as a result of their illness, the professional could speak on behalf of the service user to ensure that s/he receives the best outcomes from services which they require. In exercising their duties as Mental Health Nurses (MHN) advocacy is a core skill required in affording the ability to do their job well. One of the ways this could be done is to write letters of support if a service user is applying for housing or Department of Work and Pension (DWP) benefits. Hannah needed help with writing letters and said:

> *‘‘I need help with writing like writing my letters someone needs to help me writing my letters I can write letters but not much.’’* (Hannah, 43yrs, female, Schizophrenia).

The researcher examined closely the responses given by the participants when asked what they would say are their main needs. Some of the participants including Robert wanted help with his housing situation but had not received it.
Robert stated:

> *“Both mental health/physical. I need support with my request. I need support with housing. I don’t need everything, when I requested to move, I did not receive it, instead they start giving me medication. So, I didn’t receive what I asked for. I was concern about where I was living, they allocated me to a doctor. They say it would take a long time. The environment I was living in, they could have helped. I am talking to social services. I am still in the same place I am still waiting.’’* (Robert, 43yrs, male, Schizophrenia).

There have been links to suggest that poor housing can lead to poor mental health. This means that adequate housing is a key factor to enable the service user through their mental health recovery journey. Paula described how she needed to be moved from her previous flat as she was experiencing anti-social behaviour, noise, and stress from her neighbours. Paula stated:

> *“The problems I was having in 2002 was after a while my husband died and then I was living in a place where there was a lot of anti-social behaviour so I was stressed and I had the little kids now they were young so I was the only one to make decisions on everything and I am under pressure almost all the time. I was not sleeping well because of the noise in the night and everything and my worries when I sleep try to sleep there was a lot of banging upstairs. I could not sleep so it became a problem I had moved house and after that I think I was suffering from it. It’s been a hard time for me, but I must say that they have been helpful getting me through it.’’* (Paula, 47yrs, female, Schizophrenia).

The concept of *'social isolation'* was discussed by some of the participants in this study. They described how they felt lonely. Ali talked about being lonely and agreed for others to move into his flat. He had not anticipated the danger of his actions. The impact of his actions related directly on his housing situation, his mental health and personal safety. Ali stated:

> *"Obviously I have issues to deal with drugs because I'm on drugs as well but I have come off drugs and it's a long story I don't want to go through it but what I wanted to say is that I have lost my accommodation and because basically I was letting the drug dealers in. Yes, because I was lonely, so I have let them in and …. I'm Muslim been doing drugs, but I have not taken any drugs for the past week. When I saw my mum two years ago after 15 years of not seeing her, I went back on cocaine and I spent a lot of my money on it. Yes we're going to the council and everything I have always wanted to move because I have not felt safe in my flat and I wanted to start afresh I have been in the same flat for 24 years so wanted to start afresh.''* (Ali, 49yrs, male, Schizophrenia).

Charles was another BME participant who was placed in more supported accommodation. He expressed how he felt about his situation and said:

> *"Yes, I've been there for about 5 1/2 years, to start off with I was in semi-independent living I was there for about 3 1/2 years and they move me to a 24-hour care and that wasn't because of my illness. It's because they did not like the people that was knocking for me that was the main reason, I was moved to 24-hour care it was not because I could not take care of myself."* (Charles, 42yrs, male, Paranoid Schizophrenia*).*

Dominic equally was not totally happy with his living accommodation. That is because he was living in a residential care setting and getting help from staff to manage his money. When I explored with him why that was, he stated that he used to be in independent living and used to spend all his money on drugs. That meant he had no money to buy food or pay his bills, which could result in a situational crisis and lead to his hospitalisation. Dominic stated:

> *"I don't like being stressed out, so I take one goal at a time. My main goal at the moment is to get my own flat, that is my main goal at the moment, I would like to get my driving licence, I would like to be in charge of my own finances,'' (Dominic, 30yrs, male, Schizophrenia).*

When asked about his main needs Guy commented:

> *"Housing,''* (*Guy 23yrs, male, schizophrenia).*

Robert also felt he needed help with housing and other forms of support. Robert said:

> *"Housing, support from Doctor/Care Co-ordinator,''* (Robert,43yrs, male, Schizophrenia).

Another participant who got help with obtaining accommodation was George who said:

> *"I find my meetings with my CC helpful, she tries to help me with getting myself back into the community, umm the benefits from the council. She has also tried to help me get a flat."* (George, 36yrs, male, Schizophrenia).

The evidence above suggests that BME participants require support in accessing and maintaining suitable accommodation.

5.2.1.2 The Need for Specialist Services

Previous research has shown that the service user from a BME background are disadvantaged in accessing and using mental health services. Some of the reasons for this has been discussed in Chapter Two and will be discussed further in Chapter Six.

Specialist services within mental health care are of absolute importance in the recovery journey for people who use mental health services. The fact that several the participants identified one of their relapse indicators to be substance misuse, they identified the drug and alcohol service as an important part in the treatment for those who had a drug and alcohol problem. In thinking about this Andrew commented:

> *“yeah psychology and drug and alcohol awareness if I start using again they promptly tell me to come to (xxxx-drug and alcohol service) so those services I still use because when I talk about things I get it off my chest and I feel like I don't have to carry a weight. So some of these services you know what I mean, to get over their mental health and the stress of day-to-day life people passing and things in the family and then when I go to psychology all of that sort itself out, I can let it all out you know what I mean yeah those are the main things.’’* (Andrew, 31yrs, male, Schizophrenia).

Like Andrew other participants from a BME background found psychological services have helped them and viewed it as a means of support. They felt that talking about issues helped them greatly and it served as an adjunct to medication. When asked about his main needs Jacob said:

> *“Counselling the need for counselling.”* (Jacob, 24yrs, male, Schizo-Affective Disorder).

Some of the participants in this study identified specialist services such as psychology and the drug and alcohol service as an area of need. Notwithstanding, as suggested below it appeared that they had to wait for varying lengths of time to access the service.

5.2.1.3 BME Participants had to wait for varying periods of time before accessing specialist services-Timelines.

It appears some BME service users had to wait a considerable amount of time before getting help from psychological services. Grace stated:

> *“In general my mental health but because over the years I have had a lot of side effects from the medications like mood and sometimes do still get depressed I get support from my care coordinator’ you know, encouraging me and I have had issues in the past that produced negative feelings in me so now I am getting extra therapy from psychology. I started a few months ago.”* (Grace, 51yrs, female, paranoid schizophrenia).

There seem to be a suggestion from Thomas that he benefited from psychology but felt that medication seemed to be the first choice of treatment. As he has now had a few sessions with a Psychologist he found them to be more beneficial than taking medication. Thomas stated:

> *"it's pretty difficult for me to say because there has not really been any other alternatives and I have just started to see a psychologist now so maybe if that was put forward first, I would have maybe received it. I can say that the conversations that I have had with people have been more beneficial than taking medication. I feel like being offered different tools and strategies in dealing with situations that occur I feel has been more beneficial to me than taking the medication."* (Thomas, 31yrs, male, paranoid schizophrenia).

When asked about his main needs Luke stated**:**

> *"It's more psychodynamic so it's more talking therapy and it's the first time I have had it on a one-to-one and I find that it is helping as well as going through a lot of things that have affected me in the past. I found I have not managed to deal or to get through some issues, so I think not only me but that a lot of people are going to get the opportunity, or they don't know what services are out there. I think the more people that get this help in the long run because I have notice from being in hospital some people never ever get out of that loop…"* (Luke, 34yrs, male, Schizo-affective disorder).

Luke felt that the delay in getting the right support and treatment for his brother had an impact on him. He attributed his hospital admission to the stresses and strain of caring for his brother who also had a mental illness.

Luke said:

> *"This was the longest time I have been out of hospital, well however my brother fell ill in 2005 in the first instance he was not treated properly at the time. The crisis team will get involved and they would not actually help in fact it actually prolonged your progress. His illness was affecting me and actually handed in my resignation at work because I was taking time off to look after my brother and bringing him places. I could not handle it any more thought I*

> *needed time off, so I handed in my resignation down to look after my brother, but I think it was too late and within a month I was admitted."* (Luke, 34yrs, male, schizo-affective disorder).

The participants above highlighted the time it took for them to receive a psychological intervention. Thomas was clear that he would have accepted that rather than take medication. They all seem to suggest that talking through issues with a psychologist helped them tremendously.

5.2.1.4 Involvement in care plan

Collaborative working is essential in the care planning process as it ensures that the BME service user recognises, that they are involved in the process. Engaging in such a collaborative process will allow service user needs to be identified. Mental Health Services will also respond by having services to meet that need. Some of the responses from the BME participants seem to suggest that the participants did not encounter that they were participating fully. Gloria described her experience of attending her care plan meeting and said:

> *"There is a lot of talking to you and it's a lot of talking at you and if you try to express yourself it's like you are being confrontational, but you're not, you are just trying to explain yourself with what you are going through and how you feel.''* (Gloria, 43yrs, female, paranoid schizophrenia).

The care planning process has been put forward as a partnership between the service user and the mental health service providers. The idea is that the service user should be consulted in decisions about their care. In as much, through a care planning meeting their views should be sought by the mental health professional. The service user can then express what their needs are or have the support of an advocate to express them on their behalf. Further analysis of the interviews looked at the development of the care plan and how involved the participants felt in that process. Some participants felt that they were involved while others felt less involved.

Harry said:

> *"I have a care plan meeting ever so often, every month or so, I see it and I read it, it's very good. They say I am looking after myself, I am cleaning my room and I am no trouble to the public sort of thing,"* (Harry, 61yrs, male, Schizophrenia).

Equally Mary stated:

> *"Well whenever anything is required, I'm usually consulted so I do have a good participation in it,"* (Mary, 29yrs, female, Schizophrenia).

This was the same for Grace.

> *''Yes, they usually do,''* (Grace, 51yrs, paranoid schizophrenia).

The excerpt below indicates that Grace placed a great value in the support she gets from the mental health service. Grace further explained how she valued the support she gets from the mental health service. She felt that in order to keep well such input was important to her. Grace stated:

> *"When I keep well, I realise is the consistency with how the NHS has structured my care because I find that it's when I liaise with the different umm people in the NHS that have helped me. I noticed that I tend to feel better when like umm when my Care Coordinator visit or like the therapy, I am getting now on a weekly basis like going home I feel better, so I feel like interacting with people. My daughter being there and giving some support I tend to feel better, but I find like if it's not there for long time, I just feel like I am going down!"* (Grace, 51yrs, paranoid schizophrenia).

With specific reference to participants' experiences concerning the use of mental health services in the Trust, all the participants were happy with the care that they received. Nonetheless, some of the participants seem to link any discrimination/stigma to come from external agencies such as the Police, Criminal Justice System, Employment and the wider society. Paula felt wronged by the police, because a record of an offence was registered on the Disclosure Barring

Service check (DBS). This meant checks show that she has a record of an offence. She felt that as she was given a caution it should not have been placed on her record, since applications for job were always negative. Her exact words were:

> *"They say they will call you back and they never do,"* (Paula, 47yrs, female, Schizophrenia).

Charles stated:

> *"So as a black man I think I have not experienced any racism, I think they are fair."* (Charles, 42yrs, male, Paranoid Schizophrenia).

Equally Robert said:

> *"They treat me like everybody else, but at the same time I don't want it because I am not sick. I am struggling with the same spiritual battle,"* (Robert, 43yrs, male, Schizophrenia).

Hannah (pseudonym) did not believe that she required help from the
Mental Health Trust and stated:

> *"I don't have any needs it's the decision of the psychiatrist to treat me."* (Hannah, 43yrs, female, Schizophrenia).

Charles was of the same view and said:

> *"To tell you the truth, I was ill, and I am better now. I am fine now so I need them to let go of me."* (Charles, 42yrs, male, Paranoid Schizophrenia).

As an organisation the Mental Health Trust is structured to provide care and treatment for people who have a diagnosed mental health problem. It could be argued that what is being offered and service users' needs do not always correlate. Notwithstanding, in this study most of participants were able to articulate what their needs were and how they were being met, even though not all participants felt their main needs were that of support.

5.2.1.5 Support from the Care Coordinator and/or the Mental Health Team

Since the inception of the Care Programme Approach in 1990, the CC has been identified as having a pivotal role in managing the care of service users with mental health problems. Therefore, a mental health professional namely, Doctor, Nurse, Occupational Therapist, Psychologist can assume that role. Whilst much has been written about the role of the CC, service users themselves rely on that individual to offer the support they require in their journey through mental health service.

All the BME participants placed great emphasis on meeting with their CC and recognised that the CC was central to their care as they can call upon the CC to help them manage a range of situations. Grace said:

> *"In general, my mental health but because over the years I have had a lot of side effects from the medications like mood and sometimes do still get depressed I get support from my care coordinator."* (Grace, 51yrs, female, paranoid schizophrenia).

Whilst it is essential that a Care Coordinator steps out of their natural role (Nurse. Doctor Occupational Therapist, Social Worker) to provide a well-coordinated package of care, they work collaboratively within a mental health team to enhance their skills to provide quality care for service users.

Peter stated:

> *''Support with medication/financial.''* (Peter, 52yrs, male, Schizophrenia).

George stated:

> *"My main needs were to sort of get a recovery plan of getting better, yes a recovery plan, recovery plan getting better.''* (George, 36yrs, male, Schizophrenia).

The participants also differentiated where the support came from. They felt they required support from the Mental Health Team, from their Care Co-ordinator and from their family. When asked about their main needs Grace said:

> *"Support from Care Coordinator."* (Grace, 51yrs, female, paranoid schizophrenia).

Whilst Roger said:

> *"Meeting with my Care Coordinator."* (Roger, 41yrs, male, Bipolar Affective Disorder).

Some of the BME participants felt that they needed support to help structure their day. In managing service users' care a holistic approach need to be taken to ensure that as much as possible all needs identified are addressed. Equally, having a diagnosed mental health problem can cause the service user to experience isolation on two counts. Firstly, due to the side effects of their medication and/or the negative symptoms they may be experiencing the service user may not wish to go out or maintain social contacts. Secondly, due to the stigma they face by society which could worsen the sense of isolation; thus, the service user might choose not to go out in public. Ali attended Mind Day Services and said:

> *"basically my needs were that I needed more of a structure during the day, because I was going to Mind everyday sometimes I was staying at home and I needed a structure like the staff said why don't you try voluntary work is basically is more structured during the day.''* (Ali, 48yrs, male, Schizophrenia).

Gloria said:

> *"I need support with taking medication. I need help as well from social services and the mental health team."* (Gloria, 43yrs, female, paranoid schizophrenia).

Emma stated:

> "*When I am cooking the staff help me to cook, when I am washing my clothes the staff help me to wash my clothes what I need help with is writing because I want to start college in January 2014. I want to find something to do."* (Emma, female, 31yrs, Schizophrenia).

Rose said:

> “*I have a support worker; any time I call her she comes to assist me,”* (Rose, 41yrs, female, Schizophrenia).

Ryan recognised that he needs more support if he is experiencing a relapse in his mental health. Ryan said:

> “*well basically is that a lack of motivation and it's just having that contact and support to know that the day when I do a relapse, because when I do relapse and I do tend to withdraw myself. I can't even speak when I relapsed, I go mute and my Care Coordinator has been very good in identifying my illness. Is just that support I need when I'm relapsing. When I'm feeling very good, I need just a little contact on the phone but when I'm relapsing, I need more support.”* (Ryan, 40yrs, male, Schizo affective disorder).

Recovery in mental health is about developing a skill set to afford the service user the ability to get well and remain well. It is likely that those skills are learnt and developed over time depending on the service user’s mental health journey. Some people recover quickly, others take a much longer period to get to a place of a fulfilled physical, social, psychological, and spiritual wellbeing. Almost all the BME participants had a view on what support they needed to enable them to get to a state of recovery.

5.2.1.6 Information about illness and treatment

The participants from a BME background were asked about their diagnosis and what information they were given. Most of the participants were able to articulate what their diagnosis was. However, the participants displayed different levels of understanding of what the term schizophrenia meant. Paula stated:

> *“They were not very clear, but I also read the letter that was written about me that said I had a condition, because I have been suffering from a condition for ten years now because every time I came in it’s a different diagnosis. When I was here last time, they said that I am suffering from Schizophrenia or something like that.’’* (Paula, 47yrs, female, Schizophrenia).

A number of the BME participants were told that their diagnosis was schizophrenia. Albeit, participants seemed to misunderstand the meaning of this term. There were able to discuss symptoms such as hearing voices, olfactory hallucinations, and paranoia. Some of the participants identified with the term as it is portrayed in the media.

Still thinking about mental illness and being discriminated against Paula said:

> "*I must say it's okay, I haven't experienced any discrimination or anything like that, I have always felt that the doctor diagnose me because that's what it is not because I am black and he wants to burden me with things that I am not having, but I don't know if that can happen any point because I feel it is a strange name to give a disease that I have. I feel like why is it me? I have to have that disease, I feel what did I do or what really happened but they can't fully explain what really happened to me then I got the illness because it is not something you catch it just that happenings in your mind.''* (Paula, 47yrs, female, Schizophrenia).

Thomas' experience was like Paula's as he felt uninformed about his illness. Thomas stated:

> *"If I'm honest I wasn't given any information about my illness when I first came into hospital. I was pretty uninformed about what my diagnosis was and what treatment options were open to me. The alternative to medication I was not given any. It was as though I was just swept up in the process rather that given any information.''* (Thomas, 31yrs, male, paranoid schizophrenia).

Whilst Thomas felt *'swept up'* in the process Paul seemed to have a different experience. Paul explained:

> *"Well the doctor explained to me, that I have a condition, that I am schizophrenic and that I will be on medication, they gave me a pack telling me what the medication does what it will do and how to take it and explain to me my rights and stuff.''* (Paul, 38yrs, male, Schizophrenia).

Luke's experience was like Paul's and stated*:*

> *"I think it was after my last admission I saw a very good doctor and I mentioned all the symptoms that I went through, she was giving me some information about it and then I said yes this is exactly what I went through, then she said it was schizo-affective disorder which is not schizophrenia but it is a mixture between schizophrenia and bipolar."* (Luke, 34yrs, male, Schizo-affective disorder).

Although Grace noted that information was given to her, she also felt that as she was ill, she might not have had the ability to process the information that was being discussed and given. Grace stated:

> *"Yes as time progressed because when I first went into hospital I was ill so you know I use to have once a week sessions with the psychiatrist in charge plus other members of the team, they would have sessions at the hospital with me, assess me and my needs and my family members would have to be there. So that was a form of giving me information but I was closer to being ill then so I wasn't really aware of a lot of stuff, and then later on like when I got discharged they have like CPNs where they talk about my care needs each time and stuff like that."* (Grace, 51yrs, female, paranoid schizophrenia).

In answering the question on what information was given at the time of contact with the mental health service a number of the participants spoke about their mode of admission. Some came into hospital via the criminal justice system, while others were admitted following assessment by the Mental Health Team. Gloria stated:

> *"It worked out that I was given an assessment they don't initially say you are on section. You go for an assessment first and then I was told that I suffer from psychosis and then I was sectioned and I don't know what section but I was at Holloway police station and from there I was transferred to the Mental Health Trust on a section 48/49 of the Mental Health Act which was a bit confusing because I have a lot to do with umm what you call them? Secretary of State, the Secretary of State ah yes, I was on a Home Office section it was a bit more confusing I had a criminal lawyer there. I think it was in 2009 when I first came in contact with the mental health trust. I was admitted at xxxxx xxx's hospital just so I thought it was before or after I was transferred from*

> *Holloway prison.''* (Gloria, 43yrs, female, paranoid schizophrenia).

Charles said:

> *"I cannot remember that was almost 20 years ago. The first time I got ill it was almost 20 years ago. Aah yes they say that I had a breakdown caused by stress that was my first diagnosis, then I was given medication which I felt at the time I did not need, they diagnose me as paranoid schizophrenic."* (Charles, 42yrs, male, Paranoid Schizophrenia).

Nathan said:

> *"Umm I don't know what really umm but when I was seen way back in the days it used to be paranoia and voices back in the day, but I've been well for quite a long time now."* (Nathan, 29yrs, male, Paranoia).

The information from the BME participants suggest that they were aware of their diagnosis, but some needed further clarification in understanding how the illness presents in terms of symptoms and treatment options.

5.2.2 Theme Two: participants from a BME background would like to find gainful employment.

When asked about their main needs some of the BME participants identified being employed as a need. A number of the BME participants talked about the negative experiences they encountered in their attempt to gain employment. Others felt that they required extra support to return to work. Those two areas have been broken down into subthemes

5.2.2.1 BME participants experienced being stigmatised in their attempts to find work.

Paul used to be in employment on a part-time basis. He said:

> *"Is that aspiration to get back to work, my aspiration is to get back to work also in catering I have done level 2 supervisory role. A lot of people they go*

> *into hospital they started wondering why nothing is going right for them but they don’t realise, so my support team encourage me that I could do things for myself, If I can one day support my family I want to get a move,’’*
> (Paul, 38yrs, male, Schizophrenia).

Paula has not been able to find work and she feels no one will employ her. She said:

> *‘‘I experienced the same problem one time I think in 2006 and the police was involved because I had taken my son to school and there was an issue whereby, I touched somebody’s child. They say that was battery, so they called the police in and they cautioned me they gave me a caution, but they put my name in the CRB records so it’s like I am a criminal now. So that is the only thing I am carrying negative about the whole thing the psychiatrist could not help the police can’t understand!”* (Paula, 47yrs, female, Schizophrenia).

Another participant spoke about her experience in a sheltered work area when she did catering. She was concerned that the lady who was teaching the group did not follow proper procedure. The participant linked that behaviour to the negative views of people who have a mental illness. She described the teacher’s attitude as ‘*slapdash’*. Gloria stated:

> *“I feel as though they don't put their whole heart into it, they just want to give people a slapdash course. To me it is ridiculous because if you're working in a different environment you would have to wear the hair net because if any hair goes in the food if any hair went in the customers food you would be in trouble.’’* (Gloria, 43yrs, female, paranoid schizophrenia).

Whilst many employers are not mental health professionals, liaison with mental health staff would offer greater support for service users and the employer.

Paula talked about side effects of her medication which resulted in her having to leave her work.

> *“Yes when I come off it I get ill so it’s just one of those things I just have to*

> *stick with the medication because changing the medication might be another thing but so far I have not needed to change the medication but I did change from 2001. There was a time about three months I was on injection it was not good for me that's why I had to leave work because I was feeling sleepy during the day and I was feeling tired and feeling I was just lethargic all the time. When I stopped and I went back to the medicine I used to take before I felt fine and I am fine up to now.''* (Paula, 47yrs, female, Schizophrenia).

The participants above experienced stigma in their efforts to find work. This has no doubt impacted on them in several ways including social, financial, and psychologically. The experience has hindered their progress in reaching a place of fulfilment.

5.2.2.2 BME participants require extra support in returning to work.

A number of the BME participants spoke about their desire to return to work but also recognised that they needed extra support in returning to work. In particular, some participants cited a less intense environment to enable them to adjust after a period of sickness. Some participants felt that engaging in leisure activities such as playing the guitar or going to the gym gave them structure which allows them to build their confidence in preparation to return to work. Ryan stated:

> *"I will say that she is a role model, she encourages me to participate in things like for instance I have decided now so for instance I just wanted to work and my last job was two years ago and since then I have been unwell three or four times and so I just wanted to get back to work, but right now I am not in the right place to go back into work and it's my Care Coordinator that really showed me that I have to focus and concentrate in my mind re-educating my mind. Find hobbies, find interest first of all and then eventually I can get back into the work situation and all that, yes, I have just got to look at it from my perspective.''* (Ryan, 40yrs, male, paranoid schizophrenia).

Nathan was of the same view and said:

> *"when I started coming here about six months ago my Care Coordinator told me that I should try and get back into training like going to the gym and*

> *everything because that's what I like doing, going to the gym and doing weights and everything and in the future I'm going to try and get a job. That is because I am on benefits, I can only work 16 hours. Well that 16 hours is still something so I would like to get myself a part-time job but I'm alright how things are at the moment.''* (Nathan, 29yrs, male, paranoia).

Grace, one of the BME participants placed a huge emphasis on the need to be employed. However, she felt that for those who have attempted to find work they faced certain challenges and described the service users as *"going around in circles".* In thinking about her experience of being in hospital, being discharged and trying to find employment, Grace had a message for the NHS, potential employers and possibly policy makers:

Grace said:

> *"excellent care, the only thing I would mention here is that there is a system in place for people, like I got ill so you are in hospital and within that time you go to therapy like making things or whatever so that the provision and then you come out of hospital and you get to be discharged and you, maybe discharged to somewhere like this where you have a Care Coordinator and a Psychiatrist where you have medication. But I feel within the NHS something should be in place for like to take patients beyond that like umm … to get you back into work or get you back into society rather than going around in circles. Because now I only just start getting psychotherapy but that is on based on things that happened to me before but remember that it has been 12 years!"* (Grace, 51yrs, female, paranoid schizophrenia).

Grace continued:

> *"It's taken me 12 years to get to that point so I just feel that there should be something specific because you do have people getting relapse and going back to hospital repeatedly but what about people who take a longer time to have a relapse like myself cause my 1st relapse was after 10 years, but what would happen to people who, is like I feel like I am in limbo because I keep trying to do stuff but I keep getting pushed back. So, I think on a physical scale something should be in place to work physically with people like me.''*

> (Grace, 51yrs, female, paranoid schizophrenia).

Those participants who had been employed contended that they could not always be at work due to the frequency of their relapse. This meant that they had to take time off work. Luke stated:

> *" at the time I was working at HMV records service I would lose sleep I would have strange ideas, there are times I needed to take time off work because I could be highly stressed I used to get this really bad feeling at times.''* (Luke, 34yrs, male, Schizo affective disorder).

Understanding mental illness goes a long way in getting employers to work with the service users. Some of the participants from a BME background end up having to leave their jobs or not applying for jobs because of the difficulties they encounter in finding work. Paula said:

> ***"***so hopefully people who understand mental illness, because not every employer understands when someone is unwell what can happen but there are other employers who are quite understanding so hopefully you will get someone like that who can support you and offer employment.''* (Paula, 47yrs, female, Schizophrenia).

Andrew stated:

> *" I was there for about 2 to 3 months I spent Christmas in there I was in xxxxxxxx hospital because I was living in south east London at the time so I dealt with that and then I came out just before the summer in 1999. Then I moved back up to North London where I started working but then I relapse because I started smoking cannabis again. Then I realise that this was my main trigger I know that when I smoke cannabis it brings on my illness, so I don't smoke it."* (Andrew, 31yrs, male, Schizophrenia).

The participants above highlighted the challenges they faced in either seeking employment or keeping a job.

5.2.3 Theme Three: Recognising signs of relapse

The BME participants were asked about their needs when they experience a crisis in their mental health condition. Some of the participants talked about factors that caused them to relapse and also areas of learning which they felt has helped them in the management of their illness.

5.2.3.1 BME participants established some trigger factors that can cause them to relapse.

Andrew the BME participant above explained what use to trigger his illness. Similarly, a number of the participants were able to recognise signs of relapse. There were those who remembered what happened when they first became unwell. A few causes were cited including drug induced psychosis. Guy said:

> *"I normally suffer from schizophrenia and paranoia and that the crisis is that I get anxious and paranoid... yeah but when I'm taking the tablets yeah, I notice and sometimes getting panic attacks, I think getting panicky yeah. I noticed when that happens, but the tablet is really umm. Before I did not think that the tablets were helping I used to think it was my own self but now I realise when I don't take it I get those kinds of feelings and now when I take it everything just seems alright so it's more manageable."*
> (Guy, 23yrs, male, Schizophrenia).

It can be suggested that the service user is best placed to recognise their relapse indicators either by learning or by observational skills of the mental health staff, family and friends. When the question was asked: how do you describe a mental health crisis for you and what action do you take when that happens?

