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Investigating Access to Specialist Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) Services for Ethnic Minority Children

Investigating Access to Specialist Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) Services for Ethnic Minority Children

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Abstract

Paediatric Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is a relatively common, complex and disabling condition. CFS/ME is more common in ethnic minority adults, and is likely to be more common in ethnic minority children, but very few ethnic minority children access specialist CFS/ME services.

The aim of this PhD was to explore both the barriers and facilitators ethnic minority children face in accessing CFS/ME services, with an aim to make access more equal. Different methods were used: 1) systematic review, 2) data analysis, 3) qualitative interviews with young people, parents, community 'influencers', healthcare professionals, and 4) focus groups with community members.

I conducted a mapping systematic review to: (1) understand barriers ethnic minority children experience when accessing specialist medical services for chronic or mental healthcare conditions, (2) interventions to improve access. This synthesis describes the most common barrier to be 'Knowledge' but 'Cultural Factors' and 'Stigma' were also important. Interventions that focus on reducing multiple access barriers showed the most promise. This review also highlighted the role of facilitators, which informed the PhD.

Data analysis of the baseline characteristics of children who accessed specialist paediatric CFS/ME services and were recruited into a clinical trial showed only 3.93% of children described themselves as an ethnic minority, however data capture methods suggest ethnicity may not be accurately recorded.

Interviews with 25 participants (3 young people with CFS/ME; 5 family members, 14 community leaders and 3 medical professionals), and focus groups with 23 community participants were conducted and thematic analysis identified multiple barriers to accessing CFS/ME services, with three key barriers ('Conceptualisation of CFS/ME'; 'Cultural Factors'; and 'Going to the Doctors') and few facilitators. Terminology was also important, with "community leaders" declining the term "leader".

Participants suggested the following ideas to improve access: 1) knowledge and awareness building initiatives to increase understanding of CFS/ME and reduce stigma and 2) healthcare system improvements, including more General Practitioner (GP) consultations, shorter waiting times, and staff of different ethnicities. Future work is needed to pilot these ideas to improve access and develop interventions.

Acknowledgements and Dedication

Firstly, I would like to thank everyone who supported and participated in this study. Without you, none of this would have been possible.

I am very grateful for all the support, expertise and invaluable advice I received from my supervisors at the University of Bristol (Professor Esther Crawley, Dr Rebecca Barnes and Dr Sabi Redwood) and their dedication to this work. I am also grateful to the University of Bristol for providing the Studentship to complete this PhD, and the wider University of Bristol Population Health Sciences department, in particular the Centre for Academic Child Health.

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Finally I would like to thank my brilliant friends and family. In particular, I would like to thank my father and my sister. You always encouraged me to make the most of every opportunity and I am incredibly grateful for everything you have done to help me get to this moment. Without your patience, support and encouragement, I really could not have completed this.

This thesis is dedicated to my mother and my grandparents for always believing in me.

Authors Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's *Regulations and Code of Practice for Research Degree Programmes* and that it has not been submitted for any other academic award.

Except where indicated by specific reference in the text, the work is the candidate's own work.

Work done in collaboration with, or with the assistance of, others, is indicated as such.

Any views expressed in the dissertation are those of the author.

SIGNED: ..... DATE: .....

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Contribution Statement

Study 1: Systematic Review

Systematic Review Manuscript has been drafted and is being submitted with the following authors:

Catherine Linney, Lucie Smith, Amberly Brigden, Maria Loades, Nina Higson-Sweeney, Siyan Ye, Megan Armond, Maya Kohli-Lynch, Matilda Wyn-Griffiths, Lauren Jones, Rebecca Barnes, Esther Crawley

Author Contributions:

CL: conceptualised and designed the systematic review, created and refined the search strategy, screened all papers (title and abstract, and full text), data extraction and analysis for all papers, and drafted the manuscript.

LS, AB, NH-S, SY, MA, MK-L, MW-G, LJ: screened papers (title and abstract and full text), data extraction and analysis, and reviewed and edited the manuscript.

ML, RB: assisted with the conceptualisation of the review, and reviewed and edited the manuscript.

EC: assisted with the conceptualisation of the review, supervised data collection and analysis, and reviewed and edited the manuscript.

Study 2: Data Analysis

Data Cleaning: Daisy Gaunt (MAGENTA and SMILE)

Reviewed Statistical Analysis Plan: Daisy Gaunt and Esther Crawley

Qualitative Interviews

Double coding of interview transcripts: Philippa Clery and Roxanne Parslow

Supervised the development of the participant materials, double coded transcripts and confirmation of the analysis: Esther Crawley, Rebecca Barnes and Sabi Redwood

Conducted, transcribed and double coded 8 Community Leader Interviews: Khadija Meghrawi

A manuscript has been drafted on the Role of Schools in children with CFS/ME, with the following authors: Philippa Clery*, Catherine Linney*, Roxanne Parslow, Esther Crawley (*joint first authors)

Contributions:

EC, PC and CL conceptualised and designed this paper, CL and PC conducted data collection and analysis for the two independent studies that this paper combines, and all authors contributed to data analysis and interpretation included in this paper. PC and CL wrote the paper; RP and EC contributed to revisions.

Qualitative Focus Groups

Published as:

Linney C, Ye S, Redwood S, Mohamed A, Farah A, Biddle L, & Crawley E. (2020). "Crazy person is crazy person. It doesn't differentiate": an exploration into Somali views of mental health and access to healthcare in an established UK Somali community. *International Journal for Equity in Health*, *19*(1):1-15.

Author Contributions (as published) (1)(p.13):

"CL conceptualised the study, participated in its design and coordination, collected and analysed the data and drafted the manuscript. SY participated in the design and coordination of the study, collected and analysed the data and drafted the manuscript. SR and LB participated in the design and coordination of the study, provided verification of the analysis and reviewed and edited the manuscript. AM and AF conceptualised the study, participated in its design and coordination, analysed the data, provided verification of the analysis and reviewed and edited the manuscript. EC conceptualised the study, participated in its design and coordination, provided verification of the analysis and reviewed and edited the manuscript. All authors approve the final manuscript as submitted and agree to be accountable for all aspects of the work."

Catherine Linney Contribution Statement: Number of Participants Interviewed / Focus Groups:

Participant Group	Number of Participants	Conducted
Young people with CFS/ME (and their families)	8	8 (100%)
Community Leaders	14	6 (43%)
Medical Professionals	3	3 (100%)
Community Members	23 (4 focus groups)	23 (100%)
Totals	*48*	*40 (83.3%)*

Research Outputs during the PhD

(1) Publications from this research

Linney C, Ye S, Redwood S, Mohamed A, Farah A, Biddle L, & Crawley E. (2020). "Crazy person is crazy person. It doesn't differentiate": an exploration into Somali views of mental health and access to healthcare in an established UK Somali community. *International Journal for Equity in Health, 19*(1):1-15.

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(2) Other publications during the PhD

Loades, M.E., Chatburn, E., Higson-Sweeney, N., Reynolds, S., Shafran, R., Brigden, A., **Linney, C.**, McManus, M.N., Borwick, C. & Crawley, E. (2020). Rapid Systematic Review: The impact of social isolation and loneliness on the mental health of children and adolescents in the context of COVID-19. *Journal of the American Association of Child and Adolescent Psychiatry, 59 (11*), 1218-1230.

Brigden, A., Anderson, E., **Linney, C.,** Morris, R., Parslow, R., Serafimova, T., Smith, L., Briggs, E., Loades, M. and Crawley, E., 2020. Digital Behavior Change Interventions for Younger Children With Chronic Health Conditions: Systematic Review. *Journal of Medical Internet Research*, *22*(7), p.e16924.

Brigden, A., Parslow, R.M., **Linney, C**., Higson-Sweeney, N., Read, R., Loades, M., Davies, A., Stoll, S., Beasant, L., Morris, R., Ye, S., & Crawley, E. (2019). How are behavioural interventions delivered to children (5–11 years old): a systematic mapping review. *BMJ Paediatrics Open*, *3*(1): e000543.

(3) Presentations during the PhD

University of Bath Forensic and Developmental Psychopathology Group (Invited speaker - June 2020)

University of Bristol CFS/ME Research Dissemination Event (September 2020)

List of Abbreviations

ABM	Andersen's Behavioural Model
ADHD	Attention Deficit Hyperactivity Disorder
APA	The American Psychological Association
ASD	Autism Spectrum Disorder
BAME	Black, Asian and Minority Ethnic
BBC	The British Broadcasting Corporation
BIPOC	Black, Indigenous, People Of Colour
BLM	Black Lives Matter
BMA	British Medical Association
BME	Black and Minority Ethnic
BMJ	British Medical Journal
CAMHS	Child and Adolescent Mental Health Services
CBPR	Community Based Participatory Research
CBT	Cognitive Behavioural Therapy
CDC	The US Centers for Disease Control and Prevention
CDHS	Cultural Determinants of Help Seeking
CF	Chronic Fatigue
CFS	Chronic Fatigue Syndrome
CFS/ME	Chronic Fatigue Syndrome / Myalgic Encephalomyelitis
COVID-19	Coronavirus Disease 2019
DBD	Disruptive Behaviour Disorders
EU	European Union
FITNET	Fatigue In Teenagers on the interNET (Netherlands)
FITNET-NHS	Fatigue In Teenagers on the interNET (UK NHS)
FREC	University of Bristol Faculty of Health Sciences Research Ethics Committee
GET	Graded Exercise Therapy
GOV.UK	UK Government Information Website
GP	General Practitioner
HADS	Hospital Anxiety / Depression Scale
HCAB	Health Care Access Barriers
HCABVP	Health Care Access Barriers for Vulnerable Populations

HRA	Health Research Authority
IOM	Institute of Medicine
MAGENTA	Managed Activity Graded Exercise in Teenagers and Pre-Adolescents
ME	Myalgic Encephalomyelitis
MS	Multiple Sclerosis
MUS	Medically Unexplained Symptoms
NHS	National Health Service (UK)
NICE	The National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NSI	National Statistical Institute
OCD	Obsessive Compulsive Disorder
ONS	Office for National Statistics
PHE	Public Health England
PHQ	Patient Health Questionnaire
PIP	Personal Independence Payment
PSHE	Personal, Social, Health and Economic Education
PTSD	Post-Traumatic Stress Disorder
PPIE	Patient and Public Involvement and Engagement
RCADS	Revised Children's Anxiety and Depression Scale
RCT	Randomised Controlled Trial
REC	NHS Research Ethics Committee
SBMHS	School Based Mental Health Services
SES	Socioeconomic Status
SMILE	Specialist Medical Intervention and Lightning Evaluation
SEID	Systemic Exertion Intolerance Disease
SF-36	Short Form 36 Health Survey Questionnaire
UK	The United Kingdom
USA	The United States of America
VAS	Pain Visual Analogue Scale

Glossary of Terms

Culture

'Culture' is frequently described in the literature in terms of emphasising group based commonalities amongst ethnic minority individuals as opposed to the majority population which is not typically categorised as having a culture (2).

Children and Young People

In this thesis, 'children and young people' refers to those aged under 18 years old. All young people recruited from the CFS/ME clinic were aged between 11-17 years old at the time of participation in the study.

'Ethnicity' and 'Race':

When conducting research with individuals from ethnic minority backgrounds, the use of terminology is important. Currently there is no worldwide consensus on "*appropriate terms for the scientific study of health by ethnicity, and published guidelines are yet to be widely adopted*" (3)(p.445).

For the purposes of this research, and based on conventions used in the United Kingdom (UK), the following terminology is used consistently in this thesis:

The term 'ethnicity' is favoured over the term 'race' in UK healthcare settings, due to its acceptance amongst service users (2). The concept of ethnicity, or an individual being from an 'ethnic minority' or 'ethnic group', is a term used to refer to the group a person belongs to, or is perceived to belong to, due to shared characteristics such as geographical or ancestral origins, but the term 'ethnicity' also encompasses an individual's culture, cultural traditions and language (3). The concept includes individuals newly arrived to a country, or Indigenous individuals to a country, such as in Australia, New Zealand, the USA and Canada (4).