Paul stated:

> *"Because the reason I was unwell is because I was taking drugs. So, for me it was to be open with myself and to find out why and what made me like this you know. After all it was the drugs I was taking. When I take the drugs, I got paranoid, when I got paranoid that when things starts going wrong, and not being able to sit down with my mum and tell her this is was what was going on. I know I did not want my mum to worry because each time I*

> *came into hospital it's because the paranoia has kicked in, you get the buzz you get the high and it leads to paranoia and then you feel you cannot tell your mum these are class A drugs you can't tell no one. You don't want them to think bad out you, and so forth.''* (Paul, 38yrs, male, Schizophrenia).

Charles also talked about what triggered the symptoms of his illness and stated:

> *"You see before I was on heroin and I could not afford to feed my habit, so I had to withdraw from heroin. That was what used to trigger my symptoms so I'm off heroin now so that's why I think I have been so well."* (Charles, 42yrs, male, Paranoid Schizophrenia).

Service users might experience lack of sleep for various reasons, such as auditory hallucinations that disturb their thoughts, relaxation, and rest. Sleep deprivation can take its toll on those who are subject to it. Over time it can affect one's mood, their interaction with others and their general wellbeing. Ryan experienced lack of sleep which triggered the negative symptoms of hearing voices. Ryan said:

> *"basically I hear voices, I tend to want to harm myself, I have tried a couple of times but that's when I first became unwell but what triggers it of it's for me personally (repeated) what triggers it for me personally is when I have not slept for few nights so if I have not slept for three or four nights I start going downhill, and then I get delusional as well and sometimes I get paranoid. I get paranoid and suspicious. I have been in hospital quite a few times I have and the most I have stayed there umm, and I came in on a section. I was there for a month but ever since then I am usually umm, I am always out usually out in the week from hospital."* (Ryan, 40yrs, male, paranoid schizophrenia).

George recognised his relapse signs as experiencing voices and said:

> "*Sort of voices and yeah voices. People telling you to do things.''*
> (George, 36yrs, male, Schizophrenia).

Dominic said:

> *"Yes, I start to hear voices I start hallucinating."* (Dominic, 30yrs, male, Schizophrenia).

Hannah also experienced auditory hallucinations but did not recognise that as a relapse sign. Hannah said:

> *"Have had a crisis in the past where the voices are coming culminated into excessive pressure, but I did not identify that as a breakdown in my day to day activities.*" (Hannah, 43yrs, female, Schizophrenia).

Roger stated:

> *"Crying, don't want to do anything."* (Roger, 41yrs, male, Bipolar Affective Disorder).

The above participants discussed their trigger factors citing various reasons for becoming unwell.

5.2.3.2 Learning from previous experience of being unwell.

Jacob also had to contend with anxiety attacks and spoke about ways to alleviate it when the anxiety attack happens. In thinking about the question on recognising relapse signature Jacob said:

> *"When I'm having an anxiety attack, I usually just have a warm shower or listen to music or anything to put my mind at ease"* (Jacob, 24yrs, male, Schizo affective Disorder).

Another participant (Andrew) from a BME background, had a fifteen-year history of being involved with the mental health service. He narrated his views on drug misuse and recognised this as his relapse signs. He had several admissions into hospital following periods of substance misuse.

> *"I'll be honest with you I use a bit of drugs now but I don't relapse, obviously I'm a bit older now so when you're younger your mind is not as strong but as I'm older now as you get older you much more in control. I'm more mature now am 31 now so certain things I could not do before I can do them now and it affects me differently. I understand how people say they used drugs in order to get away you know what I'm saying, but obviously I don't use it to that extent where I cannot handle myself, I don't use it to the extent that people say. Obviously, it's just like having a drink, a bottle of wine having wine with your dinner that's how I look at it."* (Andrew, 31yrs, male, Schizophrenia).

Paul also talked about what triggered the symptoms of his illness and stated:

> *"If that happens, I can always ring my care support team they will always help me, or I can make my way to hospital. So I do know myself if I am unwell I don't sit there and leave it I will ring someone straight away as I say either the care support team or my doctor or someone to let them know I am going through problems so it does not go too far where they come and pick you up and take you instead you take yourself.''* (Paul, 38yrs, male, Schizophrenia).

Participants from a BME background discussed their learning from the experience of being unwell. They use that experience to inform how to manage their mental health.

5.2.4 Theme Four: The need for help with taking medication and medication concordance.

The use of medication is a process that have been used over many years to treat the symptoms of a diagnosed mental condition. Much research has been done in the use of medication resulting in the formulation of newer drugs which profess to have less side effects making them more palatable or tolerable for the service user. The participants from a BME background identified taking medication as one of their main needs.

5.2.4.1 BME participants link taking medication as a major part of their recovery.

Paula talked about the calming effect the medication had on her and said:

> *"I must say medication is the first thing because it help to calm me down and it help me to relax and made me aware that I am unwell and that I need to take it but also looking positively into life because I don't want to look at it as if it is something that is stigma around mental health.''*
> (Paula, 47yrs, female, Schizophrenia).

Emma had a similar view and said:

> *"Taking my medication and then I will not become sick. That is if I don't take my medication then I would be sick yeah.''*
> (Emma, 31yrs, female, Schizophrenia).

Support while taking medication was cited as an area of need by most of the participants. Paul mentioned that taking medication was an area of need and linked it to him keeping well. Paul stated:

> *''My main needs are to keep on taking the medication and to keep on being well and that knowing there is help for me with my Care Coordinator, support worker and it just helps me to stay well by taking my medication. Oh yeah filling in forms sometimes I need a bit of help with that.''*
> (Paul, 38yrs, male, Schizophrenia).

Paul had a further view on taking medication, his aim was that he could "wean" himself from taking medication if he took his medication regularly. He said:

> *"So that is why when the doctor ask me do you take drugs? So, this is when I realised that if I stay away from the drugs, take my medication for now because it's helping me, then slowly maybe I can "wean" myself off the medication now that I don't take drugs yeah. That is what I found you know being real to myself you know, because it was the drugs you know.''* (Paul, 38yrs, male, Schizophrenia).

Mary said:

> *"Yes, I would say it is the medication and the support I get from the team especially xxx. I would say the support is good because just having people around to talk to and living a normal life really I think I am not sure."* (Mary, 29yrs, female, Schizophrenia).

Jacob stated

> *"No, they just tell me what treatment would be best for me and that's it really."* (Jacob, 24yrs, male, Schizo affective Disorder).

Nathan stated:

> *"I have been on loads of medication that the one that they have put me on now so that's the only one that will work so the others did not work so clozapine was the really the last answer, it seems to be helping me and I have been stable and also even if I have got the illness that doesn't mean I cannot get on with life!"* (Nathan, 29yrs, male, Paranoia).

The above participants noted the benefits of taking prescribed medication and linked it to recovery and their ongoing optimism.

5.2.4.2 The BME participants highlighted the negative effects of prescribed medication.

A further reason for poor compliance with medication was the belief that ‘‘nothing is wrong with me’’. Paul explained that as he was well all his life, it was difficult to comprehend how could something like mental illness happen to him. However, he got to a place of acceptance and belief that the medication he was taking had a role to play in keeping him well.

> *"I have been fit all my life so I didn't really realise that it could happen to me so when it first started, I wasn't really like taking the medication. I was healthy all my life, so I started not taking my medication. It was doubtful my body was use to taking medication so my body was reacting so I was a bit in denial you*

> *know but over the years I have come to realise that it is an illness and it can be treated and with the right medication. I found over the years the best thing is to take your medication and get on with your life like my mum she is diabetic so for her all of her life she has to take medication but like I say I could not believe it you know I did not believe that thing could happen to me and stuff like that and I did not really like this side of being unwell.''* (Paul, 38yrs, male, Schizophrenia).

Having a journey because of a mental illness allows the service user to obtain valuable information about themselves. Paula seem to be at a place where she fears becoming unwell again. Although she is keen to reduce her medication, she is also aware that she can become unwell which presented her with a dichotomy.

> *"Yes because I felt well I wanted to get off medication so I felt I was well and I did not want to take any more medicine, so they said I should reduce it but I wanted to stop completely. But then it can't work that way I can't try it again I am just scared of getting unwell so I just stick to the dose that they give me but I have been asking whenever I meet with my Care Coordinator and the Psychiatrist. I ask and they say you should stay on it for a while because you were quite unwell when you came off it.''* (Paula, 47yrs, female, Schizophrenia).

Harry linked the cessation of the negative symptoms he experienced with taking medication. He said:

> "*When I do become unwell, I disappear you see but it stopped 12 years ago maybe the disappearing has stopped it may come back, again I don't know if I stop taking my medication,*" (Harry, 61yrs, male, Schizophrenia).

Rose described her illness in terms of achieving or not achieving and felt that having a mental illness was not an achievement, she said:

> *"yes it like a low achiever kind of aspect to be ill , it's not an achievement is it to be ill so for me to be on drug therapy for a long time without a break it does not seem a professional thing to do.''* (Rose, 41yrs, female,

> Schizophrenia).

Dominic talked about the side effects he experienced while taking prescribed medication and said:

> *"…they are looking towards reducing it because I have been having side effects, that's awful I feel drowsy in the morning so that is something they are looking into."* (Dominic, 30yrs, male, Schizophrenia).

Gloria talked about her issue with taking psychotropic medication and asked:

> *"Yes, that's another thing side effects why? Why is it when you take on psychosis medication you get side effects? Nowadays in this generation don't they have medication that don't cause side-effects?"* (Gloria, 43yrs, female, paranoid schizophrenia).

Concordance is about ensuring that the service user is given enough information about their medication to allow him/her to make an informed choice. This was the case for Paula believed that she had more than one diagnosis.

Paula expressed her understanding about the medication she had been prescribed:

> *"yes Abilify it treats people with bi-polar and people who see or hear things and feel like they are being persecuted in their thoughts like that I feel when I am unwell, they take that so I don't know whether I have all those illnesses or only one of them?''* (Paula, 47yrs, female, Schizophrenia).

Roger who was diagnosed with Bipolar Affective Disorder described what it was like when he was in the depressive cycle of the illness. He explained that he rather 'rough it out' rather than take prescribed medication.

> *"They say it's when I stop taking the medication, because many times I have tried stopped taking the medication rough it out sort of thing, because I try to wean myself off medication.''* (Roger, 41yrs, male, Bipolar Affective Disorder).

Harry gave his view about being cared for by the mental health service and said:

> *"Yes, it's the current section I am on when I try to get off the section, they say I have no insight into my illness. This is what they put down in the report, so I have no chance of getting off the section."* (Harry, 61yrs, male Schizophrenia).

Luke stated:

> *"No and I continued to have symptoms, there may be an alternative, but they just gave this tablet and that was it. When I relapsed the second time, I said I don't want those tablets you have to give me something else that will work but not them ones because of the negative symptoms."* (Luke, 34yrs, male, Schizo affective disorder).

Leo said:

> *"I have had made it changed as well and it has been reduced for about three years now, I have one daily dose and the injection once a month." (Leo, 41yrs, male, Schizophrenia).*

Another participant experienced side effects of taking psychotropic medication in that he felt sleepy and experienced weight gain. He also had a view on what he thought was causing his mental illness.
Robert stated:

> *"At the same time, they send me to hospital. I am an African man I see a woman in my flat, those things disturbing they say they can stop it be giving medication. It makes me sleep. I am worried about my weight. I was sleeping a lot. My heart is beating from me. If it is witchcraft medication won't get rid of it. It is not a sickness."* (Robert, 43yrs, male, Schizophrenia).

The above participants discussed how experiencing side effects of medication impacted on their daily living. However, there was a tone of joint working with the professionals in finding the medication regime that suited each individual participant.

5.2.4.3 Some BME participants experience weight gain as a side effect of medication.

Luke highlighted that he stopped taking his medicines due to the many side effects he experienced. Luke said:

> *"…and I was working as well in a part-time job and I did not know what was going on and they were giving me tablets and I was not aware what effect they were having on me. The first one was making my tongue hung out and doing this kind of things and I could not breathe and other times I was on olanzapine it made me put on a lot of weight on my face blew up, I could not feel anything emotionally a lot of these things were happening and I did not know what was going on.''* (Luke, 34yrs, male, Schizo affective disorder).

Similar to Luke, Grace cited one of the side effects of medication as weight gain. Grace talked about how she had put on weight since being on medication and she described her struggle in trying to keep a healthy weight. She said:

> *"I think I use to be able to do things but since my illness I find that I am not able to do it anymore. That gets me down I think it's the medication. I am slowed down, and my life is totally changed like before I can get up and do things, but I find I am no longer able to do that, so that gets me down. I think it's to do with the medication I am slowed down even to do chores around the house I find I get really tired. I can't do as much. I used to find if I am walking and sometimes there is an older person than me, they are shooting way ahead of me because I am so slow. Because of the medication as well I gained about 8 stone and it's been really difficult to get off sometimes, I lose it and then I end up putting it back on, really, it's a struggle.''* (Grace, 51yrs, female, paranoid schizophrenia).

The participants above struggled to maintain a healthy weight which was a result of taking psychotropic medication. This would suggest an area of need for the BME participants to maintain a healthy weight.

5.2.5 Theme Five: Service Users from a BME background experience Stigma

The term stigma has been described as ‘a severe social disapproval due to believed or actual individual characteristics, beliefs or behaviours that are against norms, be they economic, political, cultural or social,’ (Lauber, 2008). The basis of which seem to be a lack of knowledge about mental health, fear, prejudice and discrimination. Stigma in mental health has been a long-standing issue. More recently an attempt to raise awareness by the ‘young royals’ Prince Harry and Prince William, as well as Kate Middleton helped to inform the public through their *‘Heads Together’* campaign about mental illness. They are in support of the view that mental illness can happen to anyone.

5.2.5.1 Some BME participants linked the stigma they experienced as coming from the wider society.

Paula described how stigma of mental illness has affected her and said:

> *“I don’t talk about my mental health to anybody unless it is the medical profession or somebody who need to know because of certain law or something cause I don’t tell people about my mental health, don’t feel comfortable that they would keep it as secret as I don’t think they will understand that somebody can have mental health and still work or still do anything productive. It is like they are sort of doomed and they are people who have no use in society, so I have that feeling in me, but I don’t speak about it to my friends or colleagues or anybody.”* (Paula, 47yrs, female, Schizophrenia).

Paula went on further to explain that those who work within mental health seem to understand her mental health condition and hence she felt she will be treated fairly. Unlike those in the wider society whose minds are tarnished by how mental illness is portrayed in the media. Paula stated:

> *“because they know they understand what it is but outside nobody really understand because I hear in the news somebody killed somebody and then you say I have that illness I might do something evil and then people say this one might kill people or do something and people might run away from me or leave me alone so I would rather just don’t tell anybody I don’t talk about*

> *anything at all!’’* (Paula, 47yrs, female, Schizophrenia).

Luke talked about his experience as a black man and felt that the stigma he faced was not from the mental health service but in the community.

> *“…and I don't think it's really an issue personally when I do not see people who are affected in the ward but I think when you are out and you're trying to get back in the community, I think that is where it changes because I think personally as a black person I think that the youth don't have the opportunities to do things that they will be interested in that they can use, like me music is my passion. There are a lot of black men that find music as a passion and that gives them something that they can hold onto and I think there should be a lot more of that. Even sport because anything that young people did when you first become mentally ill the worst thing is you lose your love of things; you lose your passion because you think that you cannot do anything.”* (Luke, 34yrs, male, Schizo affective disorder).

Luke went on further to say how music therapy was engaging and helped him. Luke stated:

> *“… but even there was a certain therapy that can change people’s lives and I think that is way, that is where there is a problem personally because I found the Music Therapist was glad to help me. She found or she realised that music was away to communicate with the black people, I think that, I think there is a gap there because if I had that the first time round maybe things would have been different I think because I am coming up to 35 years now and I first became ill when I was 19.”* (Luke, 34yrs, male, Schizo affective disorder).

Ali had a strong belief in his faith however he stated that he did not attend a place of worship as he felt his misuse of drugs made him not worthy of being with fellow believers.

> “*Yes, I am Muslim but that sometimes because of the situation I have been in I wasn't stopped physically from going but it was just the company I was keeping stopped me from going so I have not been going.”*

> (Ali, 48yrs, male, Schizophrenia).

Ali also narrated his views about his safety. He took precautions by not attending a day service in the community. Ali stated:

> *"I'll be honest with you I don't really go now because I live 10 minutes away from here and I'm not supposed to be around here because the people I met in there may take revenge so I'll stop using it. So, I'll stop using it as I don't want to be seen that I am frequenting that place."* (Ali, 48yrs, male, Schizophrenia).

Gloria linked the voices that she experienced as an invasion of her body and saw it as a stigma. Gloria said:

> *"it's very troubling and sometimes in speaking to some Psychologist or some Psychiatrists as well when you take it and people leave with the voices from the day to day basis, but people are bewildered by voices. But I told him I don't care I cannot live with the voices because I was not born that way, I cannot live with it because I feel it's an invasion of my body. I said no way I am not saying to people that they are mad for living with it but I'm coping with it but it's not for me."* (Gloria, 43yrs, female, paranoid schizophrenia).

5.2.6 Theme Six: BME Participants had Hope for the future.

Going through a major illness such as mental illness enables the individual to build resilience. This is the substance of how well one adjusts to the devastating effects that come with such an illness that is loss of employment, breakdown in relationships, financial concerns, housing issues. Amid all these emotional and social issues, the participants discussed their journey of recovery and expressed how hopeful they were for the future. Whilst hope was the major theme, the following are the corresponding subthemes.

5.2.6.1 Service Users from a BME background demonstrate resilience

Paul contended that a weight was lifted from him when he was able to speak to his mother about how his illness was affecting him and said:

> *‘‘especially black people you know, black people don’t like saying it in front of their mums you know, you know it’s like a stigma then don’t really want to know but when you finally know the truth or telling the truth your life suddenly become better it is like something lifted. I had it then you really realise what keeping you well. Yes, the medication does help but staying off drugs and doing the right thing you know. Things such as I want to settle down, and I think I don’t want to go back to taking drugs I just want to be independent.”* (Paul, 38yrs, male, Schizophrenia).

Ryan was able to rekindle his passion for music in particular learning to play the guitar. He also had aspirations for the future. Ryan stated:

> *“I am having lessons to play a guitar I used to play when I was younger, I used to love It, but because of a set of circumstances I did not continue with it. I was very good at it and I do not continue it and now I would like to pick it up again and I'm going to try and get into a foundation Maths and English course and then IT course which is going to give me a little certificate. Something that will help me in the future, so my Care Coordinator has really shown me that concentrating on things that I like doing just to get an interest in things again.’’* (Ryan, 40yrs, male, paranoid schizophrenia).

Equally Charles attributed mental illness and as being a stigma that he wanted to leave behind and focus on his hope for a positive future. Charles stated:

> “*You see I would like to get out of that stigma of mental illness, yes I was ill once but I don't accept that I am ill now. That is how they view it, that I will be ill for the rest of my life, but I think you can get better and I think I am better, I am as best as I can be. I am not going to go back to the old me before I got ill, I am the new man now,” (*Charles, 42yrs, male, Paranoid Schizophrenia).

Grace talked about the literature that she had been reading which linked nutrition and good mental health. She felt that in her case weight gain was a particular issue and stated:

> *"You know I feel like some of that things we should be targeted with people who are suffering from mental health even the hospitals is nutrition. Because I was doing some reading not too long ago and it mentioned that one of the key, well two really of the important things with people suffering from mental health is nutrition and exercise they said they will improve based on nutrition, but when you go into hospital you don't necessarily get that type of nutrition it's just basic nutrition now.''* (Grace, 51yrs, female, paranoid schizophrenia).

Leo expressed his belief and said:

> *"There is Hope. Faith and Hope this is about my Christianity, that's worth holding onto that isn't it?"* (Leo, 41yrs, male, Schizophrenia).

Emma also advised what her hope and aspiration was for the future. Emma said:

> *"Yes, College yeah, yeah college going swimming and I would like to become a hairdresser."* (Emma, 31yrs, female Schizophrenia).

Andrew remembers the turning point in his recovery and said:

> *"…another term for turning point for me was the day the Music Therapist who came onto the ward. I didn't have any music experience, but I think that was the turning point that was the beginning of my journey then after that it was the therapy I received. There was a short course and I did do a few Cognitive Behaviour Therapist (CBT) sessions. I attended the group, but it wasn't very good at the time and generally just receiving help was a good thing, but the group was not very good.''* (Andrew, 31yrs, male, Schizophrenia).

Despite what the above BME participants are going through they demonstrated resilience with the hope of getting better.

5.2.6.2 Spirituality

Roger had a strong belief in his faith and felt that was more beneficial than taking medication. He stated:

> *"Actually, in my own opinion the drugs don't really do it for me, it's when I go*

> *for prayers and that… I just go to a Pentecostal church now and then."* (Roger, 41yrs, male, Bipolar Affective Disorder).

One of the main features of the recovery approach is instilling hope in the lives of those who have a mental health problem. The participants who were from a BME background talked about how their illness has affected them and how they see their future. Some talked about personal strength, others talked about religion, and others talked about family and friends. When asked about what has kept him well, Ali was able to make links with his faith. Ali stated:

> *"Obviously when I went into hospital, I was ill so I would not say that the medication I received was totally responsible for getting me better. It wasn't what agreed with me okay until I was put on medication that agree with me because I felt like okay. I think it's not just the medication that keeps you well, I think it's time as well. Time heals you and obviously I am a Muslim, so my Lord use me as well. He has already told me that in the dream I had several dreams from my Lord so whenever you need healing as long as you make an effort, he's my Lord. He created me and you also.''* (Ali, 48yrs, male, Schizophrenia).

There is evidence to show that a positive mental attitude towards one's illness enhances their chance of recovery, (Sagan, 2015). Paula also talked about her Christian walk and how she was conflicted about the mix between medication and prayers.

Paula stated:

> "*Also being a Christian because I am a born again Christian and I read the bible most of the time so that helps me a lot, so I am always just there just hoping. I don't want to get ill again you know because I thought I would just leave the medication and just get well by myself by just praying but it didn't work for me, so I just left. I took my medication and since 2011. I have been well, so I see it works so I don't want to feel like I am under pressure to leave any medication or anything.''* (Paula, 47yrs, female, Schizophrenia).

Ali was thankful to Allah who allowed him to see his mother. Ali stated:

> *"I don't think I am manic; I think it is just the fact that I've got issues in which you might think umm, what issues? Which you might think I'm manic. Can I tell you I never saw my mother for 20 years and I saw her for the first time two years ago in 20 years umm obviously I'm Muslim, so I thank Allah for letting me see her. Obviously since I have seen her, I have issues to deal with drugs because I'm on drugs as well, but I have come off drugs and it's a long story and I don't want to bore you.''* (Ali, 48yrs, male, Schizophrenia).

When asked: looking back on your journey in mental health what do you think was the most important thing that help you get better. Thomas said:

> *"I honestly think that I am a blessed man and I think that even through my journey it has been tough. I'm not practising but my Lord has made me well!"* (Thomas, 31yrs, male, paranoid schizophrenia).

Hannah in answering the same question was adamant that she had not benefited under the mental health system and stated:

> "*Well Hinduism and Buddhism, I've been to the Hari Krishna Temple in Tottenham Court Road…''* (Hannah, 43yrs, female, Schizophrenia).

The above narratives suggest that the participants spirituality played an important role in their wellbeing. That having a religious belief gave them comfort to know that all will be well if they only believe and have an acceptance in the good that has occurred in their lives.

5.3 Summary of Chapter 5

Twenty-four participants from a BME background were interviewed using a semi structured interview schedule to establish the research question: Do service users from a black and minority ethnic background perceive that their needs are being met within the Mental Health Trust?

Analysis of the data allowed for the emergence of six themes and subsequent subthemes. The participants were able to identify their areas of need and also expressed the negative impact of their illness on their lives. That included the side effects of the medication, the lack of opportunity to be employed and the stigma they faced in the wider community. The participants demonstrated their appreciation for the role of their CC and the help they received from the mental health service. The participants showed an awareness of how mental illness can be portrayed negatively in the media. By association, one of the participants did not talk openly about her illness as she feared reprisals by the wider community/public. Nevertheless, the participants were able to demonstrate that with the right support they were able to make plans for a better future.

5.4 Reflection on Chapter 5

Chapter 5 began by giving a breakdown of how the themes and subthemes that were found following analysis of the data. Table 5 on page 104-105 showed how Giorgio's (2009, 1985) framework was applied in this study. Equally, table 6 on pages 106-107 showed each theme and subtheme with identified participants who contributed to said theme or subtheme.

As I reflected on the participants in this study, it was interesting to note that each of the participants' diagnosis can be grouped under the heading of psychosis. Psychosis can be viewed as a severe mental illness which affects an individual's ability to function to their optimum level, by affecting areas such as daily living, personal care, and social interaction. Hence, it would be reasonable to suggest that all the participants would require long term support from the mental health service. If that support is not available, it is highly likely that the participants could experience a relapse which would hinder the progress each individual participant has made.

A means of support the participants talked about was that of housing. It was apparent that without the intervention of the CC or Mental Health Team, there would be a severe impact on the mental health of the participants. A further area of support for the participants was the use of specialist services including psychology and the drug and alcohol service. However, some of the participants described that they had to wait varying lengths of time for input from the psychology department. Some participants talked about the fact that they were prescribed medication as a first line of treatment. Noting, that if psychological support was offered, they would have accepted that rather than medication.

Involvement in care planning was an area of need highlighted by the BME participants. My observation is that while most of the participants said that they were given a copy of their care plan, they did not experience being involved in the process. It is noteworthy, that during the interviews the participants distinguished the CC as the person whom they had the most contact with and valued the vital role they had within the care team. On reflection I would say that the role of the CC is critical in the care and support of the service users.

Although the participants described what information they were given at the time they came into contact with the mental health service, there seemed to be some misunderstanding regarding the information given. For example, although knowing what their diagnosis was, some participants had a misunderstanding of what the term schizophrenia was.

Significantly, on reflection, the participants expressed that they did not have a negative experience in the care they received from the Mental Health Trust. However, they experience stigma and discrimination by the police, employment, the criminal justice system, and the public. Regarding employment, although the participants faced stigma and discrimination, their desire was to return to work. I found this to be very interesting as it appeared that the participants would like to be productive fulfilled members of society.

It was reassuring to hear that the participants were able to recognise their relapse indicators and knew who to contact when they needed extra help. Being able to seek help early is one of the hallmarks of recovery in mental illness. It seemed to me that medication was viewed as a double-edged sword. On one hand the BME participants stressed on the importance of taking medication to help them remain well. On the other hand, they talked about the unwanted side effects which fuelled an atmosphere of poor compliance with medication. Nevertheless, all things considered the participants expressed their hopes for the future. In doing so they demonstrated their resilience and their spiritual belief.

6.0 Chapter 6: Discussion of findings

The aim of the study was posed using the research question: do service users from a Black Minority Ethnic background perceive that their needs are being met within the Mental Health Trust, to ascertain their perspectives. Data was collected via semi structured interviews using the topic guide. The interviews captured some rich data which will guide the discussion in this chapter. Data analysis was conducted using the framework developed by Giorgi (2009, 1985) to identify key themes as discussed in Chapter Five. Consequently, six themes and subsequent sub themes were identified and will be discussed in detail in this chapter.

6.1 Theme one: BME Service Users require Support from Mental Health Services

Sometimes called non-tangible, support refers to the actions people take to make someone else feel cared for. In the case of the participants it is about the aspects of their mental health for which they require help. That could include social, psychological, spiritual, and physical help. So, it is the ability to have people or services that the service users can access when necessary in order to give them a broader focus and positive self-image which help to enhance their quality of life. Hence, support is the degree of aid and assistance the receiver requires.

In arriving at this theme, the researcher examined closely the responses given by the participants when asked to express their main needs. The BME participants cited several areas as their main needs that required support including: Housing, Support, meeting with Care Coordinator, medication, and Specialist Services. Whilst the above was the main theme what follows next are the subthemes which correlate with the main theme.

6.1.1 The need for suitable housing

This area was highlighted as a need for support from the mental health services. It is fitting to say that poor housing can lead to poor mental health. Pevalin *et al.* (2017) carried out a longitudinal population-based study and highlighted the following:

- Persistent housing problems are associated with poor mental health.
- Long term change in housing problems and mental health are also correlated.
- Addressing poor quality housing and removing housing problems improves

mental health.

- Mental health policy may be less effective if it does not consider housing quality.

Although the above study looked at the quality of housing and mental health, in this study some of the BME participants put forward other reasons, one of which was the need to move into more appropriate accommodation. Paula (pseudonym) one of the BME participants described how she needed to be moved from her previous flat as she was experiencing nuisance (discrimination and noise) from her neighbours. Another BME participant Dominic (pseudonym) had to be moved from independent living into a more supported environment.

Acting in someone's best interest is not a decision to be taken lightly. One of the ways in which staff can ensure that they have followed proper procedure and protocol is to make use of legislation such as the Deprivation of Liberty (2005) (Ministry of Justice, 2005), Mental Capacity Act (2005) (Department of Health, 2005c) and Mental Health Act (1983) amended November 2007. The role of the mental health staff is to ensure that service users are encouraged to be involved in the process even when legislation is used; yet, Dominic was not happy about his living situation.

Ali (pseudonym) another BME participant talked about being lonely and allowed others to stay in his flat. Unfortunately, those who stayed in his flat were dealing in illicit drugs rendering him to feel unsafe in his own home. He was able to alert his CC regarding what was going on who ensured that he was moved to more suitable accommodation. A situation such as this highlighted the vulnerability of service users in mental health. Hence, the need for a well-coordinated programme of care with regular monitoring to ensure the needs of the service users are being met. Having a mental illness can result in the service user being extremely lonely and finding ways to fulfil that void can be to the service user's detriment.

Holt-Lunstad *et al.* (2015, p. 227), theorised that living alone, having limited social network ties, and having occasional social contact are all indicators of social isolation. Whereas social isolation can be an objectively quantifiable variable, loneliness is a subjective emotional state. Loneliness is the awareness of social isolation or the subjective experience of being lonely and thus encompasses subjective measurement. The authors went on to suggest that loneliness and social isolation may be independent constructs and that one may ensue without the other. For example, while some people may be socially isolated but are satisfied with little social contact or prefer to be alone; others may have regular social contact but still feel lonely.

Holt-Lunstad *et al.* (2015, p. 228) posited that due to the theorical distinction between social isolation and loneliness, giving consideration to their relative impact on mortality may give greater understanding into possible independent pathways by which each influences risk and, in turn, guides intervention efforts. I am in support of the above authors' views on isolation and loneliness and was pleased to note that the outcome for the participant above was a good one after alerting his CC of his predicament.

6.1.2 The need for specialist services

Specific interventions typically offered in early intervention psychosis (EIP) include individual cognitive behavioural therapy (CBT), family therapy and carer interventions, medication in the form of a low-dose antipsychotic regime and social support around education, employment, and housing. Interventions such as these are recommended in the guidance for schizophrenia published by the National Institute for Health and Clinical Excellence, (NICE; 2014, 2010).

A study was conducted by Islam, Rabiee and Singh (2015), as part of the ENRICH research program on ethnicity, detention, and early intervention (EI): reducing inequalities and improving outcomes for BME patients. The study aimed to understand and explore pathways, outcomes, and experiences of care in BME groups in Birmingham. The objectives were to understand challenges facing mental health service provision in relation to cultural appropriateness, accessibility, and acceptability by BME groups and develop ways forward in providing cross-cultural mental health care to reduce ethnic disparities in care and outcome.

As part of the study the views of service users and carers on their mental health needs and their experience of EI services were sought. The views on the perceived needs and preferences of BME groups as expressed by providers of local services, including voluntary and community organisation representatives, EI service professionals, and spiritual care team representatives, as well as commissioners of local services were also included in this study.

The findings suggested that service users and carers had multiple, competing, and contrasting explanatory models of illness. For many BME service users, help-seeking involves support from faith/spiritual healers, before seeking medical intervention. EI clinicians perceive that help-seeking from faith institutions in Asian service users might lead to treatment delays. The value of proactively including service users' religious and spiritual perspectives and experiences in the initial assessment and therapy is recognised. However, clinicians acknowledged that they have limited spiritual/religious or cultural awareness training.

There was little collaborative working between mental health services and voluntary and community organisations to meet cultural, spiritual, and individual needs. Mental health services need to develop innovative collaborative models to deliver holistic and person-centered care (Islam, Rabiee, and Singh, 2015). Five key cross-cutting and overlapping themes emerged as crucial in determining the accessibility, acceptability, and appropriateness of EI services (EIS) in meeting the ethnic and cultural needs of BME communities across all stakeholder focus groups. These five themes were as follows: (a) help-seeking, (b) culture and beliefs, (c) social stigma and shame, (d) experience of EIS, and (e) improving BME access and experience of services. In this study some of the BME participants experienced social stigma and had challenges in accessing the services they needed.

Apart from psychology the drug and alcohol service also work in an advisory capacity in that they can advise staff working in generic mental health teams on the management of people who use drugs and alcohol. This approach no doubt will help support service users in their management via the use of a tailored care plan. In a study published in the Lancet by Di Forti *et al.* (2019) they found that frequent cannabis use and high-strength varieties are likely to increase the chance of mental health problems among service users. The researchers suggested that the potency of the cannabis is also important, with patterns in cannabis use linked to how often new cases of psychotic disorders arise in different cities.

Moreover, the international team of researchers reported how they studied patient data including cannabis use collected between mid-2010 and mid-2015 for 901 adults under the age of 65 who arrived at mental health services in one of 10 locations in Europe, or one in Brazil, and received their first diagnosis of a psychotic disorder that was not down to either brain tumours or acute drug use. A comparative study group of more than 1,200 healthy individuals from across the same areas were asked about their cannabis use. The participants in the researchers' study highlighted that the strength of cannabis was assessed from the name they gave to the drug (Di Forti *et al.* 2019).

After considering factors including drinking, education and use of other drugs such as ketamine, the team found those with a psychotic disorder were more likely to have used cannabis at some point in their life than those without the condition. The researchers also found that the chances of having a psychotic disorder were 40% greater among those who used the drug more than once a week, compared with those who rarely, if ever, used it; while the chances of having a psychotic disorder were more than three times greater among those who used cannabis daily compared with those who rarely if ever used it (Di Forti *et al.* 2019). The above study is significant as a number of the BME participants talked about smoking cannabis and engaging in the misuse of other substances. That was the case for Andrew (pseudonym) who was able to access psychological and the drug and alcohol service.

6.1.3 BME Participants had to wait for varying periods of time before accessing specialist services - Timeliness.

Bird *et al.* (2010) argued that the effectiveness of early intervention was in part attributable to the use of CBT and family interventions. The efficacy of these psychological interventions was found to be consistent with evidence from the wider literature base around the treatment of 'later' psychotic episodes, indicating they were helpful to an extent but are not the sole contributors to the overall effectiveness of EIP outcomes. In a later review, Bird, Premkumar, and Kendall (2011) concluded that it is an interacting set of elements that lead to improvements over 'treatment as usual', such as (1) the provision of psychosocial interventions (CBT, family work, social support) along with (2) pharmacology (low dose of antipsychotic medication), all of which are delivered by (3) staff with a lower case load ratio, employing an assertive outreach approach.

In a similar vein Memon *et al.* (2016) conducted a research study with BME service users to establish perceived barriers in accessing the mental health service and how the services can be improved. Participants identified two broad themes that influenced access to mental health services. First, personal and environmental factors included inability to recognise and accept mental health problems, positive impact of social networks, reluctance to discuss psychological distress and seek help among men, cultural identity, negative perception of and social stigma against mental health and financial factors. Second, factors affecting the relationship between service user and healthcare provider included the impact of long waiting times for initial assessment, language barriers, poor communication between service users and providers, inadequate recognition or response to mental health needs, imbalance of power and authority between service users and providers, cultural naivety, insensitivity and discrimination towards the needs of BME service users and lack of awareness of different services among service users and providers, (Memon *et al*. 2016, p. 3).

Memon *et al.* (2016, p.4), also found that participants perceived services to be limited in their response to the diverse needs of BME service users. In particular, they felt that they were offered few alternatives to drug-based treatments. Participants in the study also felt that within the community and the healthcare setting there was a limited awareness of the range of services available to individuals, limiting the opportunity to develop an individual care plan. Memon *et al.* (2016), noted that previous studies provided a mixed picture; some studies have found that BME service users were no more likely to take medication for mental health illness (Cooper, Spiers, Livingston *et al.* 2013) but others suggest that BME service users are more likely to receive medication and less likely to receive psychotherapy and other alternative therapies (McLean, Campbell and Cornish, 2003; Keating *et al.* 2002).

This is not surprising as those who are referred to psychology would normally have to wait for at least six months due to the volume of referrals the psychology department receives. In this study, some of the BME participants raised similar issues. Thomas (pseudonym) highlighted that he had to wait a length of time before he saw a psychologist. He felt that the sessions with the psychologist had been more beneficial to him. Similarly, Luke (pseudonym) who had over a ten-year history of mental illness conveyed his experience of the psychological support he was receiving. He was hopeful that others like him will be able to receive that service but warned that they need to be aware of the service in the first place.

In a study conducted by Barr, Ormrod and Dudley, (2015), participants were asked to think about their experiences of Early Intervention in Psychosis (EIP) services and to express their opinion about which elements of their treatment they valued most in their recovery from EIP. Participants respond by organising (‘Q-sorting’) a broad spectrum of statements about the topic. Service users reported that four main components of Early Intervention in Psychosis Services were helpful to them. These included, a strong and effective therapeutic relationship, as well as medication, psychological therapies, and practical help and support. Four separate factors were identified, which were interpreted and named as ‘therapeutic relationship’, ‘medical care’, ‘psychological interventions’, and ‘support, coping and recovery’.

Notably, some of the participants in this study specifically emphasised on the support they received from their CC. Having worked in mental health for many years I am not at all surprised by this due to the holistic approach that needs to be taken when managing service users’ care. For example, one participant expressed the need for help from her CC to fill in forms (perhaps housing application forms), Department of Work and Pension benefits or accessing other services. Such needs impact on the role of the CC, in that the CC would need to allow more time with that service user. In a climate where NHS staff are working under extreme pressure, the workload of CCs would need should be reviewed to ensure that they can fulfil their role competently. Caseload load weighting tools is a possible alternative although there might be advantages and disadvantages in the use of such tools.

Spernaes *et al.* (2017) contended that the management of the clinician’s caseloads is a difficult task. It is possibly misleading to only consider the number of clients on a caseload to represent workload as this does not reflect the complexity of the clients and the resources they require. Such a system does not consider many other important activities such as team meetings, administration, and travel. In view of this an online caseload management tool was developed and piloted within 11 CMHTs in Aneurin Bevan University Health Board (ABUHB) South Wales. Feedback from the pilot showed that clinicians and the decision makers liked the tool and found it useful to inform their discussion.

Staff generally felt that the scoring more accurately reflected the complexity of their caseload than the current tool proposed by (Butler, 2005; 2001). In general, the tool appeared to reduce the time spent on caseload management by caseload supervisors and, as caseload supervisees became more familiar with the tool it took less time to complete (Spernaes *et al.* 2017).

It is assumed that time is required to develop the nurse patient relationship (NPR) which in turn will help achieve optimal healthcare outcomes. Prioritising time to build and maintain the relationship is hindered by nurses' high workloads, (Wälivaara, Sävenstedt and Axelsson, 2013). The quality of the NPR affects patient's experiences of and benefits from, treatment and care. Research has pointed out that NPRs are one of the most important aspects for successful treatments (Molin, Graneheim, and Lindgren, 2016). However, it might be the case as a result of great reduction in local resources that mental health service users are limited in what they can complain about especially when you consider the added difficulties experienced by individuals with SMI. The limited resources can compound the individuals' freedom in other significant areas in their physical health. This contributes to ongoing lack of parity between physical health and mental health.

Price (2017) maintain that for a therapeutic relationship to function effectively, it is necessary that the nurse understands the patient's attitude towards nursing care and the role of the nurse. Hence, at the outset of treatment, rapport can be developed by the nurse asking the patient appropriate questions and by listening attentively (Workman, 2013).

6.1.4 Involvement in care plan

To ensure that there is *"buy in"* into the plan of care for service users, they need to be part of and are involved in that process. It means that true participation is finding out from service users what their needs are and have the services geared to help meet those needs. Therefore, one could ask, what does true participation look like? Judging by the responses of some of the participants one could argue that the service users did not get the impression that they were participating fully. For a service user to be told that *'you are confrontational'*, would leave a negative impact on the service user, resulting in relapse and possibly hospital admission.

Patient participation has been viewed as a means to enhance self-determination and empowerment of the service user. The notion of shared decision-making (SDM) as discussed by De las Cuevas *et al.* (2012) is a clinical model that promotes an interactive communication process where healthcare professionals offer their evidence-based technical knowledge, established on population averages, while patients provide information about their own preferences, values and concerns with respect to the available diagnostic or treatment options to reach a consensus on the decision (Deegan and Drake, 2006).

Wright *et al.* (2016) exclaimed that user involvement has become a central feature of the design, provision, and evaluation of mental health services. Understanding and distinguishing the importance of an individual's experience of mental distress from their own perspective has gained increasing prominence in the past 20 years. To this end, user movement is based on ideas relating to self-help, empowerment, and advocacy, (Shepherd, Boardman and Slade, 2008). Neech *et al*. (2018), stated that user involvement describes the process whereby individuals become actively involved in aspects of health care rather than passive recipients. Adult mental health services need to develop ways to adopt these requirements, whilst engaging users in a meaningful involvement process, (Neech *et al.* (2018).

Grundy *et al.* (2016) reported on a qualitative analysis of focus groups and interviews with service users recruited from UK secondary care services. Although user dissatisfaction with care planning has long been acknowledged, the study was one of the first to provide a clear framework for service quality improvement. Through in-depth qualitative data analysis, the researchers identified ten key criteria (termed the 10 Cs of care planning), that users perceive to be minimum requirements for meaningful user involvement.

Their data confirmed that users attribute high worth to the quality of the care planning process. Whilst the emergence of a theme relating to the clinician-user relationship corroborates existing knowledge regarding the importance of a working alliance, the saliency of other process features including the need for a stronger system of accountability is critically important to note.

Five key categories of response emerged from the data set suggesting five distinct process-centred elements that were critical to care planning success. From the user perspective, successful user involved care planning necessitated: (1) an emotional connection between users and clinicians; (2) a demonstrable contribution to care planning content; evidence of (3) care planning currency; (4) care consolidation and (5) care planning consequence.

Less prevalent in user dialogue, but nonetheless still evident were agent-centred elements of user-involved care planning. Five key categories emerged from the data, suggesting that two user-centred characteristics (capacity and confidence) and three professional behaviours (propensity for consultation, choice, and clarity of expression) were essential for successful service user involvement, (Grundy *et al.* 2016). Notably, the above results of which displayed *'an emotional connection'* between users and clinicians, has been discussed by numerous authors (Wyder, Bland and Compton 2013; Russinova, 1999; Perkins and Repper, 1996); all of whom have called for this concrete, yet at times illusive, therapeutic relationship between professionals and service users.

Notwithstanding, Perkins and Repper (1996) recommended that the relationship between a service user and a professional can best be measured, by the extent to which the client is empowered in living the life they wish to live and achieving their own goals. The authors further stated that relationships need to provide a safe atmosphere which allows the service user to consider their own wishes, recognise their own strength, accept their limitations and mobilise their personal resources (Perkins and Repper,1996, p. 41).

Nevertheless, one such strategy that has been used to work jointly with service users is the concept of Co-production. Co-production gives a platform for using reciprocity to develop relationships between professionals and service users to plan and develop support together. This process has been recognised as a means to improve social inclusion, address stigma, and improve skills, aid prevention and well-being (Slay and Stephens, 2013).

Nonetheless, not all the BME participants in this study felt their main needs were that of *"support".* One participant was adamant that she did not have any needs and that it was the Psychiatrist's decision to treat her. Similarly, Charles (pseudonym) another BME participant, viewed the help that he was being given by the mental health team as a hindrance and he needed the mental health professionals to *'let him go'*. Interestingly, those responses were from participants who were unable to connect with their relapse recovery signatures because they would not accept that they have a mental health problem. The view of the above two participants were not dissimilar to Memon *et al.* (2016), who found that some BME service users were:

> *"unable to recognise symptoms of mental illness and unwillingness to accept a diagnosis of mental illness. This was seen as key barriers to seeking help from health services, particularly for individuals who had grown up in their native countries"* (Memon *et al.* 2016, p. 3).

It has been suggested that the concept of poor insight refers to a multi-dimensional clinical construct (clinical insight) (Pousa *et al.* 2017). Poor clinical insight is an important problem as it leads to delay in accessing treatment, poor treatment compliance and follow-up (Sendt, Tracy and, Bhattacharyya, 2014; Ayesa-Arriola *et al.* 2011; Beck *et al.* 2011). Arango and Amador (2011) stated that most patients with schizophrenia present with difficulty in making sense of their experiences such as hallucinations and/or they may be unaware of many aspects of their illness (including the need for treatment and negative social consequences). Bora (2017) suggested that deficits for patients to comprehend and take account of other peoples' opinions and beliefs about behavioral changes in themselves contribute to poor insight. Cooke *et al.* (2005) contended that such insight is a complex concept and a number of factors including severity of symptoms, psychological denial and neurocognitive deficits play a role in poor insight in schizophrenia.

However, towards the end of the interview the above BME participants were asked about their journey in mental health and what they thought was the most important aspect of care that have kept them well. They both highlighted the CCs' role in meeting with them on a regular basis. On further examination of the responses by those two BME participants they stated that they did not have a care plan, but they had a CC. One could argue that in their efforts to dissociate themselves from the mental health service, they would not accept the care plan structure even if that is what is guiding their care. However, all the other BME participants stated that they did have a care plan, read it and was given a copy. Based on the transactional nature of what was being discussed around care planning it would seem that there is room for a renewed focus on the care planning framework to contribute greater levels of recovery.

A government's mandate to NHS England for 2017-18 inferred that people with mental health problems should receive improved quality of care at all times and access the right support and treatment during all stages of life. There is an expectation that NHS England would strive to reduce the health gap between people with mental health problems, learning disabilities, autism, and the general population. “*They should be supported to live full, healthy and independent lives”* (Department of Health, 2017, p.11).

Further analysis of the interviews looked at the development of the care plan and how involved the BME participants felt in that process. Some participants felt that they were involved while others felt less involved. One of the participants Gloria (pseudonym) felt that she was being talked at rather than having a discussion with her. This scenario has been highlighted previously by the Department of Health (Department of Health, 2000a, p. 88). Notably, this situation is likened to the Parent, Adult, Child (PAC) model as seen in figure 7 below, (Berne, 1961 as cited in Barrow, 2015, p. 170). She said that she was told that she was being *‘‘confrontational”.* However, the participant explained that in CPA meetings she tried to explain her viewpoint and discuss the things that were affecting her. Is it that in such situation’s professionals miss hearing the authentic voice of the service user? This question give Mental Health Professionals *“food for thought”* as it is likely the above scenario capture a power dynamic between the professional and service user where the professional come from the position of an adult and speaks to the service user as if she was a child. Such an atmosphere would cause the service user to feel less involved in their care planning process.

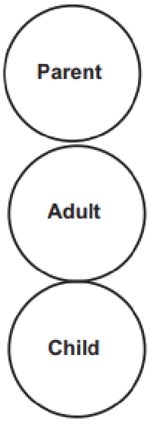


Figure 7: Parent, Adult, Child model (Berne, 1961 as cited in Barrow, 2015: p 170)

6.1.5 Support from the Care Coordinator and/or the Mental Health Team.

Participants were asked what their main needs were regarding using the mental health service. The essence of that question was to establish from the participants firstly whether they can articulate what their needs were and whether those needs were being met. As an organisation the Mental Health Trust is structured to provide care and treatment for people who have been diagnosed with a mental health problem. It could be that what is being offered and what the service users need do not always correlate. Smith and Wessely (2015) contended that:

> *"it is disheartening that half of the things that have been called for … including – proper liaison psychiatric services have such robust evidence bases… should have happened a long time ago*" (Smith and Wessely, 2015, p. 747).

The researchers emphasised the *'disgrace'* of inadequate numbers of hospital beds (maximum of 18 weeks to treat people with mental problems). Smith and Wessely (2015, p. 747) reinforced that if these areas were addressed mental health care would be comparable to the level of physical care provided and delivered to service users.

In this study most of participants were able to articulate what their needs were and how those were being met. All the participants emphasised the importance of meeting with their CC. They recognised that not only is the CC central to their care, but this is also the person they can call upon to help them manage a range of situations. Hannigan *et al.* (2018) stated that the appearance of the CPA reflected international trends towards the adoption of case management for people using Specialist Mental Health Services. They purported that at its simplest, case management is concerned with the coordination, efficiency, and effectiveness of services. Whilst I would agree with the ethos of case management /CPA, the presence of this structure has placed a huge demand on the CCs' role over the past three decades. Such demands include the number of service users on the CC's caseload, their involvement in mental health assessments, administrative duties and involvement in policy and practice development.

These roles were brought to the fore when Ryan (pseudonym) stated he lacked motivation and just having that contact was important to him. He felt that his CC was very good in identifying when he was becoming unwell.

Since the inception of the CPA in 1990, (Department of Health, 2017; Department of Health, 1999b), the CC has been identified as having a pivotal role to manage the care of service users with mental health problems. A mental health professional- Doctor, Nurse, Occupational Therapist and Psychologist can assume that role. Whilst much has been written about the role of the CC (Conway, O'Donnell and Yates, 2017) service users themselves rely on that individual to offer the support they require in their journey through mental health.

Within the Mental Health Team each professional group namely, Doctor, Occupational Therapist, Social Worker, Psychologist and MHN are required to work jointly together to provide a well-co-ordinated package of care for the service users under their care. Each of these groups have core skills that are specific to their identified profession. Therefore, working within a Mental Health Team should afford them the ability to draw on the skills of their colleagues to provide such care. Each of the participants talked about the input from their CC, even those participants who did not accept that they had a mental health problem. It was certain throughout all the interviews that the CC was the main person that the BME participants would contact as part of the management of their care.

Grace (pseudonym) spoke eloquently about the input from her CC and how it is important in keeping her well. She stressed on the term *'consistency'*. It is without doubt that inconsistency in care results in poor service users' satisfaction. Hence having an identified CC who would act as the person to co-ordinate a service user's care will offer that consistency. I would surmise that she had experienced changes in CC, Psychiatrist or other Therapist. Such a situation may well have left her feeling vulnerable and mistrusting the mental health service.

Whilst it is common practice for staff to change jobs and move on for their growth and development, it is about how this change over process is conducted. Hence the ideal would be a planned handover, with the new CC being introduced to the service user by the outgoing CC. However, that is not always the case.

What Grace described resembles the nursing values put forward by the CNO known as the 6cs; Care, Communication, Compassion, Courage, Commitment and Competence (Cummings and Bennett, 2012). It may be that Consistency should be added as a 7th C, as it encompasses each of the above values and if each NHS health staff was to embrace those values the result would be a service that is world class as has been expounded by the (Department of Health 2017, 2008).

One of the main components in establishing a nurse-patient relationship is building trust. It becomes difficult if there is a frequent turnover of staff which can happen for various reasons including nurses leaving the service, internal management changes, service redesign or staff being on long term leave. A therapeutic relationship has been described as a process of developing engagement, (Segaric and Hall, 2015).

Equally, Freshwater (2002) suggested that the nurse and the patient enter into a shared and reciprocal relationship that permits the delivery of nursing care that is individually tailored to meet the patient's needs. The nurse–patient relationship was conceptualised as one including partnerships, intimacy, and reciprocity. It also involved education, providing comfort, and deploying the environment for the benefit of the patient (Roberts, 2013). This seem to be the case for George (pseudonym) who said that his main need was to get a recovery plan and get better.

6.1.6 Information about illness and treatment options

As the researcher, I thought it would be useful to find out from the BME participants whether they knew what their diagnosis was and what information they were given about their illness and treatment plan. All the participants were able to articulate what their diagnosis was as identified in figure 6 on page 108. There are many degrees of understanding the term schizophrenia. Implications for the participants were that they were able to discuss symptoms such as auditory, olfactory hallucinations and paranoia. Participants associated schizophrenia with information according to the media, which was portrayed negatively, but impacted profoundly on them.

It was evident that Paula (pseudonym) did not understand what the term schizophrenia meant and felt it was a strange name to give an illness. Paula (pseudonym) also suggested that it is a disease and questioned whether it is *'something you can catch'*. On discussion she felt it is not a disease you can catch, as it is affecting the mind. Such misunderstanding could be borne out of the information that was given to the participants when they came into contact with the Mental Health Services. It supported the view that when the service user is in the acute phase of an illness information need to be revisited when the service user is more settled in their mental state.

The Care Quality Commission (CQC), in its most recent annual report on monitoring the use of the Mental Health Act 1983 amended November 2007 (MHA), found that there are still services that continue to fail in their legal duties to give patients information about their rights verbally and in writing as soon as possible, after their detention or when a community treatment order (CTO) commences. It found no evidence that staff had discussed rights with the patient on admission in 11% (378) of patients' records. In a further inspection of 9% (286) of records, no evidence could be found to suggest that patients received the information in an accessible format, (CQC, 2018).

The above statement indicated that mental health professionals need to ensure that whenever new information is given to service users, it is crucial that they have understood the information. Professionals could also help by repeating the information at the next available appointment. Otherwise, service users might be living with a misunderstanding of their illness which can cause further anxiety. Such proactive measures to ensure a clear understanding, could also lead to improved compliance with medication, thus helping to manage unwanted symptoms. It is critical that service users receive further support when they experience side effects of medication (another reason for poor compliance). It was evident in the interviews that some of the BME participants stopped taking medication because of the side effects they were experiencing.

Advocacy is a further safeguard that the nurse, family, friend, or voluntary agency can offer when information is communicated, because service users have to contend with several factors regarding their illness and might not comprehend the information at that particular time. For example, the service user may be feeling anxious which could blur their ability to process what is being said. To this end, Corlett (2014) reinforced that the rights of service users are respected, as well as the importance of accessing advocacy services. This was the case for Grace (pseudonym) who stated that she was so ill when she was admitted into hospital, she was unable to take in the information that was being given to her at the time. Corlett (2014) observed that this practice was patchy even for those detained under the Mental Health Act 1983 (MHA) or protected by the Mental Capacity Act (2005) (Department of Health, 2005c). People with mental health problems often struggle to understand their rights and articulate their wishes when they are unwell and are most vulnerable. If they are to have the same right to make choices as others, advocacy must be available as a right for anyone who would not otherwise be able to make decisions about their care. CQC (2018) detected similar issues regarding the use of advocacy and stated *that "Mental Health providers are required to take practical steps to make sure that patients subject to the MHA are aware of the help that is available from Independent Mental Health Advocates (IMHAs)"* (CQC, 2018, p. 24)

In their study, Islam, Rabiee, and Singh, (2015) suggested that BME users and carers need a better explanation about the course and outcome of psychotic disorders with improved understanding of recovery, management of illness, and realistic outcomes. This is not dissimilar to the way in which health professionals promote self-management for chronic conditions such as, diabetes. Equally, Islam, Rabiee, and Singh, (2015, p.13), found that "*several BME users equated recovery with cure, a return to how things were before the illness occurred".*

6.2 Theme Two: BME Service Users would like to find beneficial Employment

Several people with mental health problems are unable to work hence placing them at a disadvantage in their ability to earn a regular wage. It is essential that they get the right support to access benefits from the Department of Works and Pension (DWP).