In the UK, an individual's self-definition of ethnicity is the favoured option for collecting ethnicity data, as this is based on the individuals' perception of themselves, but self-definition has issues with the heterogeneity of ethnic groupings (3). In this thesis, the term 'ethnic minority' is used to describe individuals who belong to a minority ethnic, BME (Black and Minority Ethnic) or BAME (Black, Asian and Minority Ethnic) group in the UK. The term BAME is commonly used in the UK in both scientific research and healthcare settings but can be problematic and can homogenise all minorities (5,6). The UK Civil Service website (7), and GOV.UK (8) Ethnicity Facts and Figures website, has proposed using the term 'ethnic minorities' instead of BAME or BME (7). Media coverage has also reported on BAME being outdated and insufficient (9), and on 'ditching' the terms BAME and BME (10–12). For this thesis I am being consistent in the use of the term ethnic minority, but I recognise that other descriptors may be more commonly accepted. In the USA, BIPOC (Black, Indigenous, People Of Colour) (13) is becoming more commonly used, and this can be preferred by individuals from UK ethnic minority communities. In this thesis, I am using study participants' self-descriptions of their ethnic identity e.g. 'Somali', 'mixed-ethnicity', and for any literature referenced I am using ethnicity as described in the paper.

I recognise (as of writing this thesis in 2020/2021), that there are different views and guidelines globally on using capitalisations when reporting ethnicity (14–19). Articles in some UK journals, for example the British Medical Journal (BMJ) (20) and articles in some UK newspapers, such as the BBC (11) and The Guardian (21) do not consistently capitalise ethnicity. The following UK academic and government sources do capitalise ethnicity: previous work in this topic area (1,22,23), recommendations from the Civil Service and GOV.UK Style Guide for writing about ethnicity (7,8,24), reporting from GOV.UK (25), 2011 UK Census ethnicity reporting from the Office for National Statistics (ONS) (26), reporting from Public Health England (PHE) (27), National Institute for Health Research (NIHR) Toolkit for increasing participation in research (28), and a journal article presenting a 'glossary of terms relating to ethnicity and race' (3). Therefore, based on UK guidance and sources, all ethnicities are capitalised in this academic context "*to signify its specific use in this way* [reporting ethnicity]" (3)(p.443), for example (in no particular order): Black British, White British, Somali, South Asian.

Healthcare Access

The ‘use of health services’ or ‘healthcare access’ is a process of seeking medical/healthcare from a professional with the aim of treating or preventing health issues (4). A healthcare access ‘barrier’ is defined as a limitation that restricts a patients use of health services, and only affects some individuals, or is present under specific circumstances (4).

Chapter 1: Introduction

1.1 Rationale for the Research

Statement of the Problem:

Ethnic minority children do not access specialist services for CFS/ME as much as expected, despite evidence suggesting that ethnic minority children are equally, if not more affected, compared to White children. It is important to understand why these children do not access specialist CFS/ME healthcare services, as by not accessing services, they are not receiving evidence-based management that will improve their chances for recovery. Ethnic minority individuals can be excluded or have difficulties in accessing healthcare and it is crucial to identify and address any health inequalities to enable equitable service provision for the whole population (29).

The National Institute for Health and Care Excellence (NICE) guidelines (30) for the management of people with CFS/ME says that all children should be offered access to management within six months (including those with milder symptoms) and those with severe symptoms should be offered management immediately (30–32).

To my knowledge, no previous work has investigated CFS/ME in ethnic minority children. Therefore, this research is important, to improve the health of ethnic minority children and the wellbeing of their families, by informing interventions to improve access to specialist medical CFS/ME services.

The combination of projects in this thesis investigates the barriers and facilitators for ethnic minority children accessing specialist CFS (Chronic Fatigue Syndrome)/ME (Myalgic Encephalomyelitis) paediatric services. The aim of this work is to understand what barriers ethnic minority children face in accessing specialist healthcare services for CFS/ME, what has helped to access services (facilitators), and to capture ideas to develop solutions to reduce the barriers and enable more equitable service access (intervention ideas).

The output from the thesis will be a description of the barriers and facilitators ethnic minority children encounter when accessing specialist CFS/ME services specifically, and healthcare services generally, along with proposals for interventions to improve access.

1.2 Aims, Research Questions and Objectives of the Thesis

This thesis will contribute to, and further the evidence base and understanding of the barriers ethnic minority children encounter when accessing specialist CFS/ME paediatric services, what factors (facilitators) helped service access, along with intervention ideas.

Aims and Research Questions of the Thesis

The overarching aim of this thesis is to:

Understand the barriers and facilitators experienced by children from ethnic minority communities to improve access to specialist CFS/ME services.

This thesis is comprised of three interrelated projects; the results of the individual projects combine to fulfil the overarching aim of the thesis. The specific research questions and objectives of the individual projects are as follows (Table 1):

Table 1: Research Questions and Objectives of the Individual PhD Projects

Project	Research Question	Objective
Project 1: Systematic Review	What are the barriers* ethnic minority children with chronic health conditions and their families face when accessing specialist medical services?	Review and synthesise the existing evidence on the barriers* experienced when ethnic minority children access specialist services
	What kinds of interventions have been directed towards reducing inequalities in healthcare access for paediatric patients from ethnic minority communities?	Map the different types of interventions that have targeted ethnic minority children and healthcare access
Project 2: A descriptive statistical analysis of children in CFS/ME specialist services	What are the wider characteristics of ethnic minority children compared to non-ethnic minority (White) children who access specialist paediatric CFS/ME specialist services?	Determine the characteristics of individuals currently in CFS/ME specialist paediatric services
Project 3: Qualitative investigation of Patient, Family, Community, Community Leader and Medical Professional views	What can a) ethnic minority children with CFS/ME, their families and b) community leaders tell us about barriers (and facilitators*) to accessing specialist services?	Understand the patient and family views of the barriers (and facilitators*) they perceive in accessing specialist services Establish the community views of the barriers (and facilitators*) they perceive in ethnic minority children accessing specialist CFS/ME services
	What can GPs/ Medical Professionals tell us about how they make a diagnosis in a child with fatigue?	Identify GPs/ Medical Professionals clinical reasoning process on the presentation of a child with CFS/ME from the ethnic minority community
	What can ethnic minority adults tell us about lay community views on fatigue and access to healthcare?	Understand the community views of fatigue and how medical care is accessed

*The original research questions and objectives for the thesis only focused on barriers. As the systematic review highlighted the importance of facilitators, all groups of participants

were asked in interviews about both barriers and facilitators (please see Section 6.2.1.7 for further details). Both barriers and facilitators are described in this thesis.

1.3 Structure of the Thesis

This thesis is comprised of closely linked projects which will triangulate the evidence from multiple perspectives using a combination of methods (Figure 1). This work includes a synthesis of existing evidence (a systematic review, quantitative analysis of existing data) with targeted primary research (qualitative work comprising interviews and focus groups) to ensure that barriers and facilitators are accurately captured and participants' views and voices are heard.

The combination of projects provides a thorough overview of the barriers and facilitators, along with ideas from participants that could improve access and reduce barriers. The output from the integration of evidence will provide findings on the barriers and facilitators ethnic minority children with CFS/ME experience when accessing medical care, and ideas for interventions from the participants.

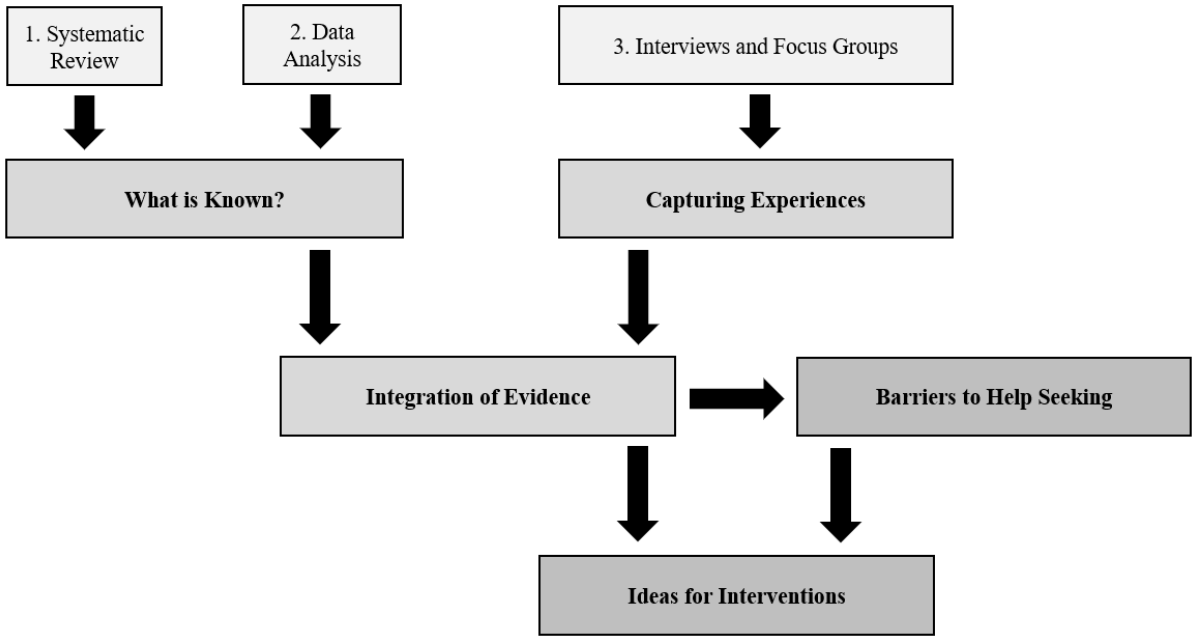

Figure 1: The PhD Projects

1.4 Acknowledgement on the Research Process

The research for this thesis has taken place between 2017-2021 and has been subject to disruption from the COVID-19 (33) pandemic in the final year of research, resulting in a smaller sample size than was originally planned.

In addition, this thesis was written during large scale demonstrations and global protests in support of the Black Lives Matter (BLM) movement (34). This occurred at the same time as a report found the mortality risk for COVID-19 in the United Kingdom (UK) is twice the risk for people of Bangladeshi ethnicity and that COVID-19 death rates were higher amongst ethnic minority individuals compared to White British (35).

These events led to an acknowledgement by the UK Equality and Human Rights Commission that there are structural racial inequalities in the UK (36). The UK Equality and Human Rights Commission is holding an inquiry to develop evidence-based recommendations to "*tackle entrenched racial inequalities*" (36)(p.1) and there is a need to improve not only access to healthcare, but the wider social determinants of health such as employment, accommodation, educational outcomes and the UK immigration system (36).

1.5 Overview of Chapters

The thesis includes seven chapters:

Chapter 1: Introduction and Rationale

This brief introductory chapter presents the 'map' of the thesis and enables readers to view the breakdown of the thesis into the individual projects and how they are interlinked.

Chapter 2: Literature Overview

This chapter provides a background to the literature relevant to this topic. Included in this chapter is a description of CFS/ME, including symptoms, diagnosis, comorbidities, prevalence and management. Relevant adult and child literature are included and research gaps highlighted. The chapter discusses ethnic minority populations and health care, CFS/ME in ethnic minority populations, and CFS/ME illness recognition, diagnosis and

management globally. Relevant healthcare access models are also discussed and factors that influence intervention development relevant to this topic area.

Chapter 3: Systematic Review (Project 1)

In this chapter the systematic review is presented, on: 1) barriers ethnic minority young people face when accessing healthcare services for any chronic or mental health conditions, and 2) interventions aimed to improve access to specialist secondary healthcare. The reasoning for choosing systematic review methodology, and the specific research questions for this review, are discussed. A description of the process of carrying out the review and the results for: barriers, facilitators, proposed strategies and solutions to overcome barriers (in terms of ideas for interventions), and interventions devised or piloted, are contained within this chapter. Finally, the results from this chapter are discussed as to how they fit in with the wider work in this thesis.