6.2.1 Participants experienced being stigmatised in their attempts to find work

The study revealed that most of the BME participants greatly emphasised the need to be employed. Nonetheless, for those who have attempted to find work they faced certain challenges such as discrimination. On close examination I would say that theme two is synonymous with theme five. Arguably, it appeared that employers who are part of the wider society hold certain prejudices against those with a mental health problem, therefore making it difficult for those with SMI to obtain work. Cartwright *et al.* (2017) inferred that people with SMI are disproportionately unemployed. This was also found to be the case by Bond and Drake (2008). One BME participant Gloria (pseudonym) experienced such stigma while attending a sheltered workshop. She felt that the teaching was *'slapdash' and* linked it to negative views of people with mental illness.

Equally, service users may experience difficulty due to the heavy demands of a work environment. A range of factors such as whether the service user is experiencing side effects of medication, and symptoms of auditory hallucinations might cause them to be less effective during a long span of duty. They may require short breaks or shorter hours; therefore, an employer would need to be prepared to make adjustments under the Equality Act (2010).

The Mental Health Foundation recognised that mental health problems in the United Kingdom and worldwide were a growing public health concern (Mental Health Foundation, 2019). Vos *et al.* (2013) also reinforced that the prevalence of mental health problems is one of the main causes of the overall disease burden worldwide. Equally, mental health and behavioural problems (for example depression, anxiety, and drug use) are reported to be the primary drivers of disability worldwide, causing over 40 million years of disability in 20 to 29-year-olds, (Lozano *et al.* 2012). Major depression is thought to be the second leading cause of disability worldwide and a major contributor to the burden of suicide and ischaemic heart disease, (Whiteford *et al.* 2013).

In a study conducted by Biggs *et al.* (2010) regarding employer and employment agency attitudes towards employing individuals with mental health needs, they found that employment agencies would consider putting forward individuals with previous mental health needs to employers, although employers had a high level of concern around employing these individuals. Employers reported issues of trust, needing supervision, inability to use initiative and inability to deal with the public for individuals with either existing or previous mental health needs. The study also found that employers had a range of negative beliefs regarding employing individuals with mental illness. They had concerns regarding clinical factors such as frequency of episodes, relapse, how well controlled the illness is, the severity of the illness and the recovery time after relapse. It might be that there needs to be a change in the law as MH patients can gain a criminal record simply through having a formal Police caution. This was alluded to by one of the participants Paula (pseudonym) who reported that despite how many times she applied for a job; a caution she had received some years earlier continued to show up. This seemed to have influenced her chances of gaining meaningful employment negatively.

In addition, concerns were also expressed about aspects of work performance including absenteeism and temperament, including difficulty following instructions, need for excessive supervision and ability to abide by rules and regulations, (Biggs *et al.* 2010). That is not dissimilar to what has been suggested in figure 8 on page 166. Krupta *et al.* (2009) who developed a theoretical framework of understanding stigma at work following their analysis of 500 key documents and interviews with 19 participants. The framework includes: the consequences of stigma, the assumptions underlying the expressions of stigma, and the salience of these assumptions, both to the people holding them and to the specific employment situation. Assumptions are represented as varying in intensity. The model suggests specific areas of focus to be considered in developing intervention strategies to reduce the negative effects of stigma at work (Krupta *et al.* 2009). Whilst the model identified several areas of stigma in this study the findings suggested that stigma by the police for example the police issuing a caution or other criminal record places the service user at a disadvantage in gaining employment.

Figure 8: Theoretical framework of understanding stigma at work (Krupta et al. 2009, p 416)

6.2.2 BME participants require extra support in returning to work

There have been many changes over the past decade or more regarding support to return to or finding work. A number of sheltered workshops have been closed due to changes in government policy which questions whether the needs of service users were taken into account. Evidently, one of the BME participants gave a description of what is needed in the Mental Health Service. For example, Grace (pseudonym) felt that there should be a service in place within the NHS to take service users beyond discharge. She felt that despite the type of service, she should be enabled to work or resume a profitable place in society. If there is truly a partnership arrangement between the service user and the Mental Health Service, then suggestions such as these need to be taken into consideration.

The benefit to service users would be profound as they will be able to regain skills within a supportive environment before finding work in mainstream society. Yet, employers need to facilitate this process to ensure the integration of those who have had a mental illness return satisfactorily to the workplace. The evidence in this study showed that most of the participants had difficulty in finding work. Two reasons were given: firstly, the lack of understanding about mental health issues in the workplace, and secondly discrimination against those who had a mental illness. Due to the stigma the participants encountered some felt unable to tell their employers or other work colleagues that they had a mental illness. The experiences of the participants in this study were upheld by Thornicroft (2006a, 2006b) who found that there was strong indication that those with mental health problems find it difficult to gain access to and retain employment. It has been suggested that people with SMI in the United Kingdom have an unemployment rate of 61-73%.

Morgan *et al.* (2017) established that there was evidence to show that compared with White British, Black Caribbean patients experienced worse clinical, social, and service use outcomes; Black African patients also experienced worse social and service use outcomes. ÆSOP-10 is a follow-up at 10 years of a cohort of individuals with a first-episode psychotic disorder initially identified in the UK (Southeast London and Nottingham). The catchment areas in Southeast London (Lambeth, Southwark and Nottingham are among the most deprived in the UK (ranked 14, 25 and 17 most deprived of 326 local authorities) and the catchment area in south-east London has high proportions from minority ethnic groups (44.3%), especially Black Caribbean (8%) and Black African (14%). Baseline social disadvantage contributed to these disparities (Morgan *et al.* 2017).

The Individual Placement and Support (IPS) model has been put forward to assist service users to return to employment. Swantson *et al.* (2014) examined the implementation of the Individual Placement and Support (IPS) Model of Supported Employment. The model suggests full integration which implies that Employment Specialists and Mental Health Practitioners work for the same agency, participate in weekly meetings together, develop strategies to help find jobs together, share office space, meet informally every day, use the same record system, and shared responsibilities, such as supporting a person who is working (Drake, Bond, and Becker, 2012).

Swanson *et al.* (2014) found that at the agency level, successful strategies included requiring employment specialists to join mental health team meetings, co-locating Employment Specialists with Mental Health Team, using fidelity reviews to develop plans for improvement involving agency leaders in defining employment as a central part of recovery and involving counsellors from Vocational Rehabilitation. All state implementation has required that Employment Specialists join Mental Health Treatment Teams and some States have also provided financial incentives for collaboration.

Bond *et al.* (2016) conducted a prospective study to determine the two-year sustainment rate of participating sites in the U.S. Those sites joined the Individual Placement and Support (IPS) Learning Community programme in the U.S. from its inception until 2012. They operationally defined sustainment as a program that continues to employ staff, maintains an active client caseload and provides direct services. They identified all programmes participating in the learning community in the U.S. as of January 2012. The sample, consisting of 129 sites in 13 states who had participated in the learning community on average for 4.5 years. Two years later they contacted these sites to determine which were still providing IPS services. A total of 124 sites (96%) were sustained over the two-year period.

In a London Mental Health Trust, Miller, Clinton-Davis and Meegan, (2014) discussed how the IPS Model was put into practice within the Trust. Reflective accounts by two service users and an Employment Specialist all gave positive feedback on the use of the IPS Model. Such a model seemed to resonate with what Grace (pseudonym) asked for as discussed earlier in this chapter.

Professor Dame Carol Black, in her role of UK National Director for Health and Work, published her in-depth review of the health of Britain's working-age population in 2008 (Black, 2008). She noted that despite the rhetoric of social inclusion and recovery, secondary mental health services were inclined to focus on crisis care and risk management for those with more severe mental illness. This is due to a combination of financial constraints and public and political preoccupation with risk. The emphasis on risk management has been at the expense of other rehabilitation goals, including employment, (Harvey *et al.* 2009). The above findings suggest that the participants are further disadvantaged on two counts. On one hand the mental health service places emphasis on managing the risk posed by service users when unwell. On the other hand, prospective employers try to manage risk by not employing service users who have a mental illness.

Harvey *et al.* (2009) found mental disorders were the leading cause of sickness absence in most high-income countries, accounting for around 40% of the total time covered by sick notes. They stated that within the Organisation for Economic Cooperation and Development (OECD) countries (comprising much of Europe, the USA, Canada, Mexico, Australia, New Zealand, Japan, and Korea) mental illness now accounts for 35% of all disability benefits. Nearly a decade on, figure 9 below shows that within the OECD countries unemployment rates among people with mental illness remains high.

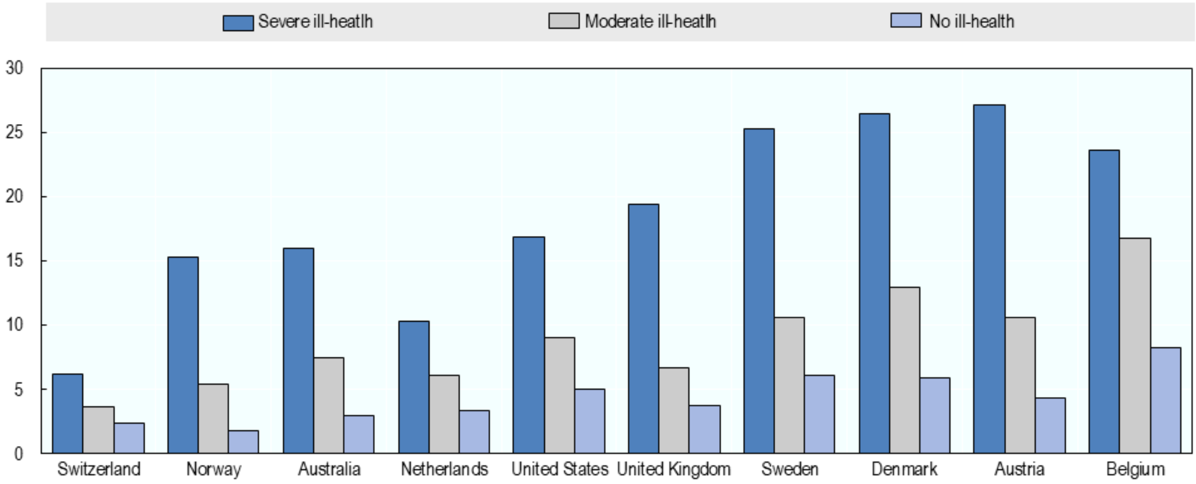


Figure 9: Unemployment rates (unemployed people as a proportion of the labour force (OECD, 2015 p 31)

Noting the importance of the findings illustrated in figure 9 regarding mental illness, Professor Black commissioned a separate report on work and mental health from the Royal College of Psychiatrists' Research and Training Unit. The report made a distinction between two separate groups; those with symptoms of common mental disorders, who account for the majority of the costs related to mental ill-health, and a smaller group with severe mental illness, of whom it is estimated only 10–20% are in paid employment, (Harvey *et al.* 2009). Harvey *et al.* (2009), found that although these two groups had somewhat different needs and experiences, they had several employment-related problems such as stigma, discrimination and a benefits system which provided perverse incentives for them to remain out of the workforce.

6.3 Theme Three: Recognising signs of relapse

The service user is best placed to recognise their relapse indicators. This occurs either through their own learning from their experiences when unwell, or by observation of mental health staff, family, and friends. However, Eisner *et al.* (2018) noted that basic symptoms may be potent predictors of relapse that clinicians miss and contended that, the best way of identifying pre-relapse basic symptoms was a verbal checklist asking specifically about these experiences. The authors noted that the use of a basic symptoms' checklist in clinical practice, in conjunction with an existing checklist of conventional early signs, may yield a richer relapse signature. It was interesting when the researcher asked: how do you describe a mental health crisis and what action is taken when that happens? The BME participants were able to articulate answers such as *'crying, don't want to do anything, I stopped taking medication, hears voices, tell my mum and my brother'*. One participant stated, *'people see the changes in my mood'.*

6.3.1 Learning from previous experience of being unwell

Richards *et al.* (2013) postulated that we need to accept that expertise in health and illness lies outside as much as inside medical circles and that working alongside patients, their families, local communities, civil society organisations, and experts in other sectors is essential to improve health. They contended that:

> *"It is about a fundamental shift in the power structure in healthcare and a renewed focus on the core mission of health systems. Revolution requires joint participation in the design and implementation of new policies, systems and services, as well as in clinical decision making" (Richards et al. 2013, pp 1-2).*

One such system is Shared Decision Making (SDM). It has been said by Deegan and Drake (2006, p.1638), that SDM offers a model for assessing the advantages and disadvantages of a treatment within the framework of recovering a life following an experience of mental illness. The development of appropriate strategies to plan psychosocial interventions and mental health treatment is an active process that involves complex decision-making between the user and the practitioner. Interventions are however frequently intended to increase the user's compliance with the practitioner's view of optimal treatment. SDM is built on a very different power relationship than compliance-oriented processes as it acknowledges both the user and the practitioner as two experts who must share their individual information and jointly agree upon the choice of intervention, (Grim et al. 2016, p. 1).

Morant, Kaminskiv and Ramon (2015) indicated that SDM about treatment options is now a widely distinguished aspect of patient-centred care that has become a modern health-care ideal internationally. SDM is recognised as a promising strategy for enhancing collaboration between clinicians and service users, due to corresponding knowledge brought to the SDM process (Morant, Kaminskiv and Ramon, 2015). Barry and Edgman-Levitan (2012) put forward the view that in SDM patient and clinician discuss treatment options in a two-way exchange of information and knowledge (formal and experiential), and together decide on a course of action. The collaborative process is based on mutual respect, open communication and consideration of individual preferences and values.

SDM has been promoted in the UK through government policies and other practice guidance (NICE, 2014, 2010). However, a study by Farrelly *et al.* (2015, p. 455) found that most clinicians thought that the Joint Care Planning (JCP) replicated work and for some, it involved generating another care plan of questionable value. While there was a verbal commitment to the value of SDM, most clinicians were concerned about the consequences of allowing service users to control the content of their JCP.

There were two main concerns, firstly, service users' choices may be at odds with clinicians' thoughts about clinical beneficence; and secondly, the mental health services may be unable to facilitate treatment requirements, either due to inadequate resources or lack of continuity between routine staff and those who would be involved in crisis care. Furthermore, many clinicians were not aware that the way they routinely relate with service users may not facilitate the equivalent exchange of information required for SDM. In this context, service users felt unable to influence treatment decisions, and years of failed attempts to do so left them feeling disempowered, and for some, unable to engage in dialogue with clinicians (Farrelly *et al.* 2015, p. 455).

These discoveries are consistent with previous research which has suggested a number of barriers to SDM in mental health care, including providing inadequate information to service users, nurses lacking sufficient time, organisational and contextual influences including a lack of structural support for such initiatives, and insufficiencies in psychiatrists' communication skills, in particular the need to remain in control (Farrelly *et al.* 2015, p. 455). However, there is growing interest in SDM in mental health, which has increasingly featured in mental health policy and good practice rhetoric (NICE, 2010) and fits well with the recovery approach that typifies modern mental health-care ideals in many developed countries.

Notwithstanding, although these were observed to be recent developments, shadows of a darker past still characterise many facets of standard mental health practice. Forms of coercion from subtle persuasion to compulsory hospitalisation or CTOs are still relatively common, (Morant, Kaminskiv and Ramon, 2015, p.1003). Many mental health service users remain disempowered, feel they have little voice in treatment decisions, or that these are not made in their interests and experience stigma (Thornicroft, 2006b). Slade (2017, p. 147) noted that the clinical justification put forward for SDM is that patients who are active contributors in the management of their care have better outcomes. Increased involvement will lead to improved engagement, advanced-quality decision making, and increased treatment compliance–all of which will improve outcome.

Though there may be instants of genuine lack of capacity, meaningful discourse can sometimes be compromised by practitioners' beliefs about lack of insight associated with mental health problems. This may amplify inequalities between service users' experiential knowledge and the scientific knowledge base of practitioners. These changing aspects are most common when mental health problems are acute or severe , but distinct understandings of threatened, perceived, or actual coercion can damage service users' long-term ability to trust and partake positively in services offered (Morant, Kaminskiv and Ramon, 2015, p. 1003). It is vitally important to point out the role of family and friends in helping service users in their mental health journey. This will enable a close relative or friend to alert the mental health team if they felt that the service user was becoming unwell. At best that would be done with the service user’s knowledge as this would demonstrate collaborative working with the service user.

6.3.2 BME participants establish some trigger factors that can cause them to relapse.

Signs of relapse and understanding patterns of behaviour take time and effort to learn about the illness. One participant who described herself as being fit all her life, could not accept that she had a mental illness. As a result, she omitted taking her prescribed medication. After several admissions into hospital, she realised that when she stopped her medication, she became unwell and required hospital admission. Consequently, following several hospital admissions she learned the importance of medication in preventing relapse. That was also the case for Guy (pseudonym) who did not think medication was helping him. He now realises that he gets panic attacks and anxiety if he does not take his medication.

Substance misuse was also found to contribute to some service users experiencing a relapse; particularly because six of the participants discussed how drug misuse contributed to their relapse. Substance misuse among psychiatric spectrum disorders is widespread (Di Forti *et al.* 2019; NICE, 2016). It was estimated that in the United Kingdom a third of patients with serious mental illness have an active substance use disorder including schizophrenia, mood, dissociative, and personality syndromes (Department of Health, 2006). Equally, similar evidence has been purported by authors such as Das-Munshi *et al.* (2020).

One of the BME participants, Paul (pseudonym), recognised that he became unwell because he took drugs. He described that he got paranoid after taking drugs which usually led to hospital admission. It was interesting to hear how another participant Andrew (pseudonym), described his understanding of substance misuse, and compared the effects on his mind as not being strong when his was younger, but now fifteen years older he feels more in control. He further rationalised the effects of taking drugs *'to having a glass of wine with your dinner'*. Research has also shown the impact of drugs on a person's mental health (Das-Munshi *et al.* 2020; Di Forti *et al.* 2019; Department of Health, 2006).

Psychosis is comparatively common, with schizophrenia being the most widespread form of psychotic disorder, affecting about seven in 1000 adults, with onset typically occurring between the ages of 15 and 35 (Kuipers *et al.* 2014, p.1). Schizophrenia has been described as:

> *a mental illness characterised by positive symptoms (delusions, hallucinations, thought disorder, disorganised behaviour), negative symptoms (social withdrawal, apathy) and cognitive symptoms (poor executive function and memory). It frequently follows a chronic course and is associated with a decline in social and occupational functioning.* (Blackman and MacCabe, 2020, p. 704).

While medication compliance played a crucial role in preventing relapse; psychosocial therapies such as cognitive behavioural therapy and family intervention based upon the stress-vulnerability model have evidenced that they also play a key role in preventing relapse (Foster and Jammoodu, 2008; Garety, 2003).

6.4 Theme Four: The need for help with taking medication and medication concordance

Kuipers *et al.* (2014) found that although many people with schizophrenia and other types of psychosis respond to antipsychotic drugs initially; around 80% relapse within five years due to discontinued medication, as many experience undesirable side effects. Equally around 75% of people with schizophrenia currently relapse and have continued disability, (Haddad, Brain and Scott, 2014).

6.4.1 BME participants' link taking their medication as a major part of their recovery

This theme was an interesting one. Firstly, some BME participants cited medication as a means of support to help keep them well. Secondly, some felt that the professionals insisted that the participants took medication to keep well. On close examination, it appears that the participants who felt that the medication offered no support to them, were participants who could not correlate stopping medication and hospital admission. There needs to be further support for service users as they might experience side effects which could be another reason for poor compliance.

This highlighted further reasons why professionals need to listen to service users and as far as possible work with service users to formulate a medication regime that is relevant to service users to enhance concordance. The notion of partnership working where service users are placed at the centre of decision-making has been proposed under the CPA. It was remarkable to hear the BME participants' views about medication. Some participants felt that taking medication helped them keep well, while others felt that medication was not good for them. One BME participant, Robert (pseudonym) talked about how he used to be bothered by witchcraft and experienced olfactory and visual hallucinations; although he confirmed that *'he is on a depot injection and does not have those experiences anymore',* yet, he did not make this connection (absence of olfactory and visual hallucinations) with taking prescribed medication.

The above train of thought has been found by Teferra and Shibre (2012) following a qualitative study among the Borana semi-nomadic population in southern Ethiopia to explore perceived causes of severe mental disturbances and preferred interventions. Most of the participants spoke of *‘the importance of supernatural influences’* in causing severe mental disturbance, namely bewitchment, witchcraft and possession by evil spirits. The concept of bewitchment was principally associated with the evil deeds of others, to retaliate for a wrongdoing or misdeed (Teferra and Shibre, 2012, p. 4).

According to the participants in Teferra and Shibre’s (2012, p. 4) study when someone is bewitched, it not only makes the person develop severe mental disturbance, it also causes loss of assets. The mental illness could also be transmitted to other relations of the person who is affected. As such a belief features highly in some people in the BME culture, mental health professionals need to be aware of such beliefs when taking a history and formulating a plan of care for the individual service user. This upholds the notion for cultural competence (Campinha-Bacote’s, 2011).

Another insight for the researcher related to how participants learned that previous experience was informative in the way they managed their mental health. An example is that, after being admitted to hospital on a number of occasions, one BME participant came to the realisation that, when he engages in drug misuse, he became paranoid which subsequently led to an admission into hospital. To help him break that cycle he separated himself from the company he kept. He felt this helped him to manage repeated hospital admissions. His personal experiences inspired me as they reflected his growth and development. Another participant–Guy (pseudonym) found he learnt from the occasions where he did not take his medication and would experience panic attacks. He stated he now realised when he doesn’t take his medication he got *‘those kinds of feelings’.*

Snowden *et al.* (2014) stated concordance described an idyllic, patient-centred process of supported decision-making that seemed to be difficult to operationalise in practice. Snowden *et al.* (2014) inferred that the terms adherence, compliance, and concordance continue to be used interchangeably in the literature on medicine management. In their study, Snowden *et al.* (2014) examined whether concordance is conceptualised differently among the disciplines of nursing, general medicine, psychiatry, and pharmacy.

They found that concordance is conceptualised differently among the disciplines discussed above. Physicians and Psychiatrists are mainly interested in concordance as an end to compliance with directives, or compliance with guidelines, thereby retaining the presumption that their opinion is the predominant factor in any relationship. They guard this position by reference to professional accountability and culpability, thereby introducing conditions into the concept of concordance that diminish its authenticity (Snowden et al. 2014, p.56).

Nonetheless, nursing literature was less sure about concordance, despite being the most passionate and the language reflects this duality. Concordance is shown to be as a universal good in some occasions, coherent with nursing policy, principle, and professional values. Pharmacists were the most forward-thinking in their deconstruction of concordance. They saw the benefit and unavoidability of going beyond education and advice in the medicine review, yet at the same time remained uncomfortable in facilitating concordance-based approaches and unconvinced as to the benefit (Snowden *et al.* 2013, p. 56). Similarly, Wakefield (2012) reviewed all three concepts-compliance, adherence and concordance and suggested that within mental health settings, due to the differences of symptoms and personal experiences of individual service users, all concepts have a place within mental health care.

Haddad, Brain, and Scott (2013) explained that medication adherence can be defined as the extent to which a patient’s medication-taking matches that agreed with the prescriber. They suggested that a range of alternative terms have been used, including treatment compliance and fidelity, but adherence is currently favoured partly due to its neutrality. They felt that the term compliance implies an unequal power balance between the prescriber and patient. I have chosen to use the term concordance as it suggests a partnership between prescriber and the service user (Chakrabarti, 2014; Haddad, Brain, and Scott, 2014). Notably, Chapman (2018) is of the same view and suggested that “*a concordant relationship encourages self-management of health; is based on trust and enables effective* *communication between patients and health professionals"*. (ibid, p.1) inferred that such a relationship accounts for best health and wellbeing outcomes.

Hon's (2012) research study aimed to explore the factors influencing the adherence to the antipsychotic Aripiprazole for patients aged over 18 years in the Early Intervention Service (EIS) to gain a patient-centred account of the experience of taking antipsychotic medication. The objectives examined the patients' adherence to taking their medication and to establish the issues that influenced their decisions. This study helped to gain an understanding of the patients' perspectives that influenced their medication-taking decisions. Taking antipsychotic medication for a person with first episode psychosis (FEP) echoed both positive and negative experiences. In addition, the study highlighted that the decision for service users to take antipsychotic medication is based on how they assess the costs and benefits of the medication.

Hon (2012) contended that the participants in his study knew with a high degree of certainty how they felt and what they wanted to achieve, which was optimal quality of life. These subjective feelings cannot be ignored when making treatment decisions. Greater awareness is required of the experiences and feelings of the patients when providing medical treatment for FEP. The EIS need to develop strategies for staff to integrate more practical, educational and psychological support to patients within standard approach to care and treatment. This involves providing enough information and support to help them accept their situation, equally, to uncover the patients' beliefs about their medication and using internal and external resources to achieve recovery and normality of function (Hon, 2012). Hence, there would be a need for negotiation with the service user which suggests a transformative care plan process.

6.4.2 BME participants experience side effects of medication

The National Institute for Health and Care Excellence (NICE, 2014) on managing psychosis and schizophrenia in adults recommended that people with psychosis or schizophrenia (especially those taking antipsychotics), should be offered a combined programme of healthy eating and physical activity by their mental healthcare provider. A suggestion which supports one of the BME participants' belief. Grace (pseudonym) believed that it will make a difference to the BME service users. Nevertheless, even with the newer antipsychotic and antidepressant medication, service users still experience a range of side effects. Thus, mental health professionals need to work with services user to establish a regime that is appropriate to that individual service user.

Several BME participants expressed reasons why they stopped taking their medication. Some suggested that they experience severe debilitating side effects from medication. There were descriptions of physical effects such as weight gain, feeling drowsy and stiffness in joints which made walking difficult. There were also descriptions of psychological effects from taking medication. Grace (pseudonym), talked about feeling *'slowed down'* in the activities she used to be able to do prior to being on medication became impaired, as her concentration and motivation to do those activities were negatively affected.

The above descriptions are not dissimilar to those suggested by Haddad, Brain, and Scott (2014) in figure 10 on page 179. It is noted in the diagram below that all the common well-known factors such as effectiveness, side effects were identified. However, missing from this diagram is a well-known factor contributing to non-adherence referred to in the literature as self-medication hypothesis. This is where a service user engages in self-medicating (Gonzales, 2018) for example with alcohol when formal medication is not working for them. It is also worth noting that one of the stated side effects of Aripiprazole is sudden death. However, it also has a benefit in that it can reduce obesity. This would point to the need to for more open transparent communication with the patient (Ali, 2017).