Chapter 4: Methodologies

In this chapter, the methodologies are described for the qualitative and quantitative work and a justification for a multi-methods thesis. The justification of the rationale for choosing the individual methods is discussed and this chapter also includes a reflexive account of the research process.

Chapter 5: Quantitative Project (Project 2) and Chapter 6: Qualitative Project (Project 3)

These chapters present the methods and results for the quantitative project (Project 2) and qualitative project (Project 3). Chapter 5 presents the quantitative work on the characteristics of ethnic minority young people who accessed the CFS/ME specialist service and were recruited into a clinical trial. Chapter 6 presents the qualitative work and includes the specific methods used, the qualitative findings on the three key 'barriers' themes to accessing paediatric CFS/ME services for ethnic minority children, and the ideas for 'improving access' in terms of facilitators, ideas for interventions, the role of schools, and ideas to improve recruitment in healthcare studies. The views of the young people, their parents, the community and medical professionals are highlighted. The qualitative results are presented in detail with relevant illustrative anonymised interview excerpts from the participants, to ensure their voices are heard throughout the presentation of results. A brief discussion of the key findings are presented in both chapters.

Chapter 7: Discussion

In this chapter, all the evidence presented in this thesis is summarised. Key findings are presented with potential applications of the research findings to improve access to paediatric CFS/ME services. How the evidence fits into the wider body of literature is drawn upon to present what is novel about this work and what provides support to existing evidence. The strengths and limitations of the projects is discussed and ideas for future research, based on the findings, are highlighted to aid researchers in devising future studies. The implications on policy, practice and healthcare professionals are also discussed. I have included my reflections on the PhD process, and the projects, at the end of this chapter.

Chapter 2: Literature Overview

This chapter (Chapter 2) provides an overview of the existing evidence base. Firstly, an introduction to CFS/ME is presented including: a definition and history of the illness, the prevalence of CFS/ME and issues with capturing prevalence rates, risk factors for developing CFS/ME, and diagnosis and current management of people with CFS/ME. The chapter also provides an overview of CFS/ME research and what is known about CFS/ME in ethnic minority populations, with barriers and facilitators for accessing healthcare. To conclude the chapter, relevant healthcare access barriers models and considerations of possible interventions to improve healthcare access are presented.

2.1 What is CFS/ME?

Paediatric CFS/ME is a chronic, disabling condition characterised by mental and physical fatigue lasting more than three months in children without an alternative explanation (30).

The first descriptions of the origin of CFS/ME are from the Victorian term neurasthenia (coined in 1869) to describe mental exhaustion, and received significant attention in medical literature at the time (37–39). There was a renewed focus on CFS/ME in the 1980s, with the informal phrase 'yuppie flu' and speculation on "*what aspect of upper class professional lifestyles made people vulnerable to the condition*" (37)(p.2367).

In 1988 the US Centers for Disease Control and Prevention (CDC) termed the condition CFS with a corresponding case definition for consistency (37). Despite the recognition of CFS/ME as a medical condition, it remains a highly stigmatised illness, with connotations such as 'yuppie flu' continuing to this day (40).

CFS/ME causes significant disability for sufferers (41). The severe mental and physical fatigue that is characteristic of CFS/ME is not alleviated by rest, sleep, or by reducing physical or mental energy demands (42). The fatigue experienced by CFS/ME sufferers has been described as "*exhaustion*", "*drained of energy"*, "*heaviness in the limbs*" and "*foggy in the head*' (43)(p.537), with the fatigue symptoms consisting of a combination of both physical fatigue and cognitive components (43). In addition, the fluctuating nature of

CFS/ME, consisting of post-exertion malaise after activity (30) is an issue for children, due to the uncertainty and unpredictable nature of symptom fluctuations, with a 'boom and bust' cycle often described (44). In severe CFS/ME cases nearly three quarters (72.5%) of children need the assistance of specialist equipment for mobility, such as stair-lifts, shower chairs, and crutches, with 64.7% of children reporting they use a wheelchair (40). In addition, only 27.5% of severe CFS/ME cases report being able to attend school in the past year (40)

CFS/ME has an impact on parents and siblings (45). Having a child with CFS/ME in the family can lead to increased expenditure, and a loss of monthly income, with a marked impact on the mental health of mothers (46). Poor parental health in families with a child diagnosed with CFS/ME is due to many factors, including: a limited understanding from others (e.g. friends), concern for their child, marital tension, and concern about the impact on other family members (e.g. siblings) (46).

CFS/ME is severely debilitating for the child, with the mean time absent from school being one academic year (47). The presence of CFS/ME in childhood can disrupt educational potential and can lead to significant career and economic problems later in life (48). Missing school can have an impact on friendships, with the loss of social interaction (44,49). Therefore diagnosis and referral to specialist services for the management of people with CFS/ME are important to reduce disability and improve function.

Worldwide there is a lack of agreement on the definition of CFS/ME, the causes of the illness, how to diagnose it and how to treat it (50). Even the name 'CFS/ME' is disputed. In the UK this is now changing to ME/CFS and in the USA, a new name has been proposed: Systemic Exertion Intolerance Disease (SEID) (51). In this thesis, the term CFS/ME will be used for consistency.

2.1.1 Prevalence of CFS/ME

Estimates of the prevalence rates of paediatric CFS/ME suggests it is relatively common (0.4-2.4%) (52–56), but studies worldwide show variations in prevalence rate due to differences in methodology and diagnostic criteria. Prevalence of up to 4.4% is found when looking at CFS-like illnesses (57). A recent systematic review and meta-analysis puts the overall

prevalence of CFS/ME in children and adolescents globally, when combining multiple data sources and study methodologies, at 0.89%, or 890 per 100,000 (58). There are methodological difficulties with recognising the prevalence of CFS/ME globally due to the varying case definitions and diagnostic methods used (58), with a lack of consistency in the diagnostic criteria used in research studies (59).

Two incidence peaks of CFS/ME have been reported; between 10-19 years old, and between 30-39 years old (60). A small qualitative interview study with 25 cases of paediatric CFS/ME found the mean age of onset of the condition in the sample was 11.7, with 76% of cases starting between September to December, coinciding with starting secondary school in the UK (47). Illness onset can be rapid, with 68% of children, in a small scale questionnaire study of 25 UK children and young people with CFS/ME, reported that their illness developed quickly over a matter of days or weeks (61), or CFS/ME can present after an infectious illness with a gradual symptom onset (62).

There are over 20 case definitions (diagnostic criteria) used to define a diagnosis of CFS/ME (63) and this has led to variations in the diagnosis of CFS/ME made in research studies (59,63,64). Prevalence can vary by as much as tenfold depending on the criteria used (58). Given these variations in research methodology, differences in prevalence is expected and drawing comparisons across data sets can therefore be challenging, with suggestions for an objective diagnostic tool to be used in all CFS/ME prevalence research globally (58,65). With varied estimates of paediatric CFS/ME prevalence, individuals can be over- or under-diagnosed, with consequences of under- or over- treating.

Furthermore there are not only variations in the diagnostic criteria of CFS/ME used, but there are also differences in study methodologies and data collection in prevalence studies, which could cause differing prevalence rates (58). There are two methods to measure the prevalence of paediatric CFS/ME in populations: either through using data from healthcare settings, where a patient has been diagnosed, or by using community-based screening data.

Most studies estimating prevalence have used data from specialist (or 'secondary') healthcare centres or healthcare referral data; when a physician refers to specialist services, it has been referred to as the "*Gatekeeper Methodology*" (56)(p.2). Using this as a sampling strategy typically finds lower prevalence rates of CFS/ME, as the methodology could exclude children

and adolescents of lower socioeconomic status or those from communities less likely (or less able) to access specialist healthcare (56), therefore they may not be counted in the prevalence estimates from healthcare settings (56). In addition, there are differences in the accessibility of healthcare services in different geographical locations and also in clinician understanding and knowledge of CFS/ME (62), along with willingness to make a diagnosis. This issue with using medical referrals to measure prevalence is especially pertinent to this work, as ethnic minority children can have particular challenges with accessing healthcare (66).

An alternative method to estimating paediatric CFS/ME prevalence instead utilises community-based screening, by sampling all individuals in one particular geographical area; this typically finds higher prevalence rates of CFS/ME, as sampling is not dependent on being able to access care, or receiving a CFS/ME diagnosis (56). However, community-based studies can be limited by a lack of a medical evaluation, as participants may not be screened and diagnosed with the condition by a medical professional (56) and they can be limited by the lack of randomly selected samples that are not representative of the wider population (67). Community-based studies can also be limited by poor response rates from participants (52). When conducting community-based screening, the self-selection of those willing to take part in the research, along with a participants' language ability or the availability of resources, such as interpreters (56) are further factors to consider. This is evidenced by one recent community-based sampling study in which only 5622 (out of 147,954) households met the eligibility criteria and agreed to take part in the study (56).

Community-based studies for the prevalence of CFS/ME has revealed that most youths who meet the diagnostic criteria are not diagnosed with CFS/ME (56). Potentially due to the vagueness of symptoms and the cost associated with accessing healthcare in the USA, a community based study estimating prevalence of CFS/ME in 5-17 year olds found that of the 42 young people diagnosed with CFS/ME during the study, only 2 (4.8%) had previously received a formal diagnosis of CFS/ME from a medical professional (56). Therefore community-based prevalence estimates typically find a higher rate of CFS/ME in young people than studies relying on healthcare data from specialist services, but may not be representative of the real prevalence.

2.1.1.1 Prevalence of CFS/ME Worldwide

There has been very little research investigating the prevalence of CFS/ME in Europe, apart from work conducted in the UK (68). Although previously CFS/ME has been thought of as a 'Western' disorder that was more prevalent in middle to upper class White individuals (37), evidence now shows CFS/ME is a worldwide illness (69). Most studies looking at prevalence rates are carried out in 'Western' countries, but a growing body of evidence has investigated CFS/ME worldwide, finding that CFS/ME is present, but that prevalence rates vary in different parts of the world (70) potentially due to methodological differences in studies. There is a lack of paediatric prevalence data worldwide, so this section will highlight relevant data on CFS/ME in both adults and children.

A recent systematic review looking at overall prevalence rates, found that prevalence in Western and Asian countries is comparable (58). In Japan CFS/ME falls under the category of Medically Unexplained Symptoms (MUS) (71), but has received greater attention since a Japanese CFS/ME Study Group was set up (72). In Japan the reported prevalence of CFS has been increasing from 0.46 per 100,000 person in the 1990s (73), to recent community studies estimating between 1% (74) and 1.5% (75) in adults.

In Korea CFS/ME has not been widely studied, but in Korean adults the prevalence of chronic fatigue (CF) is estimated at between 8.4% (76) to 17% (70), with a CFS prevalence estimate of 0.6% (76) to 1.4% (70). In Hong Kong, 3% of patients who had been suffering with fatigue for more than six months met the diagnostic criteria for CFS/ME and psychiatric comorbidity was common (77). In China, a community study looked at paediatric prevalence of CFS/ME in middle school students, and found a prevalence of 0.9% with CFS/ME peaking at older adolescence and in contrast to most literature, found a significant gender difference with a ratio of 1:0.87 male:female, compared to most research which finds a higher proportion of female sufferers (78). However, in China, little research has been conducted on CFS/ME, especially in children and adolescents, with limited knowledge of the illness among the general population and misdiagnoses as psychiatric problems being commonplace (78).

A comparative study between primary care in Brazil and the UK found similar CFS/ME adult prevalence rates of 2.1% in the UK and 1.6% in Brazil, with 11 cases of diagnosed CFS/ME in the UK medical records, but no cases in the Brazilian records (79). The term CFS/ME is

unlikely to be recognised by doctors in Brazil as either a diagnostic concept or a diagnostic label in healthcare (79).

In India, a random community survey with a sample of 3000 adult women in Goa found 12.1% of participants complained of suffering with chronic fatigue (CF) (80). Factors that contributed to suffering from CF were: older age, higher levels of socioeconomic deprivation, fewer years of education, higher levels of debt, and higher levels of hunger, with the strongest associations with CF symptoms being psychosocial factors (and poor mental health) and gender disadvantage (80).

A community-based study design in Nigeria, found the prevalence in adults of CFS-like illness is 1.3% and the diagnosed prevalence of CFS/ME is 0.68% (81). In children in Nigeria, paediatric prevalence was estimated, using parental reports of their child's symptoms, that identified a 15% prevalence of CF (defined as a lack of energy over the past six months, or missing activity due to tiredness) and a prevalence of CFS/ME at 2.4% (defined as at least six months of reported lack of energy or missing activity, plus at least four more criteria symptoms) (81).

Therefore, there is a growing body of evidence that CFS/ME is not limited to 'Western' countries. CFS/ME has been under-researched worldwide due to the lack of recognition of CFS/ME as an illness or as a diagnostic concept, this is especially true for studies of paediatric CFS/ME prevalence rates. Studies do indicate that globally CFS/ME is present and therefore additional research is needed to understand the disorder in children, and to provide adequate management.

2.1.2 Causes of CFS/ME

"*There have been numerous small case-control studies seeking to identify the biological basis of the condition. These studies have largely resolved what the condition is not: ongoing infection, immunological disorder, endocrine disorder, primary sleep disorder, or simply attributable to a psychiatric condition*"

(42)(p.428)

There is little conclusive published evidence on the causes of CFS/ME (32) but research highlights the lack of a single cause for CFS/ME developing in children (82). In recent years CFS/ME has been the subject of research to investigate the medical or biological causes, but current evidence is mixed and inconclusive. Some studies have found evidence that some of the symptoms displayed by children and young people with CFS/ME can be explained by pathophysiological mechanisms (83), but most studies are small scale and the findings have failed to be replicated (42).

CFS/ME in young people is commonly precipitated by infectious illness, such as flu or glandular fever (41,47,62), with 88% of children having an infectious onset for their CFS/ME (61). The Epstein-Barr virus provides the strongest evidence of the aetiology of paediatric CFS/ME (41), but it is not thought that there is a continued immune function abnormality (84) but rather an infectious illness precipitates CFS/ME (42).

2.1.2.1 Risk Factors for Developing CFS/ME

Paediatric CFS/ME is often triggered by infections (41,47,62). Additional risk factors are shown in Table 2:

Table 2: Risk Factors for Developing CFS/ME

Risk Factor	Evidence
Female Gender	• CFS/ME more common in females than males: there is between a 2.3:1 (62) and a 3:1 ratio of females: males diagnosed (60). • More equal gender balance in those diagnosed with CFS/ME aged 13 and under (55,85), after puberty CFS/ME prevalence increases in females but not males (86). • In adolescents 15 years and older, 2-3 times more common in females (87) • 80% of CFS/ME cases in Norwegian adolescents are female (88). • In the UK, USA and Australia, more females are diagnosed with CFS/ME than males (41)
Family / Childhood Adversity / Trauma	• Individuals who report three or more childhood adversities are associated with a 2.4-3.0 increased risk for developing CFS/ME in adulthood (89) • The higher the family adversity score, the higher the risk of chronic disabling fatigue at age 13 (55) and increased risk of developing CFS/ME at age 16 (90) • Over half of individuals with CFS/ME in Belgium report at least one early childhood trauma, with emotional trauma particularly prevalent (91).
Maternal Risk Factors	• Experiencing adversity during pregnancy increases the risk of CFS/ME developing in the child (55) • Maternal anxiety/depression before the child is age 6 leads to an increased risk of CFS/ME developing in adolescence (92) • Maternal absence associated with increased odds for a Chronic Fatigue (CF)-like illness (93) • Maternal distress associated with parental reports of paediatric CFS/ME (52)

2.1.3 Diagnosing CFS/ME

There are no diagnostic tests for CFS/ME, but blood tests are carried out on patients with fatigue to exclude other conditions that cause fatigue (30). In paediatric patients, diagnosis should be made by, or confirmed by, a paediatrician, after experiencing three months of symptoms and all other potential causes have been excluded through medical investigations (30,32), but the time to specialist services for the management of people with CFS/ME can vary (see section 2.1.4.2: Waiting Times for the Management of People with CFS/ME).

There are numerous case definitions for CFS/ME (59,63,64), used in different countries, including the Fukada definition (94), Oxford (95), Canadian (96–98) and the NICE

guidelines (30). All diagnostic tools require the patient to have suffered from debilitating physical and cognitive fatigue, with post activity symptoms or 'payback' and that the fatigue is not explained by other medical conditions (42). None of the separate criteria used "*have been well validated in broad population studies*" (42)(p.429).

In the UK, the 2007 NICE guidelines are used for the diagnosis and management recommendations for both adult and paediatric CFS/ME. These are currently under review (99) covering: diagnosis; management; supporting patients and their families (through information and education); and providing information and support to healthcare professionals (100).

The 2007 NICE guidelines (30) for diagnosing CFS/ME are summarised as follows (Table 3):

Table 3: NICE Guidelines for Diagnosing CFS/ME (30,32)(32 p.446)

"Consider the possibility of CFS/ME if a person has fatigue with all of the following features: - *New or specific onset (that is, it is not lifelong)* - *Persistent and/or recurrent* - *Unexplained by other conditions* - *Resulted in a substantial reduction in activity level* - *Characterised by post-exertional malaise and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over several days)"*
"Together with one or more of the following symptoms - *Difficulty with sleeping, such as insomnia, hypersomnia, unrefreshing sleep, a disturbed sleep-wake cycle* - *Muscle and/or joint pain that is multisite and without evidence of inflammation* - *Headaches* - *Cognitive dysfunction (such as difficulty thinking; inability to concentrate; impairment of short term memory; and difficulties with word finding, planning or organising thoughts, and processing information)* - *General malaise or influenza-like symptoms* - *Sore throat* - *Painful lymph nodes without pathological enlargement* - *Dizziness and/or nausea* - *Palpitations in the absence of identified cardiac pathology* - *Worsening of symptoms upon physical or mental exertion"*

2.1.3.1 Comorbidities of Paediatric CFS/ME

There are numerous comorbidities with CFS/ME in children, which can impact on quality of life and management of people with CFS/ME. The most common co-morbidity in paediatric CFS/ME is mental health problems and the rate is higher compared with other chronic health conditions (41). 35%-50% of adolescents with CFS/ME reach the threshold for diagnosis with a mental health problem (101,102) and estimates of depression prevalence in paediatric CFS/ME ranges from 20% to 40% (47,102–105). Although comorbid anxiety is less common than depression (85), 17% to 38% of children and young people with CFS/ME meet the diagnostic criteria for an anxiety disorder (102,103,105,106).

A recent study determining the prevalence of mood disorders in CFS/ME paediatric patients, used gold-standard diagnostic interviews with 164 children and young people with CFS/ME age 12-18 years old, and their parents, and identified that 35% of participants met the diagnostic criteria for at least one mental health disorder: 27% an anxiety disorder (particularly social anxiety and generalised anxiety) and 20% major depressive disorder (102). This study also found high co-morbidity between anxiety and depression, as 61% of the sample who had major depressive disorder also had at least one anxiety disorder (102).

Risk factors for the development of a mental health problem in children and young people with CFS/ME include: female gender, lower school attendance, higher fatigue scores, higher pain, higher levels of disability and higher levels of anxiety (104), with a "*sense of loss*" (107)(p.326) common in individuals with CFS/ME and co-morbid depression (107).

Further comorbidities include: asthma, diabetes, migraines, and attention deficit hyperactivity disorder (ADHD) (103,105). In severe cases of paediatric CFS/ME, two thirds of patients report a comorbidity such as: obsessive compulsive disorder (OCD), anxiety, depression and fibromyalgia (40). Adolescents with CFS/ME also report eating disorders (103,105) and eating difficulties (108). Therefore comorbidities are common in paediatric CFS/ME and need attention due to the impact on quality of life and management of people with CFS/ME.

2.1.4 Management of People with CFS/ME

2.1.4.1 Where is management for people with CFS/ME located?

The UK NICE guidelines recommend that some cases of adult CFS/ME can be managed in GP settings and referral to a specialist is based on a patients symptoms and healthcare needs (30,32). The NICE guidelines recommend that children with CFS/ME who are severely affected (such as those who are housebound) should be referred to specialist CFS/ME services immediately, moderately affected children (such as those missing a significant amount of school) should receive a referral after they have experienced three months of symptoms, and those who are classed as mildly affected with CFS/ME (such as attending school full time but still suffering from fatigue) should be referred after six months of symptoms (30,109).

In the UK, there are secondary specialist CFS/ME services that patients can be referred to by their GP; the proportion of individuals accessing these specialist CFS/ME services is increasing (110). Approximately 7000 adults were diagnosed with CFS/ME in 2010, after being referred to specialist services and assessed (111). An audit of CFS/ME services (with an 81% response rate) found that in 2017, 9715 adults were accepted to specialist CFS/ME services and 856 children (112), demonstrating an ongoing demand for services and a requirement for these specialist services to exist (112).

There is inequity in access to these specialist services in the UK, with a lower referral rate in the most deprived postcodes (111). In total, there are 42 specialist CFS/ME services in the UK: 30 adult only, 9 adult and paediatric combined, and 3 paediatric only services (112). There is a limited provision of specialist CFS/ME services for children and young people, with 12 services available across the UK (112) leaving areas of the country unable to provide specialist paediatric CFS/ME services (112).

Some CFS/ME services may accept referrals from outside the catchment area, with 18% of UK National Health Service (NHS) organisations referring individuals with CFS/ME out-of-area for specialist services (113). However due to the nature of CFS/ME with fluctuating symptoms and payback for energy intensive activities, travelling to the services for appointments and management can be an access barrier, by causing a relapse in symptoms

due to the energy demands required to physically attend the appointment, with patients needing time after the appointment to recover (114).

2.1.4.2 Waiting times for the management of people with CFS/ME

NHS guidelines have a maximum waiting time of 18 weeks to start non-urgent, consultant led treatments (115) and waiting times for paediatric CFS/ME services can range from 2 weeks to 4 months (112). However a 2011 study found waiting times were longer, with nearly 25% of children waiting over two years to access a specialist service (109); those who were severely ill were not more likely to be referred and seen at specialist services sooner than those who were mildly ill, and factors such as physical disability and pain did not affect the time it took to access services (109). These results suggest that the delays some patients experience to accessing appropriate healthcare services could be due to structural barriers, rather than the needs of the patient (109).

In children, once access has been gained to a specialist children's CFS/ME service, families value the diagnosis they receive (116,117). Parents view the service as useful to acknowledge their child's illness and as an enabler for communication with schools and other healthcare professionals (116), as children and young people with CFS/ME also require care from primary health care and support and input from schools (88).

2.1.4.3 What is the recommended management for people with CFS/ME?

Overall, children do better with management of CFS/ME than without it. In those with mild to moderate CFS/ME, the strongest evidence is for Cognitive Behavioural Therapy (CBT); Activity Management and Graded Exercise Therapy (GET) are also recommended (30,32), but there are no trials for these approaches in children (86). Behavioural approaches, with an aim of improving the patients' sleep and regulating their activity, are the key features of CBT, GET and Activity Management (86). Although evidence for the effectiveness of management for paediatric CFS/ME is still being researched (118), CBT based interventions provide the strongest evidence (118).

To investigate the effectiveness of paediatric CFS/ME management, several randomised controlled trials (RCTs) have been conducted using Cognitive Behavioural Therapy (CBT) (82). CBT is effective in randomised controlled trials when it is delivered face to face (119),

online (120) or in a family CBT intervention (121). Long term follow ups of patients who had CBT interventions for CFS/ME found the effectiveness was maintained over time, in terms of symptom improvements (122,123).