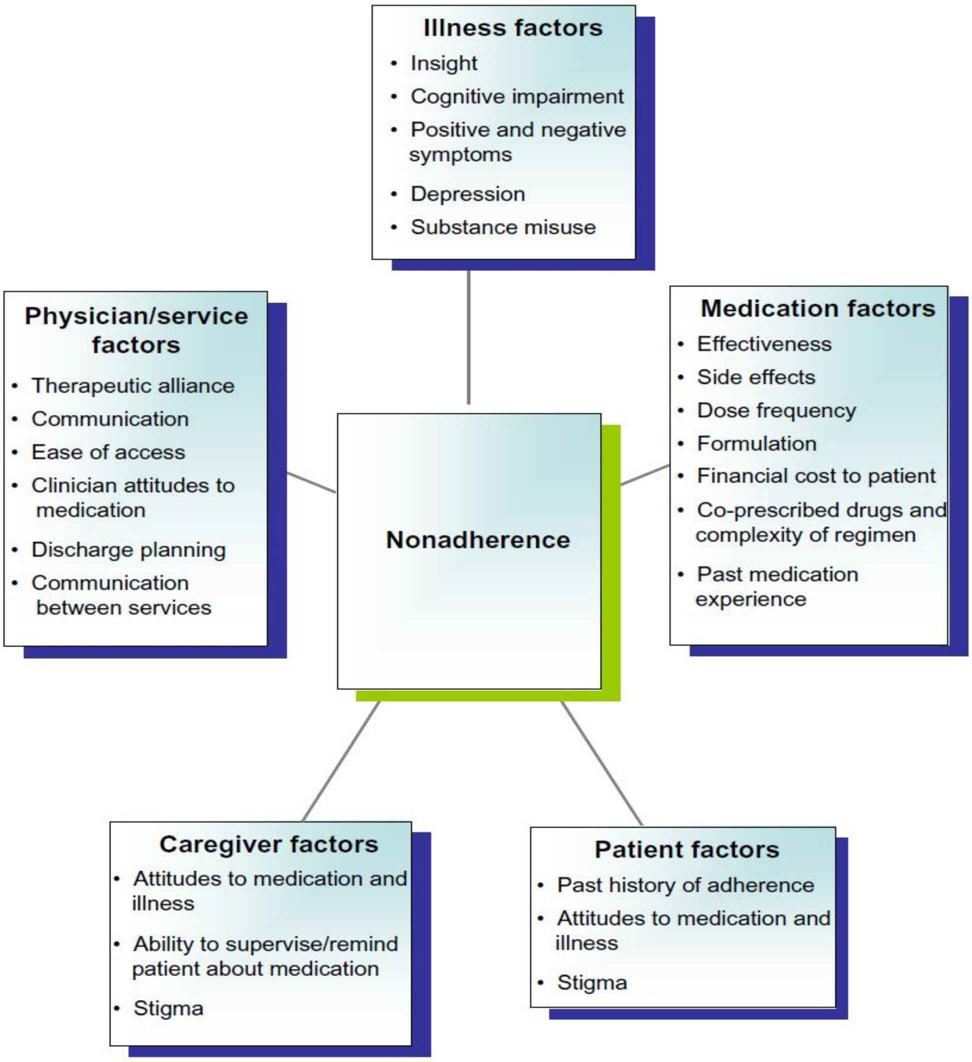


Figure 10: Factors associated with nonadherence. (Haddad P, Brain C, Scott J, 2014)

Roger (pseudonym), a BME participant who had a diagnosis of Bipolar Affective Disorder talked about his efforts to stop medication while in the depressive phase of the illness. He noted that he was doing it against the advice of the mental health professionals involved in his care. Although he became more unwell, he stated that he could *'rough it out'.* As I ponder on this expression, I am led to believe that as this participant might have been experiencing side effects, he chose to experience the negative symptoms of the depressive illness. His continued utterings became a source for concern as I pondered on the following description of depression by Greener (2014) who contended that;

> "*depression is more than feeling 'a bit down', more than 'the blues': it is a profound, debilitating mental and physical lethargy, a pervasive sense of worthlessness, and intense, deep, unshakable sadness",* (Greener, 2014, p 23).

The author further suggested that if one has never experienced major depression, it is difficult to appreciate just how overwhelming the condition can be (Greener, ibid). Consequently, I can only imagine what the above participant would have had to endure.

Medication nonadherence is especially problematic in schizophrenia and results in consequences including symptom exacerbations or relapse, greater risk or rates of psychiatric hospitalisation and use of emergency psychiatric services and worse prognosis (Phan, 2016). A further reason given for not taking medication is that the participants felt well and hence did not require the medication anymore. It may well be that this view is borne out of the lack of understanding of how mental illness presents itself and the treatment methods used to combat the illness.

This means that mental health professionals need to ensure that they spend time with service users and explain their diagnosis and treatment. Evidently, this was the case with Gloria (pseudonym), who questioned why people experience side effects when they take psychotic medication. Hopefully, time spent with her to clearly explain her condition and the use of the particular drug could help clarified her understanding.

The mode of administration of medication also presented its challenges. The long acting depot injection caused side effects such as sleepiness and drowsiness. Some BME participants talked about feeling tired and lethargic during the daytime which impeded their ability to perform simple tasks. This was the case for Dominic (pseudonym) who said that he felt drowsy in the mornings. Undoubtedly, a review of service users medication needs to be a central feature in care planning, to ensure that service users could discuss how they might be coping with the prescribed medication.

It is also important that service users are listened to as some participants indicated that when they mentioned serious concerns about their medication, mental health professionals advised them to keep taking their medication. This presented a paradox, on one hand the mental health professionals mean well by ensuring they carry out their duty of care to service users, yet service users may interpret that advice as being dismissive (Perkins and Repper, 2018) of what they might be experiencing. This proved that open communication is important to ensure that service users feel that mental health professionals carefully consider their expressed concerns.

6.4.3 BME participants experience weight gain as a side effect of psychotropic medication.

Grace (pseudonym) suggested that the food was very basic, and another participant felt that because of the medication they experienced a range of side effects. One of which was weight gain. Mwebe, Volante and Weaver (2020) stated that;

> "*weight gain is common in serious mental illness; this is partially a result of the interaction between adverse effects of psychotropic drugs and complex environmental factors in this patient population''*. (Mwebe, Volante and Weaver, 2020, p. 3).

Accordingly, people who use mental health services need help with managing their diet and food intake. A mixture of diet and exercise would be key in supporting service users in their mental health journey. The role of nutrition in both the aetiology and management of mental health disorders is a rapidly growing area of research and has implications for translation into practice (Charlton, 2015).

In examining this issue further Charlton (2015) explained malnutrition and mental health disorders as a chicken or egg scenario. Does the presence of mental illness influence eating behaviours and result in an insufficient intake, or conversely, does a poor nutritional status impair mental function and lead to worsening of symptoms? The overwhelming body of evidence suggest that malnutrition predicts adverse clinical outcomes (Slattery *et al.* 2015; Jan-Magnus *et al.* 2011) and requires innovative strategies to address this problem in practice.

One of the BME participants raised an important issue regarding nutrition. She felt that not enough thought went into the meals being offered which had an impact of her wellbeing. In mainstream society much emphasis has been placed on diet and exercise. Undoubtedly, some people invest substantial amounts to have a personal trainer or going to the gym. For people who have a mental illness there is a potential to gain weight due to side effects of antipsychotic drugs; so, the participants' idea of diet and exercise is profitable, and I concurred. Similar evidence has been found by, Usher, Park and Foster (2012) who conducted an interpretive phenomenological qualitative study to describe and construct the meaning of the experience of living with the weight gain associated with second-generation antipsychotics (SGAs).

The participants indicated that they had struggled to manage ravenous appetites and associated weight gain from the time of introduction of the SGAs. In addition, the participants told of trying to implement approaches to lose weight and how they had struggled to do so. As a result of the increased weight, the participants described many unpleasant related effects and emotions as well as feelings of shame. Significantly the participants indicated that the weight gain made them contemplate stopping the medication as a strategy to lose weight or prevent further weight gain (Usher, Park and Foster, 2012). The findings in this study showed that some of the participants including Luke (pseudonym) experienced weight gain while on psychotropic medication.

Likewise, Nash (2014) stipulated that although diet, poor nutrition and lack of physical activity in mental health service users (MHSU) are mirrored in the general public, MHSU are worse off due to the disparities they face including social exclusion, unemployment and poor housing. Therefore Small *et al.* (2017) proposed that:

> *"a more tailored approach to physical health care discussions within mental health care planning, which looks at the whole person in context with their unique needs and personal characteristics, is necessary for effective service user and carer led involvement to be achieved in practice*" (Small *et al.* 2017, p. 9).

The authors developed a conceptual framework encompassing the prerequisites required to achieve effective service user and carer involvement in physical health care discussions as seen in figure 11 on page 183.

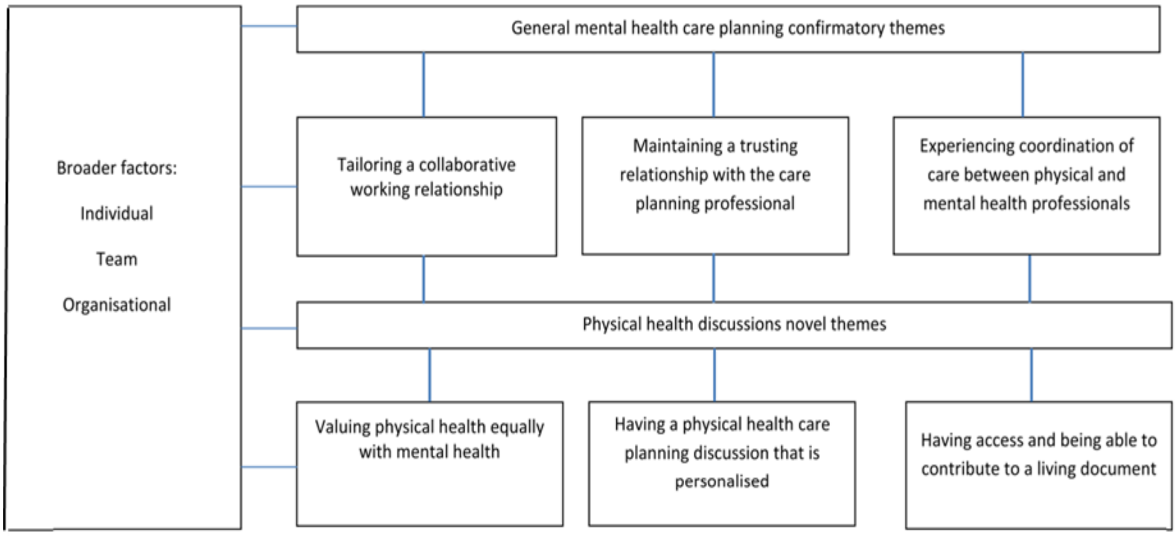


Figure 11: Conceptual framework: six prerequisites for effective service user and carer led involvement in physical health care planning and broader factors that impact on the implementation within mental health services (Small et al. 2017: P5).

The evidence in figure 12 below supports that view and shows that people with SMI are at higher risk of physical health conditions including obesity, diabetes, and hypertension.

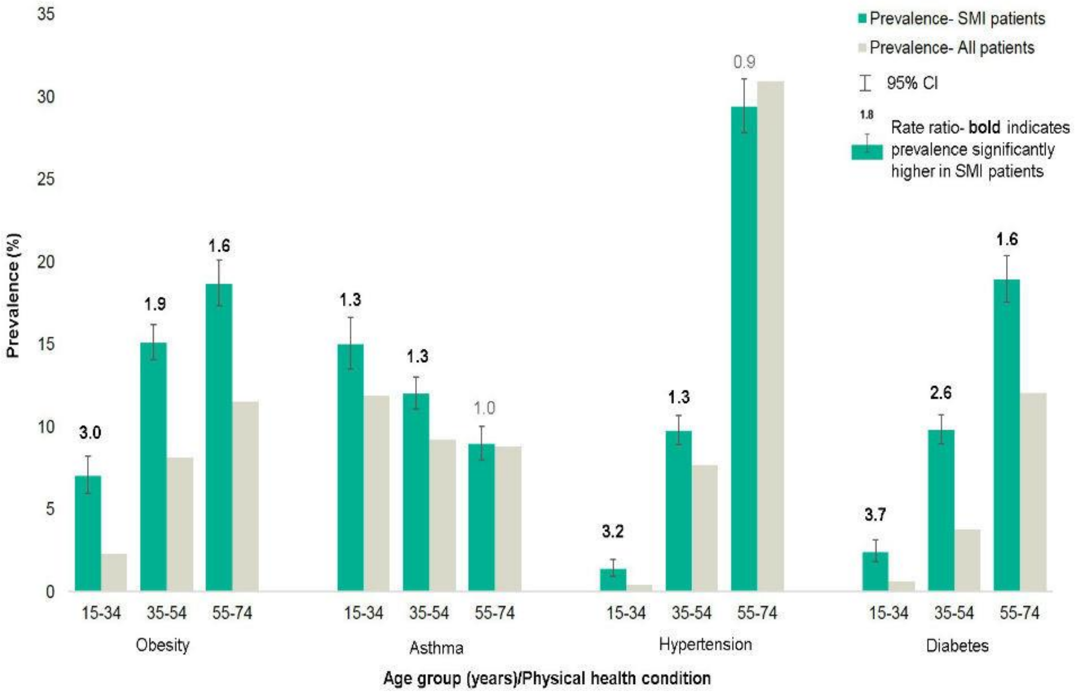


Figure 12: A graph showing prevalence of physical health conditions among SMI patients

Source: The Health Improvement Network (THIN), Active patients in England; data extracted May 2018.

For both SMI and all patients the recorded prevalence of obesity, diabetes and hypertension increases with age (Figure 12). The prevalence of asthma decreases with age. However, for all 4 conditions the level of health inequalities between the

SMI and all patients is higher for younger age groups. This analysis shows that compared to all patients SMI patients are:

- 3.0 times more likely to be classified as obese for age range 15 to 34 but only 1.6 times more likely for ages 55 to 74.
- 1.3 times more likely to have asthma for age range 15 to 34 and 35 to 54, but for age range 55 to 74 the difference is not significant.
- 3.2 times more likely to have hypertension for age range 15 to 34 but only 1.3 times more likely for age range 35 to 54.
- 3.7 times more likely to have diabetes for age range 15 to 34 but only 1.6 times more likely for age range 55 to 74.

Nonetheless, even with the novel antipsychotic and antidepressant medication service users still experience a range of side effects, many associated with obesity.The above figures indicate that health professionals need to ensure that interventions such as annual health checks are carried out for those with a diagnosed mental illness. This will help to unearth physical health conditions in a timely fashion. A further strategy that could be of benefit to people diagnosed with mental illness is the government's Tackling Obesity Strategy (Department of Health, 2020). The aim of the strategy is to help reduce obesity in the United Kingdom. The government announced in the strategy that whilst it has been known of the link between obesity and health conditions such as cancer, heart disease and type 2 diabetes, it has been noted in the last few months that being overweight or living with obesity puts one at risk of dying from COVID-19. Hence, the new campaign–a call to action to take steps to move towards a healthier weight is a key feature in the strategy (Department of Health, 2020).

In thinking about the inequality in mental and physical health provision the government put forward its mandate termed parity of esteem. The ethos of parity of esteem is the government commitment to ensure that mental health is valued equally as physical health (Department of Health, 2011, p. 2). According to the Institute for Public Policy Research (IPPR) spending needed to rise from £12bn in 2017-18 to £16.1bn in 2023-24 and reach £23.9bn by 2030-31. The report suggested that mental health spending would need to grow by 5% a year until 2024, compared with 3.4% already promised for the NHS, and by 5.5% by 2030. The IPPR urged the government to commit a further £1.1bn a year of NHS spending to support the drive for parity of esteem, (Quilter-Pinner and Reader, 2018).

The Royal College of Nursing (RCN) conducted a survey in the UK among nurses working in mental health in acute care settings. Those staff included registered mental health nurses, registered general nurses, Health Care Assistants and Students Nurses. The survey was to report on the progress and implementation of parity of esteem across the UK. The findings of the survey established three areas of focus:

- Pushing for funding into mental health services on a par with physical health services.
- Improved training- consistency, competence, and curriculum support
- Identifying areas where access and innovation around physical health has made a difference, (RCN, 2018).

No doubt those areas of improvement will serve to help the needs of those who use mental health services.

6.5 Theme Five: Service Users from a BME background experience Stigma

Participants from a BME background were asked about their experiences in using the mental health services in the Trust; particularly if they felt discriminated in anyway. All the participants stated that they did not experience discrimination in the care they received in the Trust. They seemed to link any discrimination/stigma as originating from external agencies such as the Criminal Justice System, Police, Employment, and the Wider Society.

6.5.1 Some BME participants linked the stigma they experience to come from the Criminal justice system, Police, Employment and Wider Society.

One participant Paula (pseudonym) felt that she was discriminated against both by the Criminal Justice System and through employment. She felt strongly that when the *'incident'* happened she was mentally unwell, and it was out of character for her to act in the way that she did. Unfortunately, she now has a criminal record which has affected her ability to gain employment.

Arguably, a better understanding of mental illness by the police could be improved to help address situations such as these from arising. Therefore, a planned education programme (should be recommended) on mental illness for the police and other agencies such as ambulance staff and fire brigade. This would promote essential knowledge and skills needed when dealing with people who have a diagnosed mental illness. The above incident reported by the participant demonstrated that a lack of understanding was shown. Incidentally, this participant was already in receipt of mental health services during this occurrence.

Given the above participant's experience of the police I felt it necessary to ascertain further from each of the participants whether they experienced involvement of the criminal justice system at the point of their initial or subsequent admission to hospital. Out of the 24 BME participants seven spoke of their involvement with the police or criminal justice system. This number is significant, as this is a small sample indicating that the involvement of the police is common. It was reported in the news that the police were involved in several cases where people they were dealing with have a diagnosed mental illness. The police stated that they are being relied on as an emergency mental health service and that cuts in psychiatric provision was probably to be blamed (Dodd, 2016). One of the strategies that have been implemented is for a psychiatric nurse to be based in each police station (Department of Health, 2014). This would help promote greater effectiveness in dealing with individuals who have a diagnosed mental health problem.

Cummins and Edmondson (2016) noted that although the Home Affairs Select Committee (HASC) (2015), stated that mental health work will always be part of the wider police role they have real apprehensions that increased demand will place too much pressure on strained local resources. This might well put very vulnerable people at increased risk hence new approaches should be considered. One such approach is mental health triage which is a concept that was adapted from general and mental health nursing for use in a policing context. A generic term *"street triage"* is used for the various models that have been adopted across forces.

The overall aim of triage is to ensure more effective use of resources and health outcomes. Cummins and Edmondson (2016) found that street triage had great possible benefits which involved better communication between mental health professionals and police officers, greater sharing of information that fostered improved decision making and overall improved services for service users in mental health crisis (Cummins and Edmondson, 2016; Horspool, Drabble and O'Cathain, 2016). No doubt services such as this would help channel service users to the most appropriate service to meet their needs at a given time.

One of the participants drew a parallel between those who work in mental health and those who live in the wider society. Luke (pseudonym), made a distinction and suggested that those who work in mental health understood the illness, so he did not feel stigmatised by mental health workers. However, it was different in the wider society as there was a misunderstanding of mental illness, which compounded mental illness by the media negatively. Luke's (pseudonym) noted that there is not much opportunity for young black youths to do things. He felt that young black men enjoy music so he suggested that more of that should be made available.

A diagnosis allowed service users to gain further insights about their illness and treatment. Alternatively, due to the negative portrayal in the media having a diagnosis may cause service users to feel self-conscious as they identify with the negative expressions portrayed in the media, so they become concerned that this is how they present. Knifton *et al.* (2009) suggested that stigma involves a combination of inaccurate knowledge and stigmatising attitudes, leading to individuals being excluded and discriminated against. The authors noted that different mental health problems attract particular forms of stigma including dangerousness, social distance, blame and recovery pessimism. While this behaviour is directed at those who have a mental health diagnosis, the discrimination and stigma the BME participants in this study described has been referred to as a "double jeopardy" (O'Hara, 2003), in that they face disadvantages related to both mental health such as the associated stigma (McGrother *et al.* 2002) and also of racism.

In a recent systematic review and meta-analysis, the authors drew the following conclusion and stated that:

> *"the results of the current meta-analysis indicate differences in mental illness stigma based on racial background and this result highlights the important role of racial and/ethnic background in shaping the mental illness stigma"* (Eylem, de Wit, van Straten, *et al.* 2020, p. 14).

They purported that an implication for practice was that anti-stigma strategies should be tailored according to specific racial and/or ethnic backgrounds with the intent to improve mental health outreach (Eylem, de Wit, van Straten. *et al*. 2020, p. 14).

Stigma therefore has been found to be both external (coming from the public) and internal (self-stigma) where the individual has negative beliefs about themselves including shame and embarrassment (Corrigan *et al.* 2005). This was noted by the participants who avoided going to their place of worship as they believed that they would be judged for engaging in substance misuse behaviour.

People with mental health problems are amongst the least likely of any group with a long-term condition or disability to find work, be in a steady long term relationship, live in decent housing and be socially included in mainstream society, (Mental Health Foundation, 2019). A fact file by the National Mental Health Development unit (NMHDU) (NMHDU 2010) showed that stigma and discrimination affect most areas of their life. They suggested that up to 90% of people with mental illness said they would like to work compared to 52% of people without a disability. These findings were not dissimilar for the participants in this study as more than half of the participants stated they wanted to get a job.

Doubtless to say those who work within the mental health field should uphold the principle of social justice by ensuring that they challenge stereotypes, stigma, and discrimination. They can do this through education, for example via open days in the wider community where the public can *'walk in'* and materials such as leaflets on different types of mental illness can be made available, and education campaigns such as *'Time to Change'*. One example is the *'Up my Street'* programme which informs work with young Afro Caribbean men age between 15-25 years. The aim is to develop their wellbeing in the local community (Centre for Mental Health, 2017).

Mantovani, Pizzolati and Edge (2017) examined pastors and ministers of religion views about mental illness and treatment. The authors stated that the respondents narrated only spiritually based approaches to dealing with mental health needs which signified pastors' lack of understanding of mental illness. Equally, Mantovani, Pizzolati and Edge (2017) found that the following factors contributed to stigma and in turn became obstacles to *'help-seeking'* from mental health services: cultural beliefs about mental illness; practices in faith communities; anticipation/experience of negative consequences; family kinship/relational structure; and preference for non-disclosure. Jackson and Heatherrington, (2006), also found that public attitudes about mental illness in the English-speaking Caribbean is characterised by high levels of stigma which lead individuals to turn to religious leaders, or to engage in religious coping rather than seeking psychiatric/psychological help for mental health problems.

Stigma and discrimination in mental health is of international interest. A total of 47 participants from Caribbean-Canadian and Euro-Canadian background took part in a study on Recovery, (Whitley, 2016). Whitley (2016) found that participants from both ethno-racial groups reported an overwhelming barrier to recovery was stigma. Participants described how such stigma expressed itself in every layer of social life, including interactions with family, friends, clinicians, potential employers, and the general public.

One of the BME participants described why he kept away from his family. He stated that he wanted to *'sort himself out'.* Was he being realistic in saying that he would go back when he *'sorts himself out'*? Whilst I appreciate and respect his view, and drawing on my experience as a mental health professional which is in line with the concept of phronesis (Kinsella and Pitman, 2012) it could be suggested that the support from family and friends when encountering a severe mental illness can have a positive effect in reducing stigma hence improving their quality of life (Corrigan *et al.* 2012; Corrigan *et al.* 2005) . For instance, a relative could act as an advocate to help speak on behalf of the service users. There are times when the service user might be unable to articulate his needs and wishes due to how s/he may be feeling at a time. Thus, a close relative may be best placed to offer that support at that given time. This was the case for Grace (pseudonym) who described having sessions in hospital with the psychiatrist and other members of the care team. She felt that having her family at those meetings were extremely useful.

In discerning that fact, Repper and Perkins (2003 as cited in Perkins and Repper, 2018, p. 110) observed that people come to mental health services when they are at their most disturbed and distressed state. Sometimes they struggle to express themselves and it is difficult for others to appreciate what they are experiencing. They may have used drugs or alcohol to numb their pain. They may have experienced trauma and abuse, broken relationships, debts, homelessness, loss of a job or the death of someone they love. To be diagnosed with mental illness and all that these mean in our society might be thought of as a form of bereavement, (Repper and Perkins, 1996, p. 136). One participant (Andrew) talked about the losses he had and spoke about it as *'one of those things'*. However, I detected an element of sadness during that part of the interview when he talked about his loss. He did seem perturbed and continued to the end of the interview.

6.6 Theme Six: Hope

6.6.1 BME Service users demonstrate resilience

One of the main features of the recovery approach is instilling hope in the lives of those who have a mental health problem. This theme highlighted that whilst there have been some negative experiences namely, stigma and discrimination the participants were filled with hope for the future. In this study the BME participants identified with a number of different factors which were aligned to the concept of hope. Some talked about personal strength, others about religion and others family and friends. It was clear that they all felt the intangible sense of knowing that these areas played a major role in keeping them well.

In discussing the concept of hope, Russinova (1999) hypothesised that mental health and rehabilitation practitioners are best placed to keep hope alive in their clients. This could be achieved through the overall positive belief about the potential for recovery, using external and internal resources necessary to enable the recovery process. Mental health professionals therefore should focus on such resources, for example, adequate housing, job training, and supported education services, as well as resilience, coping skills, and self-acceptance (Russinova 1999, p. 53).

There is evidence to show that a positive mental attitude towards one's illness enhances their chance of recovery (Iasiello *et al.* 2019). In her study, Sagan (2015) found that it was in the descriptions of exploring the past and moving towards *"speaking well-ness"* that the word hope emerged time and again. This was echoed by Charles (pseudonym) who felt that whilst within mental health it is viewed as he will be ill all his life, he felt that he was better and described himself as '*I'm as best as I can be'*. This is definitely a positive affirmation and is congruent with the ethos of recovery.

According to the synthesised dimensions of hope, Schrank, Stanghellini and Slade (2008, p. 426) believe that hope is a principally future orientated expectation (sometimes but not always informed by negative experiences such as mental illness) of achieving personal valued goals, relationships or spirituality, where attainment: i) will give meaning, ii) is subjectively considered realistic or conceivable and iii) depends on personal activity or characteristics for example, resilience and courage or external factors such as resource availability. Schrank, Stanghellini and Slade, (2008, p. 426) contended that hope encompasses four components: i) affective- trust, confidence, humour and positive emotions; ii) cognitive-reflecting on past experiences, goal-setting, planning and assessing the likelihood of success; iii) behavioral-motivation and personal activity; and iv) environmental-availability of resources, health care and relationships.

Although Dominic (pseudonym), was dissatisfied that he was in more supported accommodation (24-hour care) he spoke hopefully about his aspiration for the future, as he looked forward to independent living and employment. Such aspirations are no different from that of people in the wider population. As a researcher, I was humbled by the fact that despite the devastating effects of SMI some of the participants had not lost sight of their goals in life. The setting of goals is also part of care planning where the service user is central to that process. However, given the situation whereby Dominic (pseudonym) wanted to manage his finances, it might well be that at this stage much work would be needed to improve his budgeting skills. Obviously, this will be all part of a package of care that his CC needs to ensure is formulated with his involvement.

6.6.2 Spirituality

Hope is about being patient and trying to achieve what you do not already have. Paula (pseudonym), placed great emphasis on being a Christian and how Christianity has helped in her journey to keep well. However, she also expressed that Christianity on its own did not keep her out of hospital. It was a joint effort with medication and her faith that she felt had worked. In her attempts to decipher which one worked she asserted that it was the medication rather than her Christian belief.

Hope is deeply rooted in the Bible. Those who live a Christian life have hope as an anchor which guides their life and decision-making. I would like to contend that this intangible sense of knowing that the BME participants described is enshrined in the ethos of hope. From the researcher's viewpoint, if hope is a belief and an assurance that despite the difficult times there will be a brighter future; then according to spiritual teaching hope might be described as faith. Stott (2015) felt compelled to use the words faith and belief, because they reflected the language he encountered daily, and the emphasis of feelings expressed to him and other members of the Mental Health Team who worked in a prison. Stott (2015) stated that the relationship between the client and the practitioner may always have an element of mystique, but instead of attempting to deconstruct it, perhaps it should be welcomed. This view has been supported by Russinova (1999, p. 51) who contended that *"hope is something that occurs between persons in the context of a relationship; it is a shared experience between giver and receiver".*

As a result, having examined the terms hope and faith I am of the view that resilience leads to hope which in turn builds one's faith. The BME participants discussed vividly what kept them well in their journey through mental health. It has been suggested that a *'problem shared is a problem halved'*. One of the BME participants Paul (pseudonym) discussed how he hid his substance misuse habit from his mother. He described it as being a stigma in the black community. However, when he was open with his mother he felt like a *'weight'* had been lifted from him. I would suggest that this scenario is a platform from which the participant was able to grow as he found warmth and a shared understanding of what he had been experiencing. Ali (pseudonym), who was of the Muslim faith felt that his substance misuse habit was not in keeping with his faith. Whilst he had a strong belief, he did not attend a place of worship, as he felt the misuse of drugs made him unworthy of being with fellow believers. Ali (pseudonym) felt shame and embarrassed about his substance misuse behaviour.

He maintained that he came off the drugs and thanked Allah for making him see that what he was doing was wrong. In both cases the participants recognised that substance misuse is not socially acceptable on a number of levels. It starts with the individual themselves as they feel a sense of guilt about their behaviour. It then transfers to family and friends with whom they feel unable to discuss their problem. A further level is the church, which is viewed as a beacon of hope and teaches right from wrong.