One trial delivered CBT face-to-face to 29 adolescents aged 10-17 with CFS/ME and found a significantly greater decrease in levels of fatigue severity for those in the therapy group (14.5, 95% CI 7.4–21.6), functional impairment on the SF-36 physical functioning (17.3, 95% CI 6.2-28.4) with a significantly increased attendance at school (18.2% increase, 95% CI 0.8-35.5) (119).

An online RCT CBT intervention in the Netherlands (FITNET) assigned 68 adolescents aged 12-18 with CFS/ME to the therapy group and 67 to usual care (67 and 64 were analysed) (120). The intervention was significantly more effective for: full school attendance (85% vs 27%), lack of severe fatigue (85% vs 27%) and physical functioning (78% vs 20%) (120).

Family focussed CBT has also been trialled in an RCT, where 63 patients with CFS/ME aged 11-18 were randomly assigned to psycho-education treatment or the family focused CBT intervention (121). At follow up, the intervention was not more effective than psycho-education at fatigue severity, social adjustment and school attendance improvements, but school attendance was higher for those who received CBT, indicating adolescents improve more with intensive management (121).

The results are consistent with other studies which show improvements, for example a cohort study using a telephone based CBT intervention for 63 11-18 year old participants, found a decrease in fatigue levels and a significant increase in the young person's school attendance (124). Family based CBT has also been trialled with children and young people with CFS/ME aged 11-18 years old in an uncontrolled study, finding 83% of those given the family focused CBT improved according to the following criteria: a fatigue score of less than four and 75% school attendance (125). The improvements from the family based CBT were also maintained at a six month follow up (125).

In those referred to a specialist UK service, two thirds of young people class themselves as fully recovered after 3 years (126), with the median illness duration of CFS/ME in young people being three years (61). Results from Australia found over two thirds of patients (68%)

reported recovery at a 10 year follow up, with all young people reporting improved symptoms (127).

Therefore, as children and young people do better with management than without it, it is important that children and young people are given an opportunity to start management to enable them to regain full health. CFS/ME has long ranging effects, including on education and career plans of young people, and the isolation of missing school (119). Therefore early diagnosis and management of people with CFS/ME is vital to improve outcomes (126).

2.1.4.3.1 Management for CFS/ME Globally

Management worldwide for CFS/ME varies, including differences in the recommended management in European countries. In a European survey of GPs investigating CFS/ME, only the UK, Spain, Norway and The Netherlands reported that they had received guidance on management and referral pathways for individuals with CFS/ME, with Italy, Ireland, Latvia, Romania, Germany, France and Bulgarian GPs reporting no guidance on how to offer recognition, support or management for individuals with CFS/ME (128). In Poland, there are no medical services for CFS/ME or fatigue, and CFS/ME is not regularly diagnosed and poorly understood (129).

Even if a country has guidance on how to treat CFS/ME, such as in Norway, 60.6% of adults with CFS/ME aged over 16 report that the quality of care they received in primary care was poor and 71.2% rated their care coordination as poor (130). Further Norwegian research highlights the lack of medical knowledge of CFS/ME in primary care, which leads to a feeling of not being understood, or being disbelieved, and fighting the system, with patients perceiving that the GP thinks they are ‘lazy’ or suffering from a psychological condition, such as anxiety or stress (131).

In East Asian countries, no literature could be found, apart from South Korea, where traditional medicine is often used, with traditional Korean medicine being prescribed for patients in Korea with chronic fatigue (70). Korean patients can be given traditional herbal formulas for symptoms of fatigue and findings show patients reported an improvement of general symptoms, but not improvements in their fatigue and their sleep quality (132). Acupuncture is also used in Korean patients with CFS/ME (133), supported by a meta-

analyses that found acupuncture can reduce fatigue severity, but poor quality studies included in the overall meta-analysis review limit the generalisability of the findings or any potential other factors that could have improved symptoms (134).

2.1.5 Barriers to Diagnosing and Accessing Services for Paediatric CFS/ME

2.1.5.1 Challenges with Diagnosing CFS/ME

There are numerous barriers for children and young people with CFS/ME receiving a diagnosis and accessing specialist care. Despite the guidance for how to diagnose CFS/ME in the UK (30), due to the lack of a diagnostic test and the presence of invisible symptoms, there are challenges for both medical professionals and patients, with 80% of individuals with CFS/ME reporting difficulties with receiving a diagnosis (135). Fatigue is the defining symptom of CFS/ME (30), but the symptom of fatigue is not unique to the illness. Fatigue is common in young people, with 34% of teenagers feeling tired over the last month (53). Severe fatigue affects up to 20.5% of teenage girls and 6.5% of teenage boys (136), but only 31% of children experiencing chronic disabling fatigue report consulting a GP about the fatigue symptoms (55). In children aged between 8 and 19, 67% of those suffering from disabling fatigue report attending GP consultations, with 36% referred to a hospital for a specialist opinion (137). Girls attend more GP consultations with disabling fatigue than boys, with boys attending on average two appointments, and girls 4.35 (137).

There is an increased use of health services before diagnosis with CFS/ME. Children with CFS/ME attend medical appointments for consultations, tests and prescriptions at an increased rate for up to five years before being diagnosed with CFS/ME (138). When comparing individuals with CFS/ME before a diagnosis, to controls, GP consultations are more than double the control sample in the five years before diagnosis and four times higher in the year when a child was diagnosed with CFS/ME (138).

2.1.5.2 GP reported difficulties with diagnosing CFS/ME

In the UK, recognition over CFS/ME existing as a medical condition is still debated (139,140) and there is some suggestion of emotional stress and somatisation of a mental health problem causing the symptoms (139). Only 72% of GPs recognised and accepted

CFS/ME as a condition in adults, with those GPs that do recognise CFS/ME as a condition having a significantly more positive attitude towards diagnosis and management (141). In Wales, only half of GPs who responded to a survey believed that CFS/ME does exist as a medical condition in adults (142). GPs report frustrations with diagnosing and treating CFS/ME as the illness is 'invisible', leading some medical professionals to doubt the existence of the condition and how it presents in patients, due to the lack of measurement on patient functioning (143). There is a widespread lack of knowledge and understanding of CFS/ME amongst GPs (144) and this can lead to doctor-patient relations becoming strained (143).

There are barriers present within the GP consultation itself that can delay diagnosis of CFS/ME. GPs describe unwillingness and uncertainty with diagnosing CFS/ME, due to a lack of knowledge of CFS/ME, their confidence diagnosing CFS/ME and a lack of experience with how to manage the condition (23,145). GPs also report little confidence in labelling a patients symptoms as due to CFS/ME with a view that their primary role is to exclude possible physical causes for a patients symptoms (139). CFS/ME can be misdiagnosed as depression (137,146) and age, puberty or hormones are also regularly given as explanations for disabling fatigue by GPs (137). Children and young people with CFS/ME still express a need for more training for healthcare professionals to recognise and understand CFS/ME (40).

CFS/ME is a diagnosis of exclusion, with multiple medical tests needed to check for other conditions (30). The diagnosis can be difficult for GPs to make (23) and during the diagnostic process, a clinical impasse can be reached after diagnostic tests are returned negative (143). Diagnosis by exclusion and medically unexplained symptoms can be challenging for medical trainees, leading to unhelpful attitudes and views towards these patients (147) which could be a barrier for a diagnosis.

There is also a stigma with diagnosing the condition of CFS/ME and GPs have reported being unwilling to label a patient with a diagnosis of CFS/ME as it can be seen as "*a negative label*" (23)(p.277) which could mean patients might not improve (23). Further work reports GPs suggesting that the CFS/ME label could be harmful for the patient, potentially leading to a self-fulfilling prophecy (139). GPs believe they lack knowledge on how to manage CFS/ME, which could lead to the patient perceiving a lack of hope of recovery from the

illness (23). After diagnosis by the GP, CFS/ME can be difficult to manage; there is no cure for the condition and increased resources are required to work with the patient (139).

In paediatric CFS/ME, patients perceive doctors lack knowledge and understanding of CFS/ME (40,109) with parents reporting that they had to inform the medical professional of the specialist CFS/ME service to be referred to (109) and mothers reporting being persistent and proactive (116). In addition, parents also describe: being disbelieved (117); GPs are dismissive or do not believe the symptoms (40); they face blaming attitudes from GPs (109); are made to feel inadequate as a parent (109); and communication problems in the consultation, leading to conflict with the medical professional (109). Patients can use information and research gained from the Internet, and bring this knowledge into GP consultations for the GP to take action (143).

2.1.5.2.1 Difficulties with CFS/ME Diagnosis Globally

The barriers and issues described with diagnosing CFS/ME and accessing specialist services are not unique to the UK. Doctors who have trained in different countries may have different experiences and training of CFS/ME. In previous work looking at CFS/ME in ethnic minority adults, most participants reported their usual GP was from an ethnic minority community (22).

There are differences between the recognition of CFS/ME in countries worldwide, and within countries there are also variations in clinician recognition of the disorder. A high proportion of European GPs do not recognise CFS/ME as a disorder, or a diagnosable clinical entity (68). In Spain, between 30-60% of GPs recognise CFS/ME as a clinical entity, whereas in Italy and Latvia the majority do not recognise CFS/ME (128). In Norway the recognition rate varies between GPs (128), with 47.8% of Norwegian adolescents with CFS/ME waiting one year or longer for a diagnosis (103) and reporting feeling disbelieved by medical professionals (148).

Swedish GPs who had experience with CFS/ME, displayed scepticism regarding the condition and labelled it as an ‘illness’, which is regarded as less serious than a ‘disease’ (149). In European countries where CFS/ME is recognised as a condition, up to 50% of GPs do not diagnose it in their patients, and therefore it is difficult to obtain prevalence data when

looking at the number of individuals who have received a diagnosis, or who are referred, or access, specialist services (68).

As previously discussed, some GPs can be hesitant of diagnosing CFS/ME due to lack of knowledge or recognition of the condition (144). In Australia, 31% of GPs surveyed expressed disbelief that CFS/ME is a syndrome, with 70% of those reporting that underlying depression was the most likely reason for chronic fatigue symptoms (150). Children and young people with CFS/ME in Australia wait on average over 12 months between the onset of their symptoms and an initial appointment at a specialist CFS/ME clinic (105).

The presence of 'doctor shopping' is common worldwide in patients suffering from disabling fatigue in an attempt to gain an explanation, or diagnosis, for their symptoms. In individuals with CFS/ME in Japan, visiting multiple clinicians is common, with some patients misdiagnosed with mental illness to explain their symptoms (71). Adults with CFS/ME become an 'active patient' throughout the process in Japan to secure the necessary management for their condition (71). Canadian research also reveals that individuals suffering from fatigue and seeking a diagnosis have to visit multiple medical professions by 'doctor shopping', with 62% visiting more than three doctors before receiving an explanation or diagnosis for their symptoms and report having to teach their doctor about CFS/ME (151).

Similarly to UK and USA findings, Japanese adults with CFS/ME report a sense of relief at gaining a diagnosis and recognition from a medical practitioner, with a legitimation of their symptoms and a sense of liberation from self-blame for their condition (152). Often adults with CFS/ME in Japan report stigma and 'humiliation' from others before being given a diagnosis, including a disbelief of their illness, and misdiagnosis of mental disorders, therefore the diagnosis provides proof they are suffering from a condition (152). There are still barriers after receiving a diagnosis in Japan, with others potentially not regarding CFS/ME as a severe illness, or an illness at all, due to a lack of biomarkers (152).

2.1.5.3 Summary of the Barriers to Accessing Paediatric CFS/ME Services

The following tables (Table 4 and Table 5) provide a summary of the key barriers identified in the literature to accessing paediatric CFS/ME services. The barriers have been split into two tables: 1) Knowledge / Understanding Barriers and 2) Medical Care Barriers. Whilst a

search using systematic review methodology was not used to identify these barriers, a robust literature search was conducted to provide context of the challenges for children and young people with CFS/ME accessing healthcare.