Another participant talked about how Christianity helped her to stay well. Whilst she believed in the power and healing, she was mindful of the fact that prayer on its own did not keep her well. She contended that the use of medication and prayer was a good combination and she placed her hope in both. It is reasonable to suggest that this further endorsed the fact that keeping in social contact with family and friends gave service users added strength and a sense of hope. Hays and Aranda (2016) found that African-Americans tended to rely on informal sources of support, such as church, friends, and family to manage psychological problems rather that use formal mental health services.

From my point of view, on a spiritual level one could argue that God has given the knowledge to men who produce the medication which helped to keep her well. Hence prayer and medication *'sat under the same umbrella'* of a higher power. However, evolutionists would argue the opposite. I believe that whilst it is incumbent on me to look at different schools of thought; it is also absolutely important to respect the views of the participants.

Keefe, Brownstien-Evans and Polmanteer (2016) found that mothers from a BME background who adhere to their faith and belief and engaged in spiritual practices noted positive changes in their lives. Haney and Rollock (2018) contended that this phenomenon is unclear as it reflected the variety of components involved in religious experience that offer support to believers. The authors agreed that in addition to the reassurance of regular practices and comfort of social connections, religion can provide believers with frameworks through which they can find meaning, interpret their lives, and bring a sense of coherence in their experience.

To make sense of that phenomenon, Haney and Rollock (2018; Hayward and Krause 2014), theorised that there are three religiosity that may explain the relationship between religion and the mental health outcomes that it predicts: (i) extrinsic factors including religious activities and social support from a religious community;(ii) intrinsic factors, such as private prayer or the ability to derive meaning from a religious perspective and (iii) doubt; the questioning of feeling of disconnection from religious belief that may undermine spiritual processes.

While intrinsic and extrinsic religiosity are associated with better mental health, religious doubt appears to affect mental health in a negative way (Haney and

Rollock, 2018; Galek *et al.* 2007). It is felt that religious doubt may undermine the health promoting processes associated with religious coping by reducing its use of provoking shame and guilt that may impact on self-esteem and lead to cognitive dissonance (Haney and Rollock, 2018). This links very much to what Ali (pseudonym) felt about his substance misuse habit; the shame he felt prevented him from attending a place of worship.

As I pondered further about Ali's (pseudonym) view of the mix of religion and medication, he appeared to suggest that medication on its own was not what has kept him well. Ali believed that time is a healer and his faith in Allah was responsible for his healing. This in turn gave him hope for the future as he was able to live a life in the community, possibly among family and friends which no doubt gave him a more fulfilled view of life. A more fulfilled view suggested that there is hope for the future, even though hope is intangible it presents itself as a positive expectation for the future.

6.7 Implications for the Research

6.7.1 Implication for Mental Health Policy and Practice

The findings in this study highlighted the trends in mental health that are taking place nationally, within Europe and worldwide. The Institute for Health Metrics and Evaluation (IHME) provided estimates of the prevalence of a wide range of mental health disorders across all age groups based on a wide variety of data sources and a set of assumptions. According to the latest IHME estimates, more than one in six people across EU countries (17.3%) had a mental health problem in 2016 (Figure 13 on page 195) that is, nearly 84 million people, (OECD, 2018).

The most common mental disorder across EU countries is anxiety disorder, with an estimated 25 million people (or 5.4% of the population) living with anxiety disorders, followed by depressive disorders, which affect over 21 million people (or 4.5% of the population). An estimated 11 million people across EU countries (2.4%) have drug and alcohol use disorders. Severe mental illnesses such as bipolar disorders affect almost 5 million people (1.0% of the population), while schizophrenic disorders affect another estimated 1.5 million people (0.3%) (IHME, 2018). Notwithstanding, the OECD have reported that the COVID-19 crisis has had a "*marked impact on the* *mental health of both people with pre-existing mental health conditions and the general population"* (OECD, 2020, p. 65).

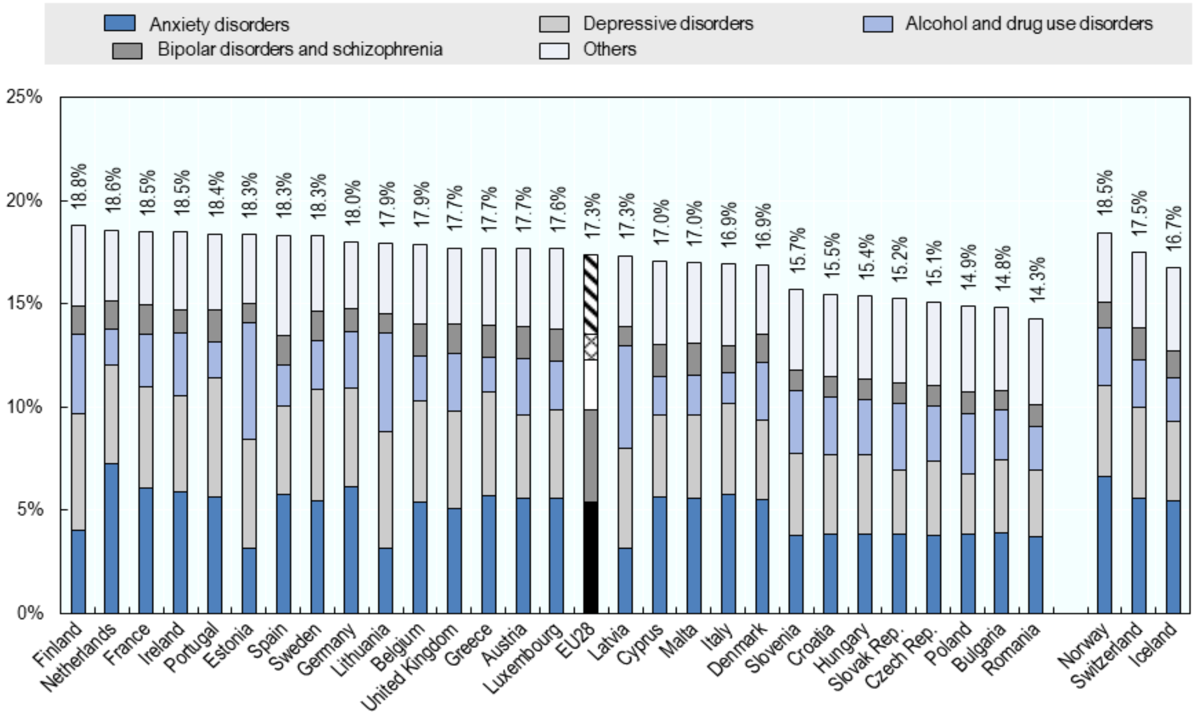


Figure 13: A graph showing the estimated prevalence of mental health disorders within the EU, (OECD, 2018).

The above information in the bar chart shows that the estimated prevalence of mental health disorders is highest in Finland, the Netherlands, France and Ireland (with rates of 18.5% or more of the population with at least one disorder), and lowest in Romania, Bulgaria and Poland (with rates of less than 15% of the population) (OECD, 2018). One of the areas highlighted in this research study is the co-existing drug use by the BME participants. There appeared to be a correlation with the statistics above and what this study revealed regarding drug use. Hence, the evidence found in this study is noteworthy when thinking about future practice.

Interestingly, the study by Di Forti *et al.* (2019) estimated that 30% of first-time cases of psychotic disorders in south London and half of those in Amsterdam, could be avoided if high-potency cannabis was not available. The authors suggested that this equated to about 60 fewer cases per year in south London. However, the biggest link between daily cannabis use and having a psychotic disorder was in Amsterdam, where the chances were 7 times higher than for those who never used the drug, (ibid, 2019).

In commenting on the research in the news, the lead author Dr Marta Di Forti from King's College London stated,

> *"If you are a psychologist like me who works in this catchment area and sees first-episode psychosis patients, this has a significant impact at the level of services and, I would also argue, family and society,"* (The Guardian, 2019).

The above remarks linked very much to what some of the participants (service users) in this study experienced. Participants, however found that the help they received from the drug and alcohol service and psychology greatly benefited them on their recovery journey.

It has been reported that several mental illnesses are more common amongst women, including anxiety, depressive and bipolar disorders. Some of these gender gaps may be due to a greater propensity of women to report these problems. However, one exception is drug and alcohol use disorders, which are more than two times more likely to occur in men than women on average across EU countries, (OECD, 2018). This study revealed what was reported by OECD (2018). For instance, out of the 24 BME participants, the six who reported using drugs were all male. Implications for this study served to reinforce the need for health promotion strategies to combat this trend and promote more healthy behaviours.

This study also focused on the use of medication. The BME participants had mixed views about medication. Some participants felt the medication helped them to get better and stay well, others suggested that medication did not help them at all. Nevertheless, most of the participants agreed that they experienced side effects from prescribed medication. This impacted on medication compliance which led to relapse and hospital admission. As medication is a significant part of service users' treatment, mental health professionals need to be observant and attentive to what service users have to say. One of those said side effect was weight gain. Luke (pseudonym), reported feeling embarrassed and ashamed of the amount of weight he gained while taking Olanzapine. Other authors have discussed side effects of second-generation antipsychotics in particular obesity, (Nash, 2014; Usher, Park and Foster, 2012). The study is significant as it supported the view that those with SMI require physical health checks coupled with a healthy diet regime.

The findings from this study revealed that the BME participants valued the support they received from the CC, Doctor and Mental Health Service. In a similar vein, Wyder, Bland and Compton (2013) explored the factors that facilitated or hindered recovery and contended that the central importance of relationships is shared humanity. They noted that healing was hindered where staff were distant, not caring, unreliable, demonstrated poor communication and listening skills, resulting in service users feeling sub-human, criminalised or infantilised. On the other hand, some service users felt respected, supported and secure; their confidence increased where staff were perceived as reliable, attentive, trustworthy, showing concern, interested in their progress and where they felt they were treated as a person and a fellow human being (Wyder, Bland and Compton, 2013, p. 578).

Perkins and Repper (2018) likened relationships as having hope, and contended that although relationships with mental health professionals might not be the most important in a person's life, but, relationships with friends, family, peers are vital to the well-being for everyone; because they can be mostly influential for good or ill. If the professionals whose responsibility it is to be help you, do not understand what you are experiencing, do not believe in your potentials, then hope is questionable, (Perkins and Repper, 2018, p. 109). The authors posed such an apt question which mental health professionals ought to consider.

In their research study, Wright *et al.* (2016) explored the nature of service users' involvement at the transition points of admission and discharge to an acute inpatient mental health ward. Analysis of the data collected found that despite the current rhetoric of recovery and involvement in policy and practice discourses, the service users' voice was lost at these key care delivery points. This was evident in the language used to describe what happened during care transitions and also the culture of the teams and organisations involved. Whilst they recognised that clinicians did not come to mental health care with the intention of working in this way, they felt that current organisational context had removed the compassion from clinicians' work. Perkins and Repper (2018) put forward similar views. Given the nursing and NHS values concerning the 6Cs (Cummings and Bennett, 2012) and the additional C being proposed from this study, the evidence in this study suggested that some of the BME participants felt that they did not participate fully in the CPA. Some also said that they had to wait a considerable period before they received specialist psychological input.

6.7.2 Implication for employment, police, and criminal justice system

Notably, the spending on the provision of mental health services is estimated to have accounted for about 13% of health spending across EU countries in 2015 (OECD, 2018). This is less than spending on circulatory diseases, the number one cause of mortality in the EU, but similar to spending on cancer care in many countries. Of the EUR 194 billion of direct health care spending on a broad range of mental health conditions across the EU spending reaches an estimated 1.4% of GDP in Germany and the United Kingdom. At the lower end, in addition to Luxembourg at 0.8% and Ireland at 0.9%, Lithuania, Bulgaria, Romania and the Slovak Republic are all estimated to have spent less than 1% of GDP on direct health care services for mental health (OECD, 2018).

Equally, expenditure on disability benefits accounted for the bulk of mental health-related social spending. It is estimated that mental health problems accounted for EUR 112 billion in disability benefits across the EU in 2015 (or 0.76% of GDP). Paid sick leave benefits related to mental health problems accounted for another EUR 28 billion (or 0.19% of GDP) in 2015, whereas unemployment insurance benefits were estimated to add another EUR 29 billion, (or 0.20% of GDP) (OECD, 2018). None of the participants in this study were in paid employment. Those who attempted to find work faced stigma and discrimination. The figures above suggested that if more is not done to try and enable service users to find suitable employment then the cost of providing and delivering mental health services will continue to increase.

Research carried out by the social exclusion unit found that the percentage of whole adult population who were in employment was 75%; people with physical health problems the figure was 65%; while people with SMI the figure was only 20% (Social Exclusion Unit, 2004). Brohan *et al.* (2010) contended that mental health discrimination is recognised as a problem, as many people with mental illness encountered unjustified restrictions in accessing and maintaining employment. Yet, Biggs *et al.* (2010) found that those suffering from depression to be associated with a stigma and being blamed for being emotionally weak or unproductive.

Earlier statistics showed that only 12% of people diagnosed with mental health problems were actively participating in the open labour market in the UK (ILO, 2000).

The scarcity of good jobs with decent pay for people with mental health needs played an important role in keeping them from attaining both economic independence and economic prosperity (Thornicroft 2006a, 2006b). To this end, Munizza *et al.* (2013) posited that in many countries there remains firm stigma associated with various mental health problems, and in some countries this stigma sits alongside a still widespread belief that it is better to simply avoid talking about mental illness.

The other area of discrimination experienced by the BME participants were from the police and criminal justice system. Given the police reports about having to deal with people diagnosed with mental illness on a regular basis, the need for education and training were crucial to the police, criminal justice system and ultimately the BME service users. Much has been written about discrimination experienced by service users with a diagnosed mental health problem. Hamilton *et al.* (2016) explained that their study was the first to explore in detail, accounts of discrimination across a variety of settings and different types of behaviour. They found it highlighted that lack of an expected level of support or understanding, whether by public services or social networks, is frequently experienced as discrimination.

The study showed how discriminatory behaviours impacted on individuals in different settings and demonstrated the difficulty people have in assessing whether a behaviour is discriminatory or not. The authors suggested that some of this could be viewed as poor customer care in mainstream society (Hamilton et al. 2016). I contend that discrimination is a deep-rooted behaviour displayed by one person to another, either as an organisation or individually which makes the other person feel devalued and powerless. Given the evidence and findings in this study, the need for education and training for the police on mental health issues are paramount and will be discussed further in chapter 7.

In October 2019 the NLMHT implemented a new team-Serenity Integrated Mentoring (SIM) which has been described as designed for High Intensity Service Users who are struggling to cope in the community. Those service users often end up being detained by the police under Section 136 of the Mental Health Act. It was suggested that whilst the first team is based in NLB2 it is hope following its success a team can be implemented in NLB1 and NLB3 (NLMHT, 2019, p. 7). It was noted that this multi-dimensional team, working intensively with the service users, agree upon care and response plans and, over time, gradually help prevent high intensity use of emergency services (NLMHT, 2019, p. 7). Notably, one of the hallmarks of this team is that police officers will be trained by mental health staff to equip them with the knowledge and skill to excise their role within the team (ibid, 2019).

6.8 Summary of chapter 6

Chapter six gave a discussion of the findings in this study. Six themes and subsequent subtheme were discussed in detail. The discussion was supported by published literature. Theme one was centred on BME participants need for support from mental health services. In terms of support the findings highlighted that housing was one of the main needs of the BME participants. The need for specialist services in particular psychology and drug and alcohol service were cited by the participants as their main needs. Other areas highlighted in this chapter was the need for support from the care coordinator and BME participants requiring information about their illness and treatment options.

The discussion regarding theme two sought to further explore the fact that the BME participants expressed their wish to find employment. The findings showed that whilst the BME participants would like to find work they faced stigma and discrimination. Additionally, the findings showed that the BME participants required extra support in returning to working. An example of a sheltered workshop was put forward by the BME participants. This chapter offer a discussion on the individual placement and support model (IPS) which seem to support the findings in this study. Theme three offered a discussion on recognising signs of relapse. It was noted that the BME participants learnt how to recognise that they are becoming unwell through their previous experience and knowing what their trigger factors are.

Notably, medication concordance was the subject of discussion in theme four. The discussion highlighted that BME participants viewed medication as a means of support. The participants noted that they experienced side effects from the prescribed medication. The experience of stigma and discrimination by the criminal justice system, police, employment, and wider society was further explored under theme five. The discussion led to a suggestion that a training need was required for the police to enhance their work with people who have a mental health problem. The chapter went on to discuss theme six and showed how BME participants spirituality and resilience helped in their recovery journey. The chapter ended with some implications for mental health policy and practice.

6.9 Reflection on Chapter 6

The term ‘support’ was highlighted by the participants as one of their main needs. I found the participants to be extremely specific in terms of the support they required. I was not at all surprised that the need for housing was seen as a means of support. That is because poor housing can exacerbate one’s mental health. Similarly, a person with mental illness can become homeless for various reasons. This reminds me of Ali, who had to be moved from his accommodation, following his agreement for a person who dealt in substance misuse to stay in his flat. It may well have been that due to his vulnerability, he was pressurised into letting the individual stay in his flat.

Housing was important for a multiplicity of reasons. As I reflected on one of the BME participant (Dominic’s) situation I pondered whether the mental health team acted in his best interest. Albeit, in an environment where mental health professionals claim to offer choice in decision-making for service users, on this occasion he was not happy about his living situation. However, when he explained the reasons why he was placed in residential care, I thought about the risk he posed to himself in that both his physical and mental health was being affected. His response seemed to show his resolve, that given time, he would need the input of the residential care staff. All things considered, it would seem that the mental health team acted in the best interest of the participant.

A further area of support was the help the participants received from their CC and the Mental Health Team. However, it was the CC that featured more times in their responses about their needs. This suggested to me the value that the participants placed on their interaction with their CC. It was interesting to note in the study by Grundy *et al.* (2016) on page 157 regarding care planning in secondary mental health services, that the emergent theme was clinician-user relationship. This study has drawn similarities with the study by Grundy *et al.* (2016) as what the participants talked about resemble features of a therapeutic relationship.

The other issue that was evident through the discussion in chapter 6 was about sharing information with service users. In particular, information about their illness and medication. Whilst it was satisfying to be informed that all the participants knew what their diagnosis was, it was disheartening to know some participants had a misunderstanding of what schizophrenia was. What was more disturbing was the fact that one participant explained her fears of divulging that she had a diagnosis of schizophrenia due to societal preconceptions. Sadly, I believe the media plays a huge role in fuelling the negative perception of people with mental illness particularly schizophrenia.

In addition to the negative media portrayal, many service users faced being stigmatised in various settings including within their communities, and the wider public. Unfortunately, this stigmatisation continues and affect the participants' attempts to find work. I am unequivocal in my belief that employers can do more to support service users to return to work or find employment. Economically, it will enable service users to earn a fair wage rather than relying on benefits. The fact that someone is going out to work would also boost one's self-esteem.

Taking prescribed medication has been a long-standing issue in the treatment of mental illness. Whilst there are known benefits in taking prescribed medication, some service users experienced side effects of prescribe medication which they report is quite debilitating. This has led professionals to suggest ways of improving compliance through terms such as therapeutic alliance, concordance, adherence, or compliance. Whilst all these terms are useful, it is about hearing from the service user what side effects they are experiencing and the psychiatrist to make the appropriate adjustment or changes to the prescribed medication.

One of the side effects experienced by some of the participants in this study was weight gain. I was intrigued by the participants in Usher, Park and Foster (2012) study stating that they would stop medication as a strategy to lose weight. As discussed, poor compliance with prescribed medication can allow for worsening symptoms to occur. This opens a wider discussion into the risks service users would undertake to avoid the adverse side-effects of their medication. To help combat this situation, the continued use of physical health checks is of absolute importance as part of the service users' care.

A further area of reflection was regarding theme six - hope. The participants demonstrated hope and aspirations for the future. Those aspirations were supported by the participants' spiritual belief and their resilience. The participants talked about concepts such as hope and faith. Most of the participants found that their spiritual belief to be a strength which is in keeping with the recovery approach.

Reflecting on some of the implications for practice, it is reasonable to suggest that health promotion strategies should continue within mental health to promote healthy behaviours. This is because of the wide range of mental health disorders prevalent in the United Kingdom and worldwide. On reflection, the BME participants who talked about their co-existing drug use seemed unaware of the ill effects of substance abuse on their mental health. For that reason, mental health professionals need to engage them in more healthy behaviours.

A further area of reflection was to do with the stigma and discrimination faced by the participants in the study. The participants talked vividly about the experiences in gaining and maintaining employment. They also discussed the stigma and discrimination experienced through their encounters with the police and criminal justice system. What the participants highlighted is not dissimilar to what has been found by other authors including the most recent report on the review of the Mental Health Act (Department of Health, 2018).

The participants were equally concerned about the negative portrayal in the media and how having a diagnosis made them vulnerable. In thinking about this situation, I suspect it must also be a frightening experience for the participants as they might believe that they may experience prejudice fuelled abuse. Consequently, participants may become fearful to go outside which could compound symptoms of the illness.

7.0 Chapter 7: Conclusion and recommendations

7.1 Conclusion

This study has shown that the aims and objectives as set out in chapter two have been met. In answer to my research question which is: do service users from a BME background perceive that their needs are being met within the Mental Health Trust? The views of twenty-four BME service users were sought using semi structured interviews. The findings of this study showed that the concept of need was explored. A discussion regarding the participants' views on their perception as to whether their needs were being met occurred within the study. The participants described what their needs were and how those were being met. Also, in addressing the research question a literature review was carried out which highlighted some research studies regarding BME populations and access to care.

Hence, it would be incumbent that when a needs assessment is carried out in the Trust, the areas highlighted in the findings of this study would need to be taken into consideration. The findings showed that the needs of the BME participants were met to some extent. For example, all the participants emphasised the value in meeting with their CC. However, on issues such as housing, specialist services and medication the BME participants stated that they needed further support.

Housing or accommodation was a need for various reasons. There were those who wanted to live independently and were not happy that they were placed in more supported accommodation. For some, the issue concerned their safety and for others it was their protection from further discrimination by the wider public. Similarly, the need for further help and support regarding medication was highlighted in this study. It transpired that more information was required regarding prescribed medication. A number of the participants expressed that they experienced side effects and required more information about other medication, with hopefully fewer side effects.

In particular, some of the BME participants experienced weight gain while on psychotropic medication. They anticipated that what they needed was a mixture of diet, exercise, and a change in their medication. This had been noted in government policy parity of esteem (Department of Health, 2012c, p. 2). However, there was also a recognition by the BME participants that medication had a major part to play in their recovery. Several were able to recall instances where they had stopped taking prescribed medication which led to a hospital admission.

All the participants understood the term CPA, but not all participants believed that they were involved in the process. One participant described her CPA review meetings as *‘being spoken at rather than speaking with* her’. Hence, it could be argued that further work in the practice of CPA meetings was needed to ensure participants experience better involvement in the process. Closer examination of the findings showed that the BME participants placed a huge emphasis on their spiritual belief. They spoke about their hope for the future and had faith that they would recover from the mental illness. However, the BME participants also believed that their spiritual belief and medication needed to go side by side as they placed equal importance in both. Research has shown that culturally spiritual beliefs feature quite highly within the BME community (Tuffour, 2020; Hays and Aranda, 2016; Keefe *et al.* 2016). Hence, the findings in this study are noteworthy for mental health practitioners and other staff in the health and social care sector.

The findings showed that all the BME participants knew what their diagnosis was as identified in figure 6 on page 108. However, there was some misunderstanding of the term schizophrenia. One participant said that it was a strange name to give an illness and associated it with the negative portrayal in the media. Additionally, the need for psychology as a specialist service was also highlighted in the findings of this study. Some of the BME participants stated that they had to wait for varying lengths of time before they were offered a psychological service. At least two of the participants mentioned that if they were offered psychological support instead of medication, they believe they would have benefited from it.

The evidence in this study suggested that whilst the BME participants would like to work they experienced difficulties in seeking employment. The participants experienced discrimination and stigma. One of the participants found employers would not respond to her application once she disclosed, she had a mental illness. In addition to discrimination and stigma some participants cited side effects of medication as a cause that kept them from being in employment.

A number of the participants said that they experienced drowsiness and lethargy which made their concentration span difficult. Some participants recognised that they were not ready to return to work hence needed to concentrate on doing activities such as going to the gym, having music lessons, or attending a sheltered workshop. Those areas of interest were seen as a less demanding and would help *‘ease’* them back into employment when they felt ready.

This study also considered service users’ experiences and whether the participants felt discriminated against when being cared for in the Mental Health Trust. Although they did not express any negative views about the Mental Health Service, the participants suggested that the discrimination they faced came from the police, criminal justice system, employers, and the public at large. One participant who had been given a police caution some years earlier found that it impacted on her ability to find work as the DBS checks would show she has a criminal record.

Over the past years, many research studies have taken place regarding the causes of mental illness and the best treatments available to treat the illness. However, there is still much work to be done to bring mental health on a similar level as physical health. In that there will be an acceptance of the individuals’ experience of mental illness and the availability and accessibility of appropriate resources. Indeed, such evidence of these issues are thought provoking, and consequently this raises the question why is this so? How have we come to be (population as a whole and mental health professionals) more accepting of a physical complaint or illness and not a mental illness?

Could it be that physical illness is more visible, hence more treatable while mental illness is more a subjective experience which might make it more incomprehensible? It is however encouraging to note that in 2018, the Centre for Mental Health set up a new Commission to investigate inequalities in mental health and produce recommendations to bring about system change for equality. The Commission for Equality in Mental Health intended to take evidence during 2019 from people and organisations about their knowledge, experience and understanding of mental health inequalities and what can be done at every level to reduce them, (Centre for Mental Health, 2019).

The Commission identified three key areas of interest namely:

1. Addressing the social, economic, and political determinants of mental health.
2. Ensuring equal access to support for mental health.
3. Improving quality and outcomes from mental health support (Centre for Mental Health, 2019).

It is worth noting that the findings by authors such as Islam, Rabiee and Singh (2015) were not dissimilar to what has been presented in this research study. Those authors reported that BME service users and carers wanted good care from skilled, experienced and culturally informed clinicians and services. To this end, BME service users should expect to receive care that is based on their specific mental health needs. That the care they receive is geared to meet their cultural and spiritual needs. This has been highlighted in this study as an important aspect of what BME service users' need. The participants also placed equal importance on the role of the CC and how this has helped in their mental health journey.

The problems and challenges associated with ethnicity and mental health are complex, therefore they need to be explored fully in order to make a difference to those who have a diagnosed mental illness. It is hoped that this study has helped to understand some of these complex issues, and consequently help to inform and change the practise of mental health professionals. I have employed ethical principles and ensured that all the service users who consented to participate, agreed that their rights and privacy were respected throughout this process. I considered the theoretical perspectives of the design to ensure that I have applied the appropriate strategies to plan, develop and carry out this research project.

The themes identified suggested a number of areas in which the participants needed help. Taking that into consideration, the implications for practice and the need for further research, were key aspects in the findings as they are relevant to Mental Health Staff, policy makers, stakeholders, voluntary and spiritual organisations.

7.2 Recommendations

The findings in this study showed that BME service users experience stigma from the wider public. They also experience discrimination by the police, criminal justice system and employers. In order to eliminate discrimination, the Mental Health Trust set out key objectives as discussed in chapter 1. A key objective was to continue early intervention and prevention services and improve access to the range of services that service users need. Therefore, taking a public health approach would help with the education of the police about mental illness.

Although some of the BME participants experienced stigma and discrimination from the wider society, the participants indicated through this study that it is the discrimination they experienced by the police, criminal justice system and employment that seem to affect their lives the most. Also, given the fact that the police themselves reported that increasingly they come in contact with people experiencing a mental illness, it was necessary for the police to demonstrate appropriate expertise to exercise their duties in a confident and efficient manner. The outcome should be an improvement in practice as people with mental illness will be channelled to the appropriate service to meet their needs at that given time. A model of training such as the Crisis Intervention Team (CIT) model as described below could be implemented.