Table 4: Knowledge / Understanding Barriers for Accessing Specialist CFS/ME Services Identified in the Literature

Barriers	Literature References and Examples
Unfamiliar	• CFS/ME unfamiliar and unknown illness in terms of individual, society and medical understanding (117) • Lack of understanding from schools (117)
Understanding	• Illness poorly understood by others (153)
Stigma	• Stigma from others, due to a lack of understanding (49) • Illness regarded as laziness (153,154)
Fatigue symptoms not viewed as an illness	• Not viewed as a proper illness by others (153) • CFS/ME perceived by others as mental illness and "*in their imagination*" (153)(p.2653) • Not believed about fatigue symptoms (154) • Bullying from classmates related to uncertainty of CFS/ME as an illness (154) • Not believed about fatigue from teachers, family and friends – lack trust, dismiss illness (154)
Invisible symptoms	• Lack of visible illness – invisible symptoms are difficult to explain (153,154)

Table 5: Medical Care Barriers Identified in the Literature

Barriers	Literature References and Examples
Medical Care Barriers	• Parents report frustrating experiences of consulting a medical professional (109,116) • 'Conflict' with healthcare providers due to diagnostic delay and feeling blamed (109) • Feeling disbelieved (117) / Felt doctors did not believe the symptoms (148) / felt unsupported (49) / felt GPs dismissed the symptoms as normal part of childhood (109) • Felt patronised by GPs, abandoned by medical system, 'inadequate' as parents, and their concerns not listened to (109) • Lack of non-verbal empathy from GP (including body language and facial expressions) and a verbal lack of empathy (109) • Parental difficulty explaining their child's symptoms, difficult to verbalise or answer probing questions (109) • Mothers had to be "*proactive and persistent*" (116)(p.137); Mothers had to acquire additional knowledge to bypass gatekeepers (116) • Parents had to inform the GP about specialist CFS/ME services available and the referral criteria (109)
Delays in diagnosis (49,148)	• Numerous healthcare appointments with different professionals (109,116) • Waiting times for healthcare appointments (116); Wait for funding to access CFS/ME service (116) • Multiple blood or diagnostic tests (116) • Long period of uncertainty during delay in diagnosis (117) • Misdiagnosis (148) • Co-morbid conditions complicate the diagnosis, masking CFS/ME symptoms (116)
Knowledge / understanding from medical professionals	• GPs and Paediatricians lack knowledge about CFS/ME, management or available care (109,116) • Lack of medical professional awareness and understanding (117) • Medical professionals uncertain about CFS/ME diagnosis (116) • GPs lack understanding of the recommended NHS guidelines for CFS/ME (109) • GPs and Paediatricians lack of understanding on the referral process (109) • Doctors warned of the 'stigma' of a CFS/ME diagnosis (109) • Parents given unhelpful information about CFS/ME or information that could not be put into practice (109)

2.2 Ethnic Minority Populations and Health Care

2.2.1 An Overview of the Ethnic Minority Population in the UK

The United Kingdom (UK) has a large ethnic minority population, and this is increasing in size (26,66). The most recent Census conducted in 2011 showed that the UK population is becoming more ethnically diverse; individuals identifying as being from a White ethnic group in England and Wales has changed from 94% in 1991 to 86% in 2011, with White British identifying individuals comprising 80.5% of the population (155). In addition, 7.5 million people in England and Wales (13% of the population) were born outside of the UK in 2011 (155), increasing to over 9 million people by 2019 (156).

There is a trend for ethnic minority individuals to concentrate in UK cities, in particular London (157), with 40.2% of residents in London identifying as being from an ethnic minority group in the 2011 Census (155). There is a lack of statistics and information on asylum seekers and migrant workers, and these groups could be underreported in Census counts (66), but other data sources can be used to estimate the overall UK ethnic minority population. In UK state-funded schools in 2015, 1 in 5 (19.4%) of children have a first language other than English and a total of 30.4% of primary school pupils and 26.6% of secondary school pupils identify as being from an ethnic minority background (158).

2.2.2 Ethnic Minority Populations and Health Care Access

Equal access to healthcare services for all individuals encompasses more than a service just being available as: "*provision alone cannot ensure access to care for all people regardless of their religion, culture or ethnic background*" (66)(p.142). There is also a need to provide appropriate information to enable people to access services and provide services that are sensitive to needs (66).

There are "*entrenched inequalities experienced by people from different ethnic backgrounds in all areas of life in Britain*" (159)(p.2). The UK Equality and Human Rights Commission Report (159) recognises the disparities in healthcare access and outcomes amongst ethnic minority individuals, and urges the UK Government to:

"*Take action to close health inequalities experienced by ethnic minorities. This should include:*

- *improving access to information about available services, providing these in different languages and formats;*
- *collecting data on access, experience and outcomes from health service users;*
- *ensuring healthcare professionals understand the different needs of ethnic communities;*
- *and trialling interventions to assess what works in improving the healthcare experience for ethnic minorities*"

(159)(p.6)

Ethnic minority individuals in England and Wales suffer not only poorer health compared to the White British population, but they also have poorer access to healthcare (160). There is confusion amongst the rules of entitlement to services and there are barriers to registering with a GP (160), further limiting some individuals accessing healthcare. Some ethnic minority communities have worse access to healthcare than others, with Chinese identifying individuals making the least use of healthcare services of all ethnic minority groups in the UK (160).

In the UK, a recent report highlights health inequalities, in terms of disparities in healthcare quality and lower patient satisfaction with healthcare access and provisions amongst ethnic minority individuals (2). This is not a new finding, as it has been historically recognised that some ethnic minority groups in the UK experience health inequalities and inequities in access to healthcare services (157). Adults, children and young people from ethnic minority communities have poorer healthcare (66) and cultural differences and structural barriers and injustices affect how different populations access healthcare services (22). Factors that influence healthcare access and delivery can include: how the illness is perceived; attitudes towards healthcare providers (including trust); patients health and wellness belief systems; and views of healthcare practitioners (66).

2.2.3 Recruiting Ethnic Minority Individuals to Research Studies

Despite the increasing diversity of the UK population, individuals from ethnic minority groups are underrepresented in health research, which can affect how generalisable study results are and how service resources are allocated (161,162). Factors that affect participation from ethnic minority groups in health research include: "*age, language, social class, feeling of not belonging/mistrust, culture and religion*" (161)(p.149). Ethnic minority individuals are willing to participate in health research if the work "*has direct relevance to them and their community and if they are approached with sensitivity and given clear explanations of what participation involves*" (162)(p.342).

2.2.3.1 Public and Patient Involvement and Engagement

To ensure research studies have direct relevance to participants, and to improve representation and inclusiveness in research studies, Public and Patient Involvement and Engagement (PPIE) is important throughout the research process. Public involvement in research is defined as research being carried out 'to', 'by' or 'with' members of the public, instead of research being 'about' or 'for' them (163). Involving patients and the public within the research process can improve the relevance of the study to the population it aims to target, the validity of the findings, and ensure the public's needs are incorporated (164). PPIE is important in devising research tools, such as using feedback from public contributors to ensure research materials are easy to read and understand (165). PPIE also can improve the cultural relevance of a research study and provides cultural understanding of the research context (165). PPIE was incorporated into different elements of this PhD project as this was an area I had limited prior knowledge of and I recognised the need for inclusive research practices and cultural sensitivity throughout. The exact PPIE engagement in this thesis is detailed in section 6.2.1.3 and section 6.2.2.1.

2.3 CFS/ME in Ethnic Minority Populations

2.3.1 Prevalence

Although historically CFS/ME has been thought of as a White middle-class disorder (37), CFS/ME is more common in ethnic minority UK adults with a prevalence of 0.8% in White British and 3.5% in those from the UK Pakistani community (166). This large population

study in the UK found that all ethnic minority adults have a higher risk for CFS/ME compared to White British individuals (White, 0.8%; Irish, 1%; Black Caribbean, 2.5%; Bangladeshi 3.4%; Indian, 3.1%; Pakistani 3.5%) (166). CFS/ME is also "*at least as common in ethnic minorities in the USA*" as compared to White individuals (167)(p.2).

Despite finding that CFS/ME can be more common in ethnic minority individuals, there is limited research investigating the prevalence of CFS/ME in those identifying as being from an ethnic minority background. Of the studies carried out, the results can be conflicting depending on the study methodology, and the ethnic groupings used in the studies can be arbitrary, leading to difficulties in measuring prevalence rates across different ethnic groups (41).

In the USA, a systematic review found Latinos are less likely to be diagnosed with CFS/ME compared to African Americans and Native Americans but more likely to be suffering from chronic fatigue, with Native Americans having the highest prevalence of CFS/ME (168). Despite lower prevalence rates found in Latinos, Latina females with CFS/ME report experiencing a higher severity of CFS/ME symptoms than White Americans and African Americans (168). This contrasts with a study in Georgia, USA that found similar prevalence rates for White American and African American adults, but a significantly higher prevalence amongst Hispanic American adults (169).

When looking at just chronic fatigue (not CFS/ME specifically) using a telephone screening program in San Francisco, USA, CFS-like illness prevalence rates were higher among African Americans and Native Americans, and the symptoms were the least prevalent among Asian Americans (170). Evidence from Seattle, USA from community screening, found that Black/African Americans accounted for 9.5% of cases of chronic fatigue, compared to 4% of the general population (171); White Americans were under represented, accounting for 82.5% of cases of chronic fatigue, compared to 90% of the Seattle area population (171).

A further study sampled 28,673 adults in Chicago, via telephone screening, and medically evaluated symptoms from individuals with CFS/ME (67,172). This study found the highest prevalence rates of CFS/ME in Latino Americans (in particular Latina females), with higher overall prevalence rates in Latino Americans and African Americans, compared to White Americans (67,172). Numerous reasons were proposed for this finding, including: stress,

behavioural risk factors, healthcare seeking differences, access to appropriate healthcare, and housing and unemployment differences (172), but methodological differences could explain the disparity between the findings in the USA prevalence studies on the prevalence of CFS/ME in Latinx/Latino/Latina in the USA.

In children, there is limited evidence on the prevalence of CFS/ME in ethnic minority individuals. A recent community study (56) sampled 10,119 young people aged between 5-17 in the Chicagoland area of the USA, with the prevalence of physician diagnosis of CFS/ME in the sample of 0.75%, and a higher prevalence found those who identified as African American (1.1%) and Latinx (1.3%) compared to White American (0.6%) (56). Of those diagnosed with CFS/ME in the study (56), less than 5% had previously been diagnosed with the illness, highlighting a lack of diagnoses of CFS/ME in ethnic minority children (56). When looking at CFS-like illnesses, in a community sample in the USA, Latino children and adolescents had the highest rates of the illness (173).

Therefore despite the evidence being limited, studies do consistently show a higher prevalence rate in ethnic minority individuals. Investigating the prevalence of CFS/ME is challenging as many prevalence studies do not collect or analyse data on the self-identified ethnicity of the study participants (37,67). In addition, CFS/ME may be less commonly diagnosed in primary care in UK ethnic minority patients (174) and community based studies may not include a medical examination to diagnose CFS/ME (58).

2.3.2 Ethnic Minority Individuals in Specialist CFS/ME Services

The proportion of ethnic minority patients seen in specialist CFS/ME services is relatively low (175) and lower than predicted from the population, with ethnic minority patients significantly under-represented in specialist CFS/ME services worldwide (37,176). As research suggests CFS/ME is more common in these groups, the low proportion in specialist services could be due to those from ethnic minority backgrounds less likely to receive a diagnosis of CFS/ME, or less likely to receive a referral to specialist CFS/ME services (41), or a difference in health seeing behaviour, not a lack of prevalence or need for services (37).