7.2.1 Training programme for the police to enhance skills when dealing with someone with a SMI.

The BME participants experienced discriminated by the police, criminal justice system and employers; for this reason a training programme as seen in appendix 15 to support police officers in each borough, to enhance their expertise when dealing with people who present with a mental illness should be provided by mental health professionals from the local Trust. Such training would offer an agenda for workforce planning in collaboration with the police service and the Mental Health Trust. This training could also be adapted and delivered to ambulance staff and fire officers, as well as local employers in video format.

Bratina *et al.* (2018) conducted a research study which examined characteristics and outcomes of encounters between citizens experiencing mental health-related

crises and Crisis Intervention Team (CIT) trained patrol officers. Findings from this study indicated encounters involving persons with mental illness (PwMI) and CIT trained officers often result in diversion to mental health services. The Crisis Intervention Team (CIT) model is an established training program used to improve police response to encounters involving persons with mental illness (PwMI). Diversion of PwMI from the criminal justice system to appropriate treatment providers in the community is one of the primary goals of the CIT.
In conjunction with policing in general, recent police encounters with citizens in crisis have gained the attention of criminal justice and mental health practitioners, criminologists and the media.

As a response to interactions involving persons with mental illness (PwMI) and the criminal justice system local jurisdictions in the United States and other countries have implemented specialised training programs to de-escalate crisis and divert PwMI to treatment services (Slate, Buffington-Vollum and Johnson, 2013). The CIT model was designed to improve police response to PwMI. It is the most widely adopted specialised police-based training program in the United States (Gostomski, 2012). It was also implemented in Australia, Liberia, New Zealand, Canada, and the United Kingdom (Kane, Evans and Shokraneh, 2017; Kohrt et al. 2015; NSW Police Force, 2014, Hartford, Carey and Mendonca, 2006).

According to Bratina *et al.* (2018) the CIT model was originally conceived in the aftermath of a 1987 incident in Memphis, Tennessee that resulted in Joseph Dewayne Robinson – a man with a history of mental illness and substance abuse issues – being fatally shot during a crisis encounter. When police arrived at the scene, Robinson was wielding a knife and seemed to be cutting himself. After failing to desist him and release the weapon, Robinson allegedly began to approach police and was subsequently shot eight times (Heilbrun *et al.* 2012). In response, a community task force comprised of law enforcement, community mental health providers, addiction professionals, and consumer advocates were established. The members collaborated and designed the CIT model (Heilbrun *et al.* 2012, Watson *et al.* 2011).

Therefore, a planned five-day training course (illustrated in appendix 15) (Bratina *et al*. 2018), needed to be agreed with the police and workforce development in the

Trust. The above evidence supports the view that a training programme for the police will help to meet the needs of those who have a diagnosed mental illness. It is hoped that the sessions on culture and diversity will help address and build bridges for the BME service users and BME communities.

7.2.2 Mental Health Professionals to continue to challenge discrimination through campaigns, video, leaflets.

In keeping with the recommendation above the participants talked about the stigma they faced by their families and the general public. This suggests that further work is needed to inform and raise awareness amongst the public. Hence, mental health professionals should continue to challenge discrimination by organising campaigns. This could be done in various forms, such as providing mental health open days in the community and issuing leaflets on mental health conditions. Service users can be invited to participate voluntarily in planning, and, during presentation on the day they can share their lived experiences. These open days can be held on a yearly basis in an attempt to engage as much of the community as possible. For example, initially in NLB1, followed by NLB2 then NLB3. In addition, other boroughs in the wider community should be invited so that they could benefit through shared information.

7.2.3 Recommendation to the Chief Nursing Officer and the Nursing and Midwifery Council regarding implementation of the 7th C.

One of the concepts highlighted in this study was Consistency in care. Consistency can be viewed on a number of levels. Consistency begins with the therapeutic relationship that service users build with a mental health professionals. The basis of that relationship can determine the path service users might take in their engagement with mental health services. If service users find acceptance, warmth, and a non-judgemental attitude towards them, it is highly likely that they will engage with the treatment that is being proposed. In contrast, if service users experience negative attitudes for example, being judgemental and dismissive of what the service users were experiencing then the likelihood of them engaging with the professionals and other services will be greatly reduced.

Newman *et al.* (2015) conducted an integrative literature review to identify mental health service users' experiences of the use of mental health services. The main finding from this review suggested that while people may express satisfaction with mental health services, there are still issues around three main themes: acknowledging a mental health problem and seeking help; building relationships through participation and care and working towards continuity of care. These findings have been supported with the findings of this research which provides stronger impact.

Consistency in care also reduces the need for repetition. When service users come in contact with the Mental Health Services an initial assessment will be carried out to establish specifically their presenting complaint and how best to manage and treat through a planned programme of care. It is likely that service users would be allocated a CC, who would then co-ordinate their care by accessing a range of services to support them. However, if there is a high turnover of staff it is likely that service users might find it difficult to engage with different CCs, hence possible disengagement with services.

Arguably, if there is Consistency in the 6Cs Care, Communication, Compassion, Courage, Commitment, and Competence that service users will experience a health service which operate at a high standard, delivering care that is timely, skilled and efficient. Likewise, the application of the 6Cs in nursing have greatly improved practice in healthcare in the UK since it was introduced in 2012. Additionally, the term *Consistency* highlighted in this study is the reason why the researcher is proposing the addition of this term as a 7th C, as seen in table 8 below.

Table 8: Consistency as a new term to be added to the 6Cs

7th C	6 Cs
Consistency	In care
Consistency	In communication
Consistency	In showing compassion
Consistency	In having courage
Consistency	In commitment
Consistency	In competence

7.2.4 Transformative approach in the negotiation and regular review of the Care planning process.

It was noted in the findings of this research that some BME participants put on a significant amount of weight while on psychotropic medication. This suggests that more needs to be done to ensure the best treatment options are made available to the service users. Equally, in describing their experience of attending CPA meetings one of the participants described *“being talked at*” rather than having a discussion with her. Given the transactional nature of the above experience it would be fitting to suggest a more transformative approach including a pathway to well-being (mental, medication, and physical in the form of exercise/movement) to care planning where the service user’s input is valued.

7.3 Contribution to practice

The research study allowed for the authentic voice of BME service users to be heard. I believe that much can be learned in practice from the evidence presented for all service user groups and for the four groups in this study. Literary sources suggest that BME service users have encountered difficulties in accessing and utilising mental health services and explained institutional racism as a reason (Halvorsrud *et al.* 2018; Davie, 2014; Mallinger and Lamberti, 2010). Other authors suggested there was a misunderstanding of cultural needs of BME service users. Those authors suggested that what BME service users want is not specific BME services but to be cared for by skilled, competent staff (Islam, Rabiee and Singh, 2015; Rabiee and Smith, 2014).

This ideology is in keeping with government policy, regulatory bodies such as the Nursing and Midwifery Council, (NMC) General Medical Council (GMC) and professional bodies such as the Royal College of Nursing (RCN) and the Royal College of Psychiatrists (RCPSYCH). It was suggested that apart from mental health staff being culturally competent they need to be spiritually competent as well (Islam, Rabiee and Singh, 2015). One of the lessons learnt in this study is the importance of religious and spiritual practices within the BME community. It appeared that several of the participants either attended a place of worship or believed in a spiritual being, either God or Allah. They stated that having Faith in a spiritual being gave them Hope for the future. Some participants attributed that being guided by a spiritual source made them change behaviours such as smoking and misuse of drugs. One of the BME participants explained that he kept away from being among other worshippers as he did not feel worthy to be there because of his habit (substance misuse) which went against the spiritual teachings.

However, when he was able to change or stop the misuse of drugs, he found peace within himself and was grateful to Allah for giving him such peace. This in turn allowed him to build his Faith which gave him Hope for the future. Given the fact that Spirituality featured as one of the themes in this study it should be incumbent on Mental Health Staff to integrate this in their practice. In doing so it would allow for a greater partnership working with BME service users. Ledger and Bowler (2013) found that training on Spirituality can help mental health professionals meet patients' spiritual needs by increasing their confidence in addressing the subject.

The evidence in this study suggested that the participants encountered socio-cultural experiences including stigma and discrimination in areas such as the employment, in the wider society, by the police and criminal justice system. This is not dissimilar to what has been found by other authors including (Department of Health, 2018). Hence, a lesson learnt is the need for mental health professionals to challenge discrimination within mental health practice and the wider society.

In addition to Faith and Hope, the concept of resilience was also shown in this study. Living with SMI impacts every area of one’s life. Yet, through all this the participants made plans and effectively kept a positive outlook on life. One of the areas was their desire to get back into work. Even if they had experienced discrimination it had not deterred them from having this as one of their goals. An implication for practice is to have facilities that will help address this situation. One of the participants suggested that a service that bridges the gap between hospital and work in the open market would be a valuable resource. This suggested that the implementation of sheltered workshops to assist those with SMI to obtain or return to work would be of great benefit to mental health service users.

A further lesson learnt in this study was about the beliefs surrounding the causal effects of mental illness. One of the BME participants who experienced visual and olfactory hallucinations believed that they were caused by witchcraft and that medication was not going to help him as he did not think he had an illness. Hence, in practice mental health professionals to continue to maintain cultural competence and work with service users to establish the best outcomes in their care and treatment.

Further examination of the findings suggested that the participants placed a huge emphasis on the CC role. All the participants spoke highly of the support they received from the CC. Other authors, (Lennard, 2012; Department of Health, 2005b), emphasised that the role of the CC is crucial within the CPA. Whilst this study did not allow for the exploration of the role of the CC, I am led to believe that further research is needed in this area. Equally, the use of workload tools should be routine in practice to measure what the CC does ensuring fair distribution of workload.

Further implication for practice is about sharing information with service users. Whilst BME service users would welcome this means of support it would also be of benefit to all service user groups. This would involve spending time with service users to explain their diagnosis and mode of treatment or treatment plan. One of the BME participants questioned whether schizophrenia was a disease and wondered if it *'could be caught from one person to another'.* The participant also pondered and suggested that it was a strange name to give to an illness. The BME participant also identified with the negative views portrayed in the media about mental illness and because of that she revealed that she *'don't talk about her illness to anyone unless it is a mental health professional'* who she believes understand what she is going through.

Another reason for giving information concerned taking prescribed medication. The participants expressed their views about taking prescribed medication. Several of the participants talked about stopping their medication because of the side effects they experienced. Those side effects range from weight gain, feeling drowsy and lethargic and feeling slowed them down in doing daily activities.

Mental health professionals need to spend time explaining to service users about their diagnosis and treatment. It may be that service users might be in an acute state on admission into hospital therefore, the mental health staff would need to repeat the information given regarding the service user's illness and treatment at a later date when s/he is more settled. Equally health professionals should actively listen to what the service user has to say about the medication they have been prescribed. If service users perceive that they are not being heard, then it is likely that they will stop taking the medication which could lead to non-adherence to their treatment plan. There may be times that a mental health professional may not have the time during their span of duty to revisit the information given to service users. The expectation is that they would handover adequately to the oncoming shift and record in the service user's notes what was done.

The evidence in this study suggested that the BME service users experience was that they were offered medication rather than psychological input. The participants spoke of the value they received from having psychological intervention and contended that it should have been offered to them as a treatment option rather the use of medication. The participants also discussed the length of time it took to be seen by a Psychologist which they felt impacted on their recovery.

Hence following initial assessment of service users, it would be incumbent on the mental health professionals to ensure that service user were given information about the range of treatments available as well as appropriate support and guidance, so that they can make an informed choice which would enhance participation in their care. Equally having access to an advocate to support the service users in making decisions about their care. Whilst advocacy would be a valuable resource to all service user groups, specific to the four black groups studied culturally appropriate advocacy would be of absolute importance.

7.4 Limitations of the study

A limitation in this study was the concept of insider researcher which came to the fore, as I was in a senior role in the Trust and was mindful of the fact that I had to follow all the appropriate steps to carry out this study, from accessing service users as participants to conducting the semi structured interviews. In addition, as an employee and a mental health nurse the participants could have viewed me as a CC rather than a researcher. That was evident when one of the participants asked whether my meeting with him would be on a regularly occurrence. I explained what my role was as part of the research study. Whilst the objective of the research study was to elucidate information from BME service users about their experience, I was mindful that the participants could have viewed me as part of *'the system'* and felt obliged to say what they thought was appropriate especially on sensitive issues such as race and culture.

The participants were from a Black African, Black Caribbean, Black British and Black mixed race. Hence, the views expressed in this study should be ascribed to these groups and should be interpreted with attention being paid when applied to other ethnic groups not represented in this research. However, there were lessons learnt from this study which can be attributed to all service user groups and have been discussed in the previous section. It is evident that the participants placed a huge emphasis on their spiritual beliefs. It would have been useful to hear the views of staff caring for the mental health service users on how they incorporate the spiritual views of service users’ in their care. As the remit of this study did not include the views of staff, it is suggested that further research is necessary to ascertain mental health professionals’ perspective concerning how they incorporate service user’s spiritual needs in their care.

The role of the carer is central in the CPA. Government policy outlined that a carer is entitled to a needs assessment when caring for someone with a physical or mental disability due to the many demands the caring role places upon them. This study highlighted that not only did carers play a vital role in recognising relapse indicators they were also seen by the BME participants as a means of support. As the researcher, I pondered on the importance of social networks and the damaging effects of breakdown in families. Some of the BME participants highlighted that they stayed away from their family because they were ashamed and embarrassed by their illness. Undoubtedly, stigma in mental health has a great bearing on how an individual respond when they have been diagnosed with Schizophrenia or Paranoid Schizophrenia. The thoughts of Perkins and Repper (2018) have been highlighted on this issue earlier in this chapter.

Although social issues such as housing was discussed as a need for support it was not possible to explore the role of the carer as the remit of this study would become much wider. However, NICE recommended that mental health professionals need to adopt a collaborative method, that supports both service users and carers. A respect for their individual needs and interdependence would also be require, (NICE, 2014, p.13). NICE (2014) recommended that carers’ assessment must be offered by Mental Health Services allowing carers to express their needs and at the same time highlighting their strengths and views. Subsequently, formulate a care plan to address any identified needs, give a copy to the carer and to their GP, and guarantee an annually review. A carer-focused education and support programme should be made available, which may be part of a family intervention for psychosis and schizophrenia as early as possible to all carers. The intervention should be obtainable and have a positive message about recovery (NICE, 2014, p.13).

7.5 Dissemination Strategy

The dissemination of this study will include**:**

- Presentation of the findings at the Mental Health Trust Nursing Conference/Clinical Governance/ Team Leader Day.
- Writing with my supervisors and possible publication in Mental Health Journals.
- The findings of this study to be made available to the Mental Health Liaison Team, within the police service and within the boroughs of NLB1, NLB2 and NLB3.
- Possible implementation of the 7th C via liaison with the Chief Nursing Officer
- Possible implementation of the 7th C via liaison with the Nursing and Midwifery Council.
- Uploading findings onto the Middlesex University research repository where it would be accessible to other researchers to inform practice.

7.6 Summary of Chapter 7

Chapter 7 gives a conclusion on my understanding of the evidence drawn out in this research study. It has also discussed some recommendations for future practice.

This chapter also highlighted other contributions to practice noting how it would support health professionals, employer's, policy makers and the general public. Additionally, lessons learned to support service users with a diagnosed mental health problem have been discussed in this chapter. Lessons learned that were specific to the four BME groups in this study was also emphasised.

In this chapter I was able to discuss the limitations to the study and showed how as a Trust employee I needed to consider my role as insider researcher to ensure that I maintained credibility throughout the research study.

7.7 Reflection on Chapter 7

As I reflect on the value the participants placed on meeting with their CC, it reminded me of the time when I worked as a CC. I found while working as a CC there were areas such as time spent building a therapeutic relationship with service users and their family, building relationships with other professionals on behalf of the service users and those intangible soft skills that are very individualised become rather difficult to measure. Hence, whilst workload tools will measure and quantify time spent on travel, phone calls, meetings and home visits, it is not possible to measure the CCs' attributes during those interactions. It is those specific soft skills that determined what we convey to the service users we interact with and as such influence service users' responses as to whether they will engage with the service.

As I reflected on the participants experience during their mental health journey, they reported that they experienced stigma and discrimination by employers, police, criminal justice system and the wider public. Having listened to the stories of the twenty-four participants I believed that stigma in mental health continues to be a deep-rooted phenomenon even in 21st century Britain and worldwide. It was interesting to note that the police are being trained in mental health by staff in the NLMHT in the management of High Intensity Service users as discussed on page 200. It is hoped that the training of the police proposed in this study will go some way in the management of BME service users.

7.7.1 Final thoughts on professional journey and personal learning

Upon starting the doctorate programme in 2008 I was filled with excitement in the knowledge that I would complete this challenging programme. Firstly, I was curious to find out what the results of the research project would be and the knowledge it would add to my field of practice - Mental Health Nursing. As I reflect on the past years, completing the research project has been a challenge but also it helped me grow as an individual and professional. One of the challenges I faced was that I tried to balance a full-time job as the Lead Nurse for Education and Practice Development and at the same time meeting the demands of the study. Two years later I was appointed into a more senior role as Assistant Director for Safeguarding Adults. During that time balancing the two commitments was proving rather onerous, however, I continued to be focused. I was able to complete all the paperwork required to seek ethical approval to conduct the research project. Once ethical approval was granted, I embarked on the journey of recruiting participants to take part in this study as described in chapter four. I owe my greatest gratitude to the participants for taking part in this study.

In my previous roles as a Registered Mental Health Nurse I had the opportunity to work with student nurses in the development of their nursing skills in practice. With the desire to continue in learning and development, I was appointed in a role as Senior Lecturer in Mental Health Nursing at a higher education institution (HEI). In that role I faced a new set of challenges including that of being a module leader and teaching on other modules. For the first six months in the job the work required for the doctorate was put on hold as I became more familiar with the new role. During that time, I was conscious of the fact that I needed to transcribe and make sense of the data I had collected. When I finally started transcription of the tapes, it took several weeks but I continued as I was determined to complete this part of the journey.

Once the transcription and analysis of the data was completed, I embarked on the journey of writing up. This was a poignant moment for me as I felt that all the facets of this project will now be pulled together. I soon realised the mammoth task I had ahead of me and with the guidance of my supervisors I carried on making progress. The progress I had made was put on hold in the autumn of 2015 when I received an unfavourable diagnosis regarding my physical health. Following surgery and many months of treatment I was unable to complete work for the research project.

After a three-year break, I was able to resume the writing up. What I have learnt about myself through this journey is invaluable. I would describe myself as having the tenacity to carry on even in the face of adversity. To this end, my willingness to learn and develop kept me focused.

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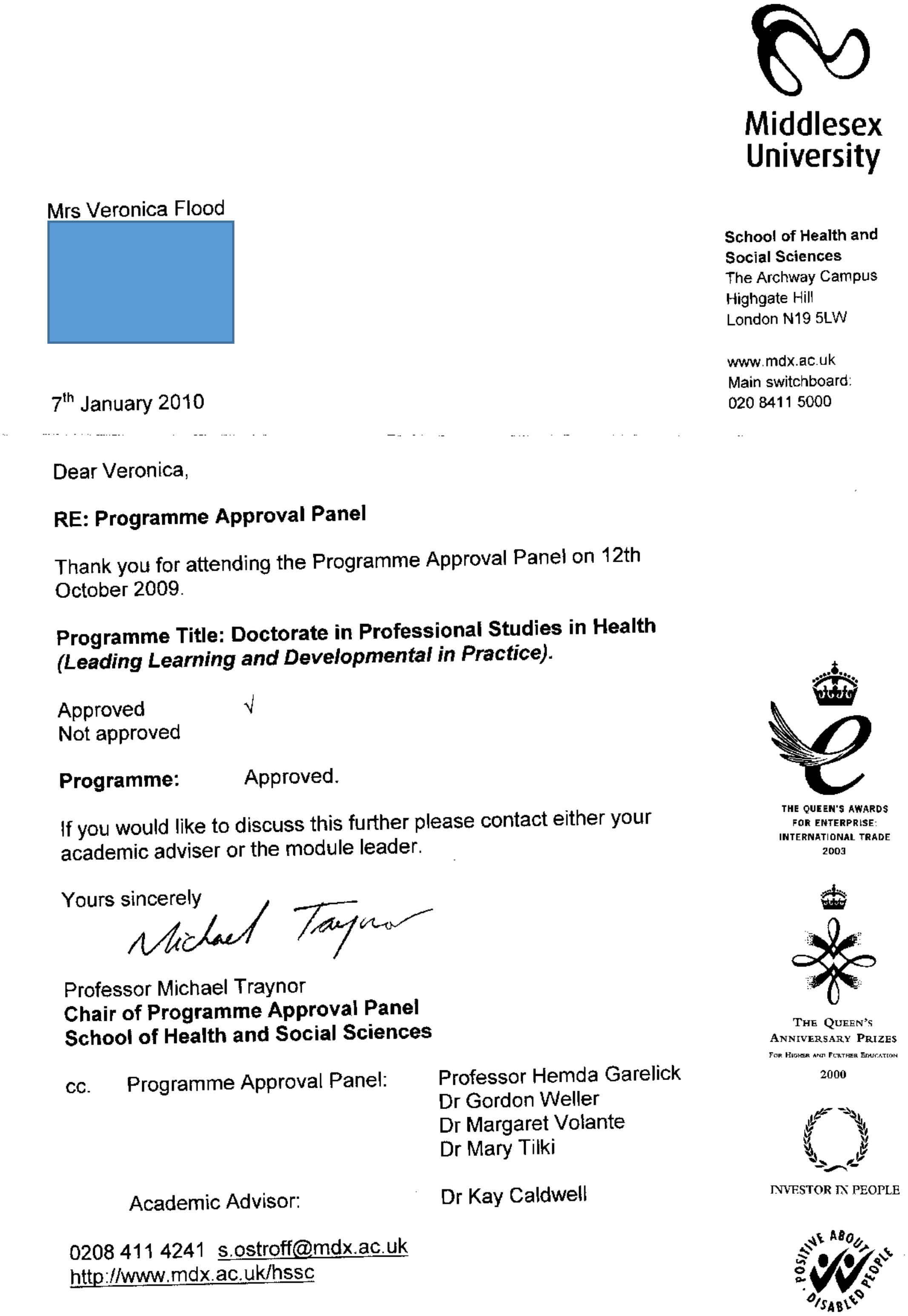
9.0 Appendices

Appendix 1: Programme Approval Panel Letter



Middlesex University

School of Health and Social Sciences
The Archway Campus
Highgate Hill
London N19 5LW

www.mdx.ac.uk
Main switchboard:
020 8411 5000

Mrs Veronica Flood
[redacted]

7th January 2010

Dear Veronica,

RE: Programme Approval Panel

Thank you for attending the Programme Approval Panel on 12th October 2009.

Programme Title: Doctorate in Professional Studies in Health *(Leading Learning and Developmental in Practice).*

Approved √
Not approved

Programme: Approved.

If you would like to discuss this further please contact either your academic adviser or the module leader.

Yours sincerely
Michael Traynor

Professor Michael Traynor
Chair of Programme Approval Panel
School of Health and Social Sciences

cc.	Programme Approval Panel:	Professor Hemda Garelick Dr Gordon Weller Dr Margaret Volante Dr Mary Tilki
	Academic Advisor:	Dr Kay Caldwell

0208 411 4241 s.ostroff@mdx.ac.uk
http://www.mdx.ac.uk/hssc

THE QUEEN'S AWARDS FOR ENTERPRISE: INTERNATIONAL TRADE 2003

THE QUEEN'S ANNIVERSARY PRIZES FOR HIGHER AND FURTHER EDUCATION 2000

INVESTOR IN PEOPLE

POSITIVE ABOUT DISABLED PEOPLE

Appendix 2: Consent Form

NHS
Mental Health NHS Trust

CONSENT FORM

Study title: An investigation of Black Ethnic Minorities Service Users' perception of their needs within North London Mental Health NHS Trust.

Name of Researcher: Veronica Flood

Please Initial Box

1. I confirm that I have read and understand the information sheet dated……………….for the above study and have the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal right being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study may be look at by the chief investigator for BEHMHT, where it is relevant in my taking part in this research. I give permission for the chief researcher to access my record. ☐

4. I confirm that I have been in receipt of mental health services for 1 year and more and have a recognised mental illness ☐

5. I agree to my GP being contacted of my participation in the study ☐

6. I agree to take part in the above study. ☐

Name of participant Date Signature

Appendix 3: Participant Information Sheet

NHS

Mental Health NHS Trust

1. Study Title

An investigation of Black Ethnic Minorities Service Users' perception of their needs within North London Mental Health Trust.

2. Invitation paragraph

I would like to invite you to take part in this research study. Before you decide I like you to understand why the research is being done and what it would involve for you. Your care co-ordinator will go through the information sheet with you and answer any questions you have. Ask your Care Co-ordinator if there is anything that is not clear.

3. What is the purpose of this study?

The purpose of this study is to collect your views on:
Your experience while you have been in receipt of mental health support from North London Mental Health NHS Trust (NLMHT)

- Your journey of recovery
- The areas of support that has helped you get better
- What has helped you maintain your health and wellbeing

4. Why have I been invited?

You have been approached as you have been in receipt of mental health support from North London Mental Health Trust for at least a year and you are considered as having a BME. Background

5. Do I have to take part?

Taking part in this research is entirely voluntary. The researcher will ensure your willingness to participate has been established through you completing a consent form before any information is collected. I would like to emphasise that taking part in this study is part of a research project and not a therapeutic intervention. If you decide now or at a later stage that you do not want to take part, this is your right and will not affect present or future care you receive from the Trust.

6. What will happen to me if I take part?

You will be sent a letter and telephoned to invite you to meet with the researcher at a time that is convenient to you. The researcher will ask you a few questions about your experience of receiving care in the Trust. This will last for 30-45 minutes**.**

7. Expenses and payments

Those who contribute to studies like this should be rewarded for sharing their experiences. In accordance to government guidance on this, a payment of £10 will be paid for taking part in the interview. In addition, other expenses such as travel cost you might have in coming to attend the interview.

8. What are the possible disadvantages and risk of taking part?

There are no know known risk or harm in taking part in this study and the care you receive will not be compromise in any way.

9. What are the possible benefits of taking part?

The information received from participants will help to make the necessary changes or additions to the care and practice in the Trust.

10. What if I have a complaint about this study?

Should you wish to make a complaint about the conduct of this research you may contact me the principal researcher, Veronica Flood, or Dr Kay Caldwell. Our contact details are detailed below.

11. Will my taking part in this study be kept confidential?

All the information collected about you during the course of the research will be strictly confidential. Any information that might identify you will be changed or made anonymous. The information you give will be used only for this study. The only exception where a breach of confidentiality might be required is if there are issues around child protection, where there are signs of significant distress, where there are signs of relapse, where you as a participant indicate that you are unwell and the support that you need is not available within a research study and where there is clear evidence you pose a risk to yourself or others

13. Involvement of the General Practitioner/family doctor (GP) Contacting my GP

The researcher will let your GP know of your participation in this study.

14. Who is organising and funding the research

This study is sponsored by NLMHT and is part of a doctorate programme at Middlesex University

15. Who has reviewed this proposed study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interest. This study has been reviewed and given favourable opinion by the Camden Research Ethic Committee

16. What happens if I become distressed or unwell?

If you become distressed or unwell, I would stop the interview and allow you time to decide if you are able to carry on. If necessary, I would contact your care co-ordinator or other relevant individual to offer you further support.

17. What happens to the Data that has been recorded and transcribed after the study has ended?

- A digital recorder will be used to record individual interviews
- The content of these interviews will be transcribed by myself the principal researcher
- The tape recordings will be destroyed in accordance with the Data Protection within 12 months to 3 years after the study is completed.