In King's College Hospital Clinic in London (UK), 10% of patients were from an ethnic minority background, as compared to the wider population that the clinic serves, which is 60-70% ethnic minority individuals (37). Further qualitative work in London, UK captured the experience of health care practitioners, who had been reported as effective by CFS/ME adult patients (140): most of the caseload of adults with CFS/ME were White British, female and middle class in contrast to the locality of the clinic in an ethnically diverse area (140). The ethnic minority patients seen in the service were viewed as middle class, but one health care professional, described as a "*holistic practitioner*" (140)(p.10), reported seeing a range of ethnicities including individuals identifying as being from Pakistani and Indian ethnicities (140). Evidence from Seattle (USA) has shown a low number of ethnic minority patients referred to the CFS/ME clinic in comparison to the ethnic diversity of the wider Seattle city population (176).

Further evidence from Melbourne (Australia) looked at children, and found that the ethnicity of the young people included in a study from the CFS/ME specialist service was not in the expected proportions related to either the ethnic diversity of the state of Victoria, or the ethnic diversity of the wider patients of the hospital, with young people from Middle Eastern, African and Asian ethnicities significantly underrepresented in the clinic (127). These findings raises the question of why ethnic minority patients with CFS/ME are not diagnosed with CFS/ME or why they are not referred to specialist services for management, along with the question of how ethnic minority individuals access healthcare and navigate care pathways (168).

There are numerous explanations for this lower proportion of ethnic minority patients in specialist services; either ethnic minority patients may be less likely to be diagnosed with CFS/ME or misdiagnosed, or these patients are diagnosed but that there are barriers in attending the CFS/ME service (37). Potential barriers could include: culturally different health seeking behaviours, the accessibility of available medical care, the recognition of the symptoms as a healthcare condition and the recognition of needing medical services for the symptoms (176). A non-peer reviewed report studying ethnic minority CFS/ME adult patients in the UK reported a lack of knowledge and understanding of CFS/ME amongst lay individuals and healthcare workers, and also issues accessing information about the illness in different languages, leading to multiple barriers and exclusions that continued once a diagnosis of CFS/ME had been reached (177).

A further explanation for the lack of ethnic minority adults in specialist care is that ethnic minority individuals with CFS/ME may use different coping strategies, including religion, denial of the illness and might disengage from services to cope with the illness, as compared to White American patients (168). Some ethnic minority patients with CFS/ME suggest that the symptoms they experience may be due to cultural explanations and may therefore consult spiritual healers for help, rather than medical professionals (23). There are also negative perceptions of clinical care, with adult ethnic minority patients with CFS/ME in the UK describing the perception that there is limited care available for them to access (22). This is mitigated by a close relationship with a cultural or religious leader, which can increase the likelihood of patients from ethnic minority backgrounds, and in particular the South Asian community, presenting to a GP with symptoms consistent with CFS/ME (22). Therefore, multiple factors may combine to form barriers that limit access to specialist CFS/ME services for ethnic minority individuals.

There are barriers for ethnic minority patients with CFS/ME that exist in the primary care appointment. Ethnic minority adult patients with CFS/ME and their carers have reported negative experiences when attending UK GP consultations about their CFS/ME symptoms, with a view that they would not consult the GP again with the symptoms in the future (23). Ethnic minority patients have discussed being believed about their symptoms by their healthcare practitioner is important and how they have had to convince the GP about their symptoms (23). There are also language barriers that impact medical appointments and management (22,145). In addition, adults with CFS/ME are wary of being given stigmatising labels, for example ‘lazy’, by their community (22), which may impact accessing management of CFS/ME or seeking a diagnosis. GPs, who are social contacts or part of the wider ethnic minority community, could be less likely to diagnose CFS/ME than a GP who is unknown to the patient (23).

Despite GPs being hesitant of giving a label of CFS/ME and patients being wary of being stigmatised from their community, ethnic minority patients have described how the diagnosis can help them cope with their illness and seek understanding, along with a way to communicate with others about their symptoms (23).

2.3.3 Presentation of Symptoms of CFS/ME in Ethnic Minority Individuals

There is limited research globally in young people from ethnic minority backgrounds with CFS/ME and in adults, the literature is mixed. One community based study, which entailed a screening telephone survey, with those identified as having CFS/ME completing a second interview, found that adults with CFS/ME from ethnic minority communities had more severe symptoms such as: a higher lack of energy, greater fatigue levels after physical exertion, and poorer cognitive functioning (178). A meta-analysis found ethnic minority individuals with CFS/ME experience more severe symptoms, including more severe fatigue (168). Whereas contradictory evidence found no significant differences between CFS/ME symptoms in ethnic minority and White patients referred from primary care to a specialist service, with the exception of less social support and lower rates of major depressive disorder (176). Ethnic minority individuals who do make it through to specialist services appear to have no significant differences from White individuals (176), whereas those who do not make it through to specialist services (a community sample) appear to have more severe symptoms (178).

When referred to specialist CFS/ME services and given NICE recommended management, a study found that both ethnic minority and White British adults showed a significant improvement on the severity of fatigue and physical functioning measures (179). This study (179) investigated outcomes in adult patients referred to specialist CFS/ME services in London, UK and patients self-categorised their ethnicity into 'White British' or 'BME' (179). The BME group in this study made up 19% of participants (n=67) compared to 81% White British (n=285) and BME ethnicities were mixed with the largest proportions self-categorising as Black or Black British, followed by: Asian or Asian British, and Caribbean (179). The proportion of female participants was significantly higher amongst the BME participants (88.1%) compared to White British participants (71.2%), but no significant differences were found between the two groups in terms of CFS/ME illness duration, age, education, and work (179). Despite this, at baseline, BME participants had significantly higher "*scores relating to catastrophising, damage beliefs, all-or-nothing behaviour and avoidance/resting behaviour*" (179)(p.255). The CBT outcomes demonstrated a significant improvement in both White British and BME participants in terms of fatigue severity and physical functioning, despite the significantly higher baseline attributes, demonstrating that CBT is effective for CFS/ME adult patients from diverse BME backgrounds (179). Further

qualitative work could investigate the acceptability of CBT and if it is culturally sensitive and appropriate (179).

Adults with CFS/ME in England from diverse ethnic backgrounds, found that a lack of recognition of CFS/ME is especially difficult for ethnic minority groups, with participants reflecting that they have never heard of an ethnic minority individual who has the illness, and the view that it is a "*White middle class illness*" (180)(p.6). Individuals from ethnic minority backgrounds in the study reported a particular difficulty in accessing healthcare along with social care support, with more stigmatisation experienced and they reported receiving stereotyped responses from professionals, including a Caribbean woman stating that because of her ethnicity, her symptoms were not taken seriously and explained as due to a psychiatric cause (180). Adult ethnic minority participants stated their need for workers from their cultural background, who could relate to their illness and symptom presentation (180).

As seen in Section 2.1.5.3, there are numerous barriers to accessing specialist CFS/ME services for children. These barriers explain some of the factors that children and families face when accessing specialist medical care however it is important to focus on ethnic minority children as there has been limited work investigating CFS/ME in children from ethnic minority communities. To develop effective recommendations for removing the barriers for ethnic minority patients accessing specialist medical services, we need to first define the barriers this population face. This is the literature gap this thesis aims to fill.

2.4 Healthcare Access Models

Healthcare professionals, policymakers and researchers state that appropriate and timely access to care is vital in eliminating healthcare access disparities (181). Many factors combine to limit access to care for certain individuals (66) and multiple healthcare access models have been proposed to provide frameworks to capture reasons why individuals might not (or cannot) access care. Four models will be briefly discussed, along with their relevance to this PhD work:

1) The Health Care Access Barriers Model (HCAB) (182)
2) Andersen's Behavioural Model (AMB) of Health Services Use (183,184)
3) The Updated Institute of Medicine (IOM) Model of Access to Health Services (181)

4) The Cultural Determinants of Help Seeking (CDHS) Model (185)

The models illustrate different ways barriers to accessing healthcare have been measured and what is known about the barriers generally. All the models are general and do not differentiate what is in the parents' domain and what is in the child's domain. This PhD work will capture the barriers to accessing specialist CFS/ME services from child, parent, community and medical professional perspectives.

2.4.1 Health Care Access Barriers Model

Figure removed due to copyright.

Full figure to be found at:
Carrillo JE, Carrillo VA, Perez HR, Salas-Lopez D, Natale-Pereira A, Byron AT. Defining and targeting health care access barriers. Journal of Health Care for the Poor and Underserved. 2011;22(2):562–575.

*Figure 2: The Health Care Access Barriers (HCAB) Model **(182)**(p.565)*

The Health Care Access Barriers (HCAB) Model (Figure 2) provides a: "*taxonomy and practical framework for the classification, analysis and reporting of those modifiable health care access barriers that are associated with health care disparities*" (182)(p.562).

The model focuses on three broad barriers (financial, cognitive and structural) which lead to health outcomes, disparities through late presentation to medical/healthcare services,

decreased prevention behaviours and decreased levels of care (182). It is not intended to map all determinants of healthcare access, but instead incorporates barriers that are modifiable "*in order to serve as a practical tool for root-cause analysis and community-based interventions*" (182)(p.564).

The HCAB model illustrates the interplay between different barriers and how they subsequently affect healthcare access. The HCAB model has been used in previous research investigating health conditions in ethnic minority populations; a qualitative study used the HCAB model to investigate barriers to accessing healthcare for mixed-ethnicity vulnerable populations in Romania and found an additional theme of Psychological barriers, comprising of mistrust, hopelessness, fear and anxiety (186). This led to a proposed update of the HCAB model to become the Healthcare Access Barriers for Vulnerable Populations (HCABVP) model to account for unique barriers of vulnerable populations (186).

The HCAB model formed the basis of extraction for the Systematic Review described in the following chapter in this thesis (Chapter 3).

2.4.2 Andersen's Behavioural Model (ABM) of Health Services Use

Figure removed due to copyright.

Full figure to be found at:

Andersen R. Revisiting the Behavioral Model and Access to Medical Care: Does it Matter? Journal of Health and Social Behaviour. 1995;36(1):1–10.

Figure 3: Anderson's Behavioural Model (ABM) of Health Services Use (Phase 4) ***(183)****(p.8)*

Anderson's Behavioural Model (183,187,188) (Figure 3) has been widely used in studies investigating the use of health services and incorporates individual and contextual determinants of health service usage (4,184). The model was developed to understand why individuals access healthcare, as a tool to measure inequalities in access amongst different populations and also to inform future policy development (183,189).

The model proposes that predictions can be made on an individual's health service use based on population characteristics (including predisposing factors), resources that can enable or hinder access, and an also an individual's 'need' for care (183,184,187–190). Resources can enable, or hinder, healthcare access, and acknowledges that individuals must have the means and knowledge of the services and can use any care available (183,189). Individuals' need for care can be either: their perceived need (personal judgment on health, for example symptom severity) or evaluated need (a medical professionals assessment) (183,189).

The 'need' factor in Andersen's model is the most immediate cause of an individual's decision to seek healthcare, with the 'predisposing' and 'enabling' factors not enough alone for an individual to decide to seek treatment – the 'need' has to be present (188). This has been used in a study carried out in rural Bangladesh, with the severity of the disease (the 'need') providing a significant predictor on utilisation of health services (191), with female education also increasing health service utilisation (191). However, further work found 'enabling' variables explained more variance in individuals healthcare access than 'need' variables (192). The model has also been used to test help seeking for mental health in First Nations communities within Canada (189). Participants' characterisation of predisposing characteristics, for example: structures, health beliefs, and resources, had a high level of fit, but perspectives on the need for mental health care only had a moderate fit with Anderson's Model, suggesting the model could incorporate First Nations' cultural help-seeking beliefs (189).

There are theoretical limitations to the Anderson behavioural model. The decision-making processes that lead to an individual using a service are not incorporated in the model; the model explains the processes that are occurring but not the reasons why an individual chooses that behaviour (4). Even if a patient and healthcare provider are from the same cultural background, there can be differences in explanatory processes between the

individuals (4). For example, education, gender, generation or social class can be potential barriers between individuals of the same ethnic minority (4). All barriers are individualised to the particular patient and generalisations are difficult to make as some potential barriers are a 'potential' barrier and do not affect individual healthcare access (4).