18. What will happen to the results of this study?

Once the interview is finished the information will be incorporated into a report which will form part of the doctoral programme at Middlesex University. Any information that might identify you will be removed from the report. Therefore, the information will be reported anonymous

19. Further information and contact details

For further information please contact
Veronica Flood (Principal Researcher),
Assistant Director Safeguarding Adults
Or
Dr Kay Caldwell (Academic advisor),
Work Based Learning and Accreditation Unit
School of Health and Social Science
Middlesex University
Furnivall Building, Archway Campus
Highgate Hill
London N19 5LW
Telephone: 02084116458
Email: k.caldwell@mdx.ac.uk

Thank you so much for your time and considering taking part in the study. You will be given a copy of this information sheet and a copy of the signed consent form, should you choose to participate to keep for your records.

Thank you

Appendix 4: Patient Letter

[redacted] NHS
Mental Health NHS Trust
[redacted]

Dear

Re: research project

Titled: An investigation of Black Minority Ethnic Service Users' perception of their needs within North London Mental Health NHS Trust.

I am writing to you because you are being invited to participate in a study which is about finding out whether you feel that your needs are being met in the North London Mental health NHS Trust. Participation in this research is entirely voluntary and you can withdraw at any time.

The purpose of the interview is to enable me to gain that information. It is anticipated that the interview will last 30-45 minutes. The interview will be tape recorded; however, the information you give will remain totally confidential. Once all the information has been finalised, the tapes will be destroyed.

Participation in this research is entirely voluntary, it should offer you an opportunity to raise issues and express your concern and answer any questions you may have. Once you decide that you would like to take part, your Care Co-ordinator will give you a consent form to sign and return to him/her. If you decide now or at a later stage that you do not want to take part, this is your right and will not affect present or future care you receive from the Trust.

I as the principal researcher will contact you in due course to invite you to participate in a semi structured interview at a place and time that is convenient to you.

Please note that the invitation to participate in this research is not in any way a therapeutic intervention or treatment plan.

Thank you for considering to take part in this research. If you require further information about this research, please do not hesitate to contact me on the above telephone number.

Yours Sincerely

Veronica Flood

Appendix 5: Topic Guide

Needs for individual planning.

1. You have been receiving a service from North London Mental Health NHS Trust, what would you say your main needs are?

Ethnicity.

2. How would you describe your ethnic background?

Access to information.

Can you describe what information you were given when you came in contact with North London mental health Trust?

Meeting needs in a crisis.

3. How do you describe a mental health crisis for you, what actions do you take when this happens?

Needs for treatment and support with mental distress.

4. How would you describe the way you were included when a needs assessment was carried out?

5. Do you have a care plan which provides a statement of how you will be supported to stay well?

6. Since you have been in contact with the mental health service in North London NHS Trust in what way do you feel that you have been encouraged to participate in your care?

7. Do you feel you have a choice or encouraged to have an opinion on the following?

    - The different treatment options open to you
    - Your medication regime
    - A care co-ordinator or other allocated professionals involved in your care

8. This study is specifically looking at the experiences of service users from a Black Minority Ethnic background can you describe what your experience have been in the care and treatment that you have received?

7. Are you aware if you have a care plan and can you say what the care plan covers?

Need for ordinary living and long-term support.

9. Apart from the support you receive from North London Mental Health Trust are you aware of or do you access any other service in the community?

Need for personal growth and development.

10. Looking back on at your journey, what do you think was the, most important thing that helped you get better?

Appendix 6: Approval Letter from Mental Health Trust

[redacted] NHS
Mental Health NHS Trust

Psychosis Service Line

North London Mental Health NHS Trust
[redacted]

28 May 2012

To whom it may concern

I give permission for Veronica Flood, Assistant Director Safeguarding Adults as part of her project/study for her DProf programme to have access to Service User following discussion with their Care Coordinators in the Psychosis Service Line. Veronica is currently employed by North London Mental Health NHS Trust.

L Saunders

Yours Sincerely

Leigh Saunders
Assistant Director, Psychosis Service Line

Appendix 7: North Central London Research Consortium Reviewers Letter

Camden PCT Provider Services
North Central London Research Consortium
3rd Floor, Bedford House
125-133 Camden High Street
London, NW1 7JR

Tel: 020 73317 3756
www.camdenproviderservices.nhs.uk

Date: 8th June 2011

Dear Veronica

Many thanks for responding to the reviewers' comments. It is good to hear that you plan to focus a) on unmet needs and b) community mental health team patients. That has helped to clarify the focus of your project. The third issue, regarding whether to include people from a range of BME groups or focus on just one, is ultimately up to you and may of course be determined by whether you can recruit enough participants from any one group or whether you need to extend to include more than one. Our advice would certainly be though that including the wide range of groups you suggest may not give very helpful results and it may be better to concentrate on e.g. Black (African and Caribbean, Black British, Black mixed race) or Greek and Turkish people.

We hope you find our comments helpful and we are happy to approve it one the basis of the changes as above.

Good luck with the study

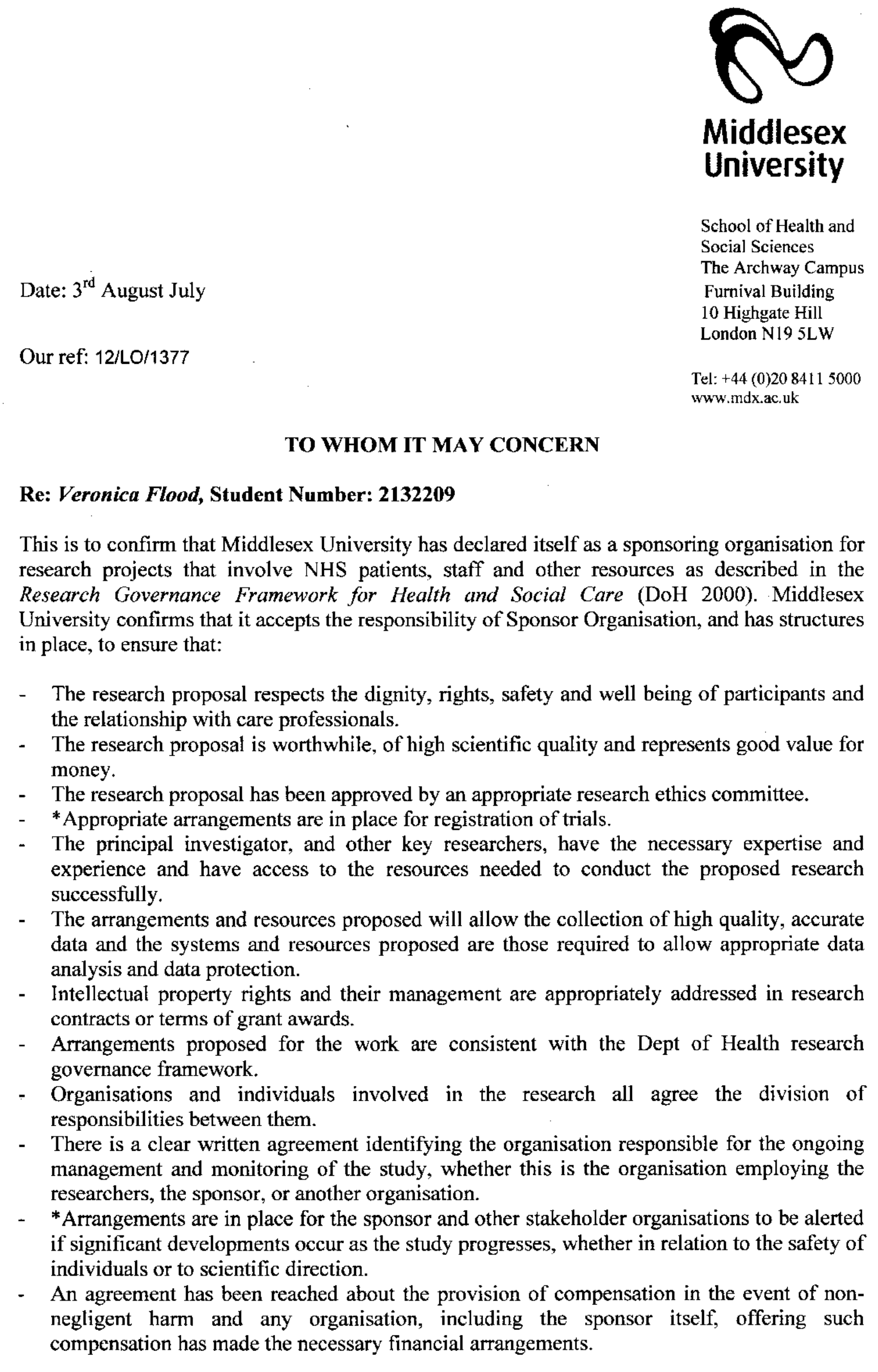
Yours sincerely

Mabel Saili

Senior Research Governance Officer

NoCLoR RandD Office

Appendix 8: Confirmation of sponsorship letter from Middlesex University



Middlesex
University

School of Health and
Social Sciences
The Archway Campus
Furnival Building
10 Highgate Hill
London N19 5LW

Tel: +44 (0)20 8411 5000
www.mdx.ac.uk

Date: 3rd August July

Our ref: 12/LO/1377

TO WHOM IT MAY CONCERN

Re: *Veronica Flood*, Student Number: 2132209

This is to confirm that Middlesex University has declared itself as a sponsoring organisation for research projects that involve NHS patients, staff and other resources as described in the *Research Governance Framework for Health and Social Care* (DoH 2000). Middlesex University confirms that it accepts the responsibility of Sponsor Organisation, and has structures in place, to ensure that:

- The research proposal respects the dignity, rights, safety and well being of participants and the relationship with care professionals.
- The research proposal is worthwhile, of high scientific quality and represents good value for money.
- The research proposal has been approved by an appropriate research ethics committee.
- *Appropriate arrangements are in place for registration of trials.
- The principal investigator, and other key researchers, have the necessary expertise and experience and have access to the resources needed to conduct the proposed research successfully.
- The arrangements and resources proposed will allow the collection of high quality, accurate data and the systems and resources proposed are those required to allow appropriate data analysis and data protection.
- Intellectual property rights and their management are appropriately addressed in research contracts or terms of grant awards.
- Arrangements proposed for the work are consistent with the Dept of Health research governance framework.
- Organisations and individuals involved in the research all agree the division of responsibilities between them.
- There is a clear written agreement identifying the organisation responsible for the ongoing management and monitoring of the study, whether this is the organisation employing the researchers, the sponsor, or another organisation.
- *Arrangements are in place for the sponsor and other stakeholder organisations to be alerted if significant developments occur as the study progresses, whether in relation to the safety of individuals or to scientific direction.
- An agreement has been reached about the provision of compensation in the event of non-negligent harm and any organisation, including the sponsor itself, offering such compensation has made the necessary financial arrangements.

- Arrangements are proposed for disseminating the findings.
- All scientific judgements made by the sponsor in relation to responsibilities set out here are based on independent and expert advice.
- Assistance is provided to any enquiry, audit or investigation related to the funded work.

** Working towards establishing the structures to achieve these indicators.*

I therefore confirm that Middlesex University will be the sponsor for the research being undertaken by ***Veronica Flood***, project title: An investigation of BME Services Users Perception of their needs in [redacted]

Signed on behalf of Middlesex University

Daniela Pantica
School Administrator
Middlesex University
School of Health and Social Sciences

Date: 3 August 2012

Appendix 9: Letter to Ethics Committee addressing issues raised following attendance at ethnic committee.

[redacted] NHS
Mental Health NHS Trust

Veronica Flood
North London Mental Health NHS Trust
[redacted]

21 January 2013

Ms Stephanie Ellis
Research Ethics Committee
London-Camden and Islington
Room 002
TEDCO Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Rec Ref: 12/LO/1377

Dear Ms Ellis,

Please be advised that the issues raised in the letter dated 2 October 2012 following the review of my application at the Ethics Committee on 24th September 2012 have been addressed. The revised areas have been highlighted in blue to aid viewing. The following are the areas that have been revised:
:

1. A revised topic guide has been submitted.

    A) The topic guide would meet the claim that social, physical, psychological, spiritual and cultural factors would be covered as in carrying out needs assessment the range of needs would fall into one of these categories. Hence question number 1 in the interview schedule has been structured to elicit what the service user perceives his/her needs to be.

    B) The essence of the study is about service user experience and not the background of staff providing the care; therefore, I have removed that statement from the revised research proposal.

2. A revised interview letter has been submitted showing changes in paragraph 3.

3. A revised Patient information sheet showing changes in section 3, 4, 7, 8, 9, 11, 17, and 18.

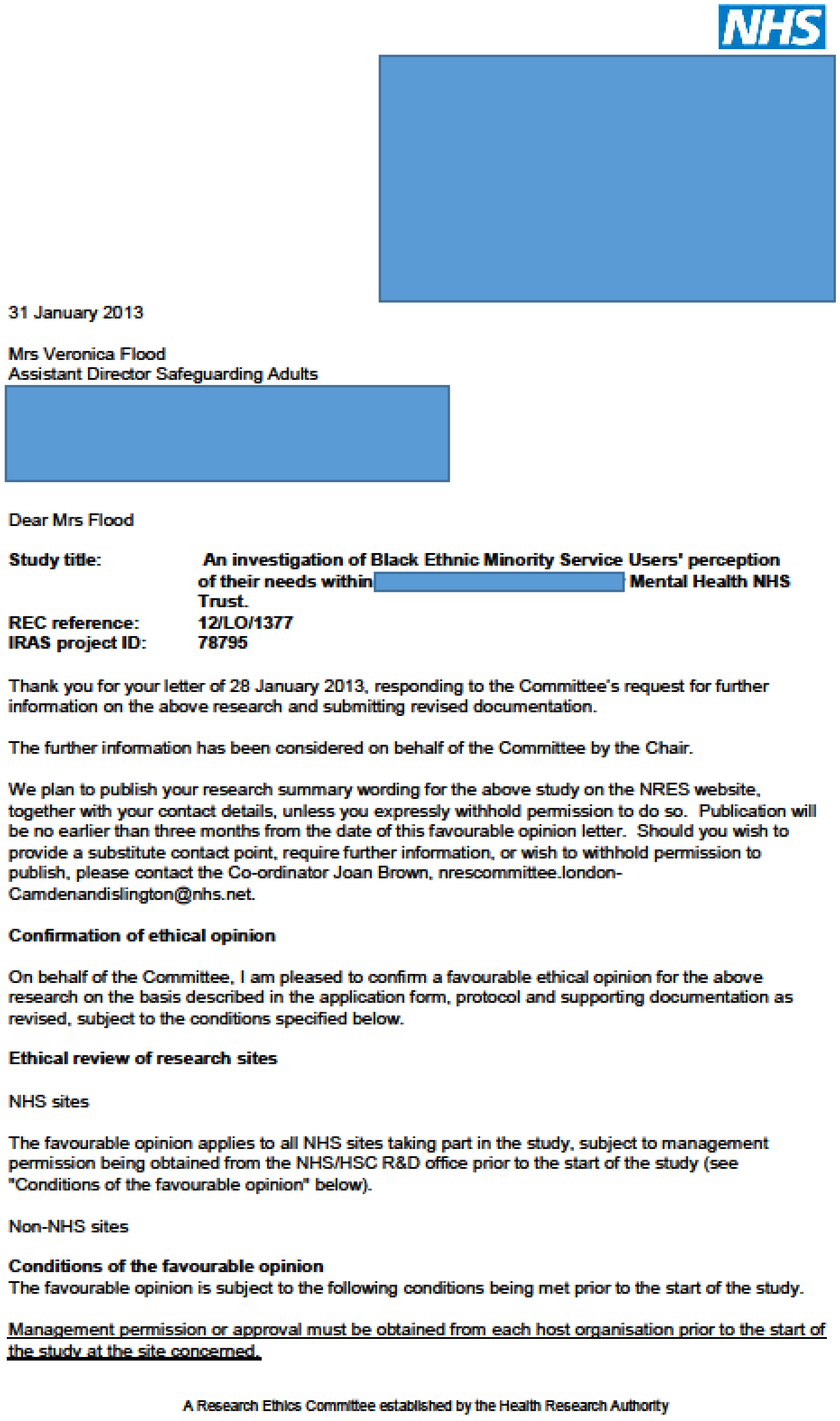
4. A revised Consent Form with suggested wording in point 3.

5. The term ‘Chief Investigator’ has been used in all the documentation to provide consistency.

Yours Sincerely

Veronica Flood

Appendix 10: Ethics approval Letter



NHS

[redacted]

31 January 2013

Mrs Veronica Flood
Assistant Director Safeguarding Adults
[redacted]

Dear Mrs Flood

Study title:	**An investigation of Black Ethnic Minority Service Users' perception of their needs within [redacted] Mental Health NHS Trust.**
REC reference:	**12/LO/1377**
IRAS project ID:	**78795**

Thank you for your letter of 28 January 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Joan Brown, nrescommittee.london-Camdenandislington@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

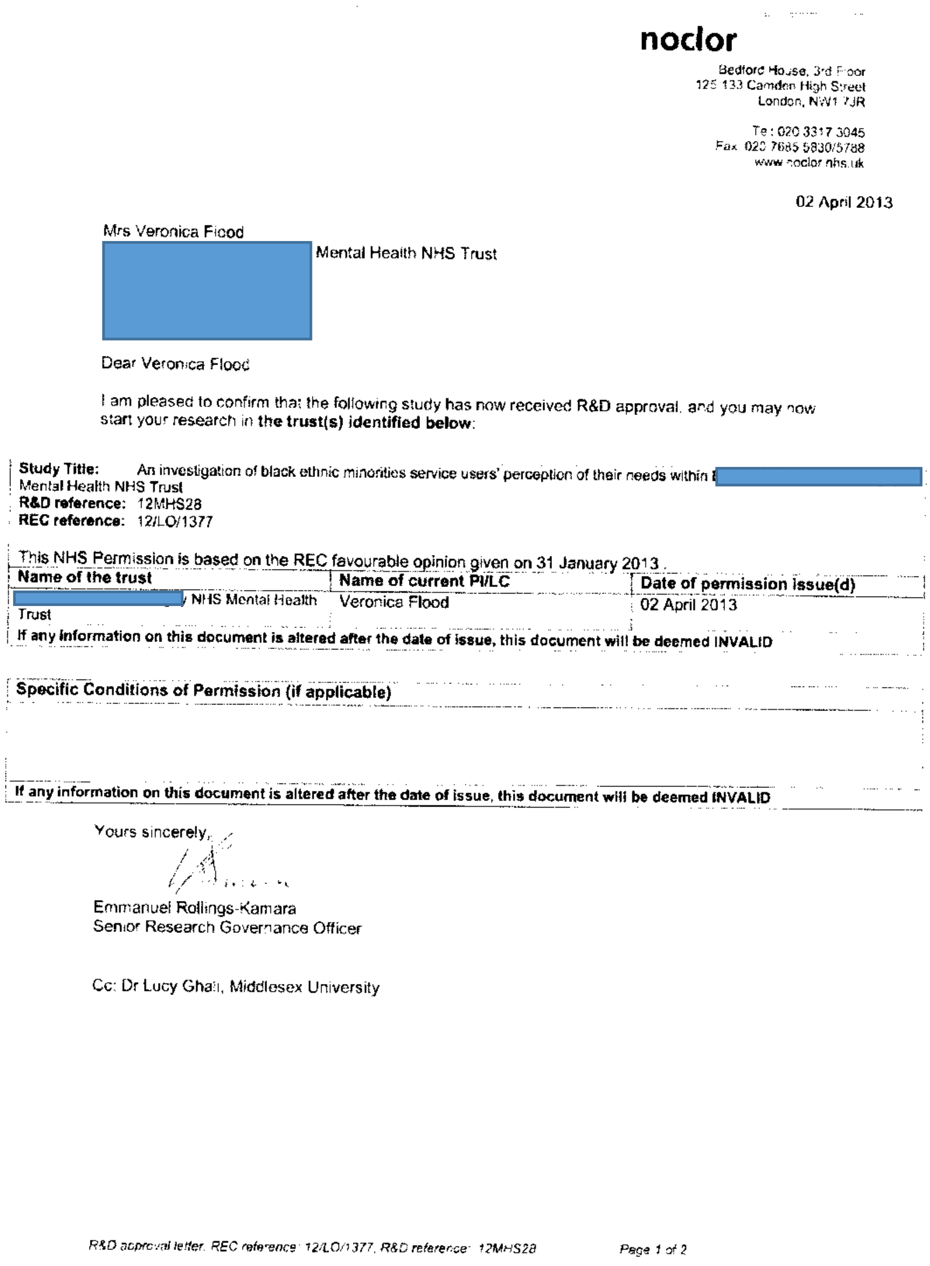
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Appendix 11: Research and Development approval letter



noclor

Bedford House, 3rd Floor
125-133 Camden High Street
London, NW1 7JR

Tel: 020 3317 3045
Fax: 020 7685 5830/5788
www.noclor.nhs.uk

02 April 2013

Mrs Veronica Flood
[redacted] Mental Health NHS Trust

Dear Veronica Flood

I am pleased to confirm that the following study has now received R&D approval, and you may now start your research in **the trust(s) identified below**:

Study Title: An investigation of black ethnic minorities service users' perception of their needs within [redacted] Mental Health NHS Trust
R&D reference: 12MHS28
REC reference: 12/LO/1377

This NHS Permission is based on the REC favourable opinion given on 31 January 2013.

Name of the trust	**Name of current PI/LC**	**Date of permission issue(d)**
[redacted] NHS Mental Health Trust	Veronica Flood	02 April 2013

If any information on this document is altered after the date of issue, this document will be deemed INVALID

Specific Conditions of Permission (if applicable)

If any information on this document is altered after the date of issue, this document will be deemed INVALID

Yours sincerely,

Emmanuel Rollings-Kamara
Senior Research Governance Officer

Cc: Dr Lucy Ghali, Middlesex University

Appendix: 12 Sample of analysis of data

Table 9: Sample of analysis of data

Data	Interpretation	Code	Theme	Sub Theme
P: Both mental health/physical. I need support with my request. I need support with housing. I don't need everything, when I requested to move, I did not receive it, instead they start giving me medication. So, I didn't receive what I asked for. I was concern about where I was living, they allocated me to a doctor. They say it would take a long time. The environment I was living in, they could have helped. I am talking to social services. I am	Require assistance from the mental health professional caring for him to find more suitable accommodation. Seem frustrated with the length of time it was taking to help him with his request.	Support with request. Support with housing. Concern with living condition	BME Service users require support from mental health services.	The need for suitable housing Support from the Care Coordinator and/or the Mental Health Team. Timeliness

still in the same place I am still waiting.'' **P:** ***Obviously I have issues to deal with drugs because I'm on drugs as well but I have come off drugs and it's a long story I don't want to go through it but what I wanted to say is that I have lost my accommodation and because basically I was letting the drug dealers in. Yes, because I was lonely, so I have let them in and …. I'm Muslim been doing drugs, but I have not taken any drugs for the past week. When I saw my mum two years ago after 15 years of not seeing her, I went back on cocaine and I spent a lot of my money on it. Yes we're going to the council and everything I have always wanted to move because I have not felt safe in my flat and I wanted to start afresh I***	The safety aspect of the participant Participant is now homeless and needed to be rehoused More suitable social contacts Participant expressed that he was lonely	Lost accommodation. Loneliness Not felt safe in the flat Engaged in drug misuse in the past but does not currently engage in the misuse of drugs	BME Service users require support from mental health services	The need for suitable housing Support from the Care Coordinator and/or the Mental Health Team.

have been in the same flat for 24 years so wanted to start afresh				

Code definition

Participants discussed what their mental health support needs were.

Appendix 13: Participant biographical details

Table 10: Participant biographical details

Number	Name	Gender	Ethnicity	Accommodation type
1	Robert	Male	Black African	Flat
2	Roger	Male	Black African	Flat
3	Grace	Female	Black Caribbean	Flat
4	Peter	Male	Black British	Supported flat
5	Paul	Male	Black British	Residential care home
6	Harry	Male	Black Caribbean	Residential care home
7	George	Male	Black African	Rented room in a house
8	Paula	Female	Black African	Flat
9	Guy	Male	Black British	Flat
10	Gloria	Female	Black British	Flat
11	Mary	Female	Black African	Residential care home
12	Ali	Male	Mixed race	Flat
13	Thomas	Male	Black British	Flat
14	Jacob	Male	Black British	Supported flat
15	Luke	Male	Mixed race	Flat
16	Andrew	Male	Black British	Residential care home

17	Ryan	Male	Black Caribbean	Flat
18	Nathan	Male	Black Caribbean	Flat
19	Emma	Female	Black African	Residential care home
20	Rose	Female	Black African	Flat
21	Hannah	Female	Black African	Residential care home
22	Leo	Male	Black Caribbean	Residential care home
23	Charles	Male	Black British	Residential care home
24	Dominic	Male	Black African	Hostel

Appendix: 14 Participant demographic details and diagnosis

Table 11: Participant demographic details and diagnosis

Number	Name	Gender	Age	Diagnosis
1	Robert	Male	43	Schizophrenia
2	Roger	Male	41	Bipolar Affective Disorder
3	Grace	Female	51	Paranoid Schizophrenia
4	Peter	Male	52	Schizophrenia
5	Paul	Male	38	Schizophrenia
6	Harry	Male	61	Schizophrenia
7	George	Male	36	Schizophrenia
8	Paula	Female	47	Schizophrenia
9	Guy	Male	23	Schizophrenia
10	Gloria	Female	43	Paranoid Schizophrenia
11	Mary	Female	29	Schizophrenia
12	Ali	Male	48	Schizophrenia
13	Thomas	Male	31	Paranoid Schizophrenia
14	Jacob	Male	24	Schizo Affective Disorder
15	Luke	Male	34	Paranoia
16	Andrew	Male	31	Schizophrenia

17	Ryan	Male	40	Paranoid Schizophrenia
18	Nathan	Male	29	Schizo Affective Disorder
19	Emma	Female	31	Schizophrenia
20	Rose	Female	41	Schizophrenia
21	Hannah	Female	43	Schizophrenia
22	Leo	Male	41	Schizophrenia
23	Charles	Male	42	Paranoid Schizophrenia
24	Dominic	Male	30	Schizophrenia

Appendix: 15 Example of a 40h crisis intervention team training

Table 12: Example of a 40h crisis intervention team training curriculum schedule.

	Day 1	**Day 2**	**Day 3**	**Day 4**	**Day 5**
8am-9am	Welcome/introductions: purpose and History	Alzheimer's: issues and Community care	Veteran Issues: PTSD Veteran's Panel	Site visit and tour of short-term residential care facility or forensic hospital	Trauma informed care
9am-11am	Historical perspectives on treatment	Substance abuse and concurring mental illness	Autism Spectrum Disorder	Site visit and tour of short-term residential care facility or forensic hospital	Depression, anxiety Symptoms Treatment
11am-12pm	Psychotic Disorders and Bipolar Illness Symptoms and medication	Cultural Diversity and Stigma of Mental illness: personal perspectives	Discretion, Decision making and Criminal Charges	Forensic issues	Suicide-Risk assessment
12pm-1pm	Lunch	Lunch	Lunch	Lunch	Lunch
1pm-2pm	Skill Set: Active Listening	Depression/ Anxiety: Symptoms, Medication: Risk Assessment for Suicide	Mental Health Act 1983, 2007 Section 136 Policy Psychology	Policy Psychology	Hostage Negotiation Teams and CIT
2pm-3pm	Skill Set: Voice, Tone, Body Language, Friendliness	Risk Assessment for Violence	Children Issues	Intellectual Disabilities	Excited Delirium; Personality Disorders
3pm-4pm	Mental Health Court Tour and Presentation Day 1 CIT	Hearing Voices Audio Tapes	Resources	Tour of Secure Behavioural Health Facility	Implementation-on, Data Collection, and State/ International CIT Data
4pm-5pm	Training evaluations	Crisis intervention Role Play Day CIT Training evaluations	Crisis Intervention Role Play; Day 3 CIT Training Evaluations	Day 4 training Evaluation	Presentation of Certificates