2.4.3 Updated Institute of Medicine (IOM) Model of Access to Health Services

Figure removed due to copyright.

Full figure to be found at:
Cooper LA, Hill MN, Powe NR. Designing and evaluating interventions to eliminate racial and ethnic disparities in health care. Journal of General Internal Medicine. 2002;17(6):477–86.

Figure 4: Updated Institute of Medicine (IOM) Model of Access to Health Services (181)(p.479)

The original IOM model of health service access included personal, structural and financial barriers, this has been modified to expand the personal and structural barriers that limit healthcare access (181) (Figure 4). The addition of personal barriers, including family (particularly relevant to children's access), patient preferences and patient involvement, have highlighted a holistic view of barriers experienced and is the first step of intervention development to eliminate racial and ethnic disparities in accessing relevant health care (181). The other healthcare access models could be classified as 'adult-centric', but in the IOM model, the inclusion of family barriers can give a holistic overview, particularly relevant to paediatric healthcare access.

2.4.4 Saint Arnault's Cultural Determinants of Help Seeking (CDHS) Model

Figure removed due to copyright.

Full figure to be found at:
Saint Arnault D. Cultural determinants of help seeking: A model for research and practice. Research and Theory for Nursing Practice. 2009;23(4):259–78.

Figure 5: Saint Arnault's Cultural Determinants of Help Seeking (CDHS) Model (185)(p.278)

The CDHS model (Figure 5) focuses on specific cultural determinants of help seeking, but does not include structural barriers that affect healthcare access (185). Therefore the model is useful in understanding the role that cultural factors can play in accessing help seeking, but cannot be used to measure access barriers. The basis of the model is rooted in the concept that individuals from all cultural groups base individual help seeking behaviour on the cultural meaning assigned to their suffering (185). Individuals attribute meaning to their symptoms based on causal attributions and social significance, both in relation to the dynamics of the social context (185). The role of cultural factors will be explored in depth in this thesis and this model provides a useful framework to understand how culture can interact with help seeking behaviour.

2.4.5 Summary of Healthcare Access Models

The following table (Table 6) details summarises the barriers found in each of the three models grouped into broad themes from the descriptions of the models. It is presented here as a comparison on the different barriers found in each model and to provide context for the barriers found in this thesis.

Table 6: The Barriers Summarised from the HCAB, ABM and IOM Models of Healthcare Access (181–183)

Themes	Barriers	HCAB	ABM	IOM
Structural	Availability			X
	Availability: Medical Home	X		
	Transportation		X	X
	Transportation to healthcare facility	X		
	Travel time		X	
	Telephone access to providers	X		
	Lack of child care resources	X		
	Street safety	X		
	Waiting time	X	X	
	Multiple locations for tests and specialists	X		
	Continuity of care / regular source of care	X	X	
	Multi step care processes	X		
	Operating hours of health care facility	X		
	Appointments			X
	How healthcare system organised			X
	Availability of healthcare facilities		X	
Financial	No health insurance	X		
	Underinsured	X		
	Insurance coverage			X
	Reimbursement levels			X
	Public Support			X
	Ability to pay for health services / income / wealth		X	
	Price of healthcare / insurance		X	
Cognitive / Mental Factors	Knowledge barriers (including knowledge of health and health services)	X	X	
	Awareness of prevention facts	X		
	Awareness of health resources	X	X	
	Health literacy	X		
	Understanding of diagnosis	X		

	Understanding of treatment	X		
	Communication barriers	X		
	Availability: interpreter services	X		
	Language concordance of signage	X		
	Availability: cross cultural communication skills	X		
	Availability: translated materials	X		
	Racial / ethnic concordance of provider	X		
	Health beliefs (including belief healthcare will help)		X	
	Health attitudes		X	
Perceived need for healthcare	Characteristics of the illness		X	
	Expected benefit from treatment		X	
	Perceived health status		X	
	Severity of condition		X	
Personal / Family / Social	Acceptability			X
	Cultural			X
	Language / literacy			X
	Attitudes, beliefs			X
	Preferences			X
	Involvement in care			X
	Health behaviour			X
	Occupation		X	
	Social relationships		X	
	Ethnicity		X	
	Education / income		X	X
Contextual Factors	Demographic and social composition of communities		X	
	Collective and organisation values		X	
	Cultural norms		X	
	Political perspectives		X	

2.5 Intervention Development for Ethnic Minority Populations

When tailoring interventions to different ethnic minority groups, the term 'cultural leverage' is useful for considering designing and implementing culturally competent interventions: "*Cultural leverage is a focused strategy for improving the health of racial and ethnic communities by using their cultural practices, products, philosophies, or environments as vehicles that facilitate behaviour change of patients and practitioners.*" (193)(p.245). The term 'culture' encompasses deeper individual characteristics, such as shared values, therefore

these values can be incorporated to develop cultural leverage at either a group or individual level (194).

Cultural interventions can occur at three possible levels (193):

1) Individual - modify individual health behaviour through behaviour change, for example by using community members for culturally specific health messaging and involving culturally tailored approaches to health (193,194).
2) Access – improve healthcare access, for example by using patient navigators to improve access, raise awareness and to increase understanding (193,194).
3) Healthcare – targeting healthcare professionals to provide culturally specific care, for example through the use of culturally specific treatments and materials or using community health workers (193,194).

Many interlinking factors combine to form difficulties in accessing healthcare for different cultural groups. Interventions aiming to improve access to health care services for ethnic minority individuals should be multifaceted (181) and address multiple barriers to bring about multiple layers of change; interventions that aim to improve access by modifying a single barrier to access are unlikely to bring about change or equality in healthcare access (194). Culturally tailored interventions are important as they can individualise care by focussing on the specific barriers facing a particular individual, in a particular community trying to access a specific healthcare service (181,194). When designing an intervention for reducing access barriers it is important that ethnic minority groups are actively involved in developing the solutions from the outset, including through the use of stakeholder partnership and community involvement (181) and involves utilising an on-going relationship, to incorporate cultural nuances and propose effective strategies tailored for the specific cultural group (193).

2.6 Summary of the Literature

This chapter has provided an overview of relevant literature illustrating the recognition, diagnosis and the management of people with CFS/ME, with different methods used to estimate the prevalence of paediatric CFS/ME globally. This literature review also provided

an overview of ethnic minority populations and healthcare access, with relevant healthcare access models used to measure barriers and intervention development.

In summary, CFS/ME is subject to much debate between researchers, but the literature shows that it is a global issue alongside limited access to care for ethnic minority individuals. Ethnic minority children with CFS/ME are underrepresented in UK specialist paediatric services and this thesis will investigate why. CFS/ME in ethnic minority children is an under researched topic area, and this work aims to fill that evidence gap by investigating what the barriers are for ethnic minority children accessing specialist services and facilitators that helped young people access the specialist services. Furthermore this thesis will cover ideas for interventions to reduce barriers and increase the proportion of ethnic minority children accessing specialist CFS/ME services.

Chapter 3: Systematic Review (Project 1)

3.1 Systematic Review Overview

This chapter presents the methods and findings for the Systematic Review project, which aimed to understand the barriers, but also described the facilitators, for accessing specialist healthcare services for ethnic minority children. The systematic review also mapped the different types of interventions that have targeted ethnic minority children and healthcare access. This chapter is structured so that a brief overview of the systematic review and the topic area is provided, followed by the methods and findings, with a brief discussion concluding this chapter.

3.1.1 Rationale for the Systematic Review:

To my knowledge, no research has investigated CFS/ME in ethnic minority children and the barriers to accessing care; therefore a systematic review could not be conducted on this topic area and this thesis aims to fill this literature gap.

I therefore decided to make the systematic review broader to capture barriers for ethnic minority children accessing specialist secondary healthcare for any chronic or mental health condition, along with interventions aimed at reducing barriers to accessing specialist care. The systematic review provided context for the subsequent PhD projects. The results and key learning points from the systematic review informed the topic guide to be used in the qualitative work presented in Chapter 6.

The systematic search for this review was run using one search strategy but the review has been split into two distinct syntheses, with the titles as follows:

Barriers to accessing specialist healthcare services for ethnic minority (Black, Asian and Minority Ethnic – BAME) children: a systematic mapping review

Interventions aimed at improving access to specialist secondary healthcare services for ethnic minority children with chronic or mental healthcare conditions: a systematic mapping review

This chapter will present both mapping reviews as one synthesis. In presenting the results of the reviews in combination in this chapter, I will illustrate that the barriers and interventions are closely interrelated and designing an intervention focused on one barrier will not improve access, as the barriers are interlinked. Future research design needs to be aware of the barriers in order to design appropriate multi-faceted interventions to improve access to specialist services for ethnic minority children

3.2 Introduction to the Systematic Review

The prevalence of chronic health conditions worldwide in children ranges from 13% to 27%, and this is increasing over time (195). Children and adolescents with a chronic health condition are at increased risk of a mental health disorder, with the presence of a chronic health condition predicting mental illness at age 13 and age 15 (196). In particular, asthma is associated with a 60% higher risk of mental illness at age 13 and age 15 (196). The prevalence of mental health disorders worldwide in children is estimated at 13.4% (197) and amongst ethnic minority populations, studies have found even higher rates of disorders including anxiety and depression (198).

Those who identify as an ethnic minority (including those from Indigenous communities) face numerous barriers to care and can receive worse healthcare in general due to delayed treatment (seeking and diagnosis), along with disparities in quality of care received (66). Difficulty in accessing health services (and in particular mental health services) for ethnic minority individuals is a problem worldwide, including in Australia (199), and the USA (200). A 2003 systematic review found racial and ethnic disparities in healthcare access is independent of socio-economic status (201). In the UK, ethnic minority individuals experience more difficulties accessing healthcare services, especially mental health services (202,203), despite numerous government interventions aiming to reduce these disparities (202).

Mental health issues in childhood affect the long-term wellbeing and functioning of the individual (204). Therefore, barriers to accessing healthcare need to be addressed to facilitate early diagnosis and treatment to prevent long-term impacts. The American Psychological

Association (APA) recognises that many ethnic minority children continue to experience poor mental health due to low levels of healthcare access and care, along with healthcare that is not culturally competent, and has developed resources aimed at addressing this (205). In the UK, the NHS is currently modernising the Mental Health Act (206) and in 2003 introduced an initiative aimed at improving mental health services for ethnic minority communities (202). Despite this, barriers and disparities still exist and there is little known about the barriers faced by ethnic minority children in accessing mental health services.

More is known about the barriers that ethnic minority adults experience in accessing mental healthcare. For Latino populations in the USA, the cost of treatment and stigma are barriers to adults receiving adequate care (207). In Australian Indigenous communities found poor mental health literacy, different concepts of mental health and well-being, and poverty are barriers to accessing formal treatment (208). Ethnic minority adults in the UK have problems accessing mental health services due to numerous personal and environmental factors (individual recognition of mental health illness, social networks, cultural identity, stigma and financial), barriers related to the relationship between the service user and providers of healthcare (e.g. language skills) and awareness of available services (203). However, these barriers are not necessarily the same ones that ethnic minority children experience. For example, it has been found that ethnic minority children with healthcare needs in the USA are less likely to have health insurance and face difficulties in care (209). It is essential that barriers to care are identified and to provide culturally competent healthcare systems to reduce disparities for those children from ethnic minority backgrounds and reduce the long term impact of mental health conditions (210).

Interventions are important to reduce any access barriers different groups face. Interventions have the ability to reduce or remove access barriers and therefore improve access to healthcare for ethnic minority children. The most promising interventions have multiple different components and involve communities to ensure that any interventions are culturally acceptable and tailored to the individual, location and healthcare service (181,194). Interventions that modify a single barrier that impacts on an individual's ability to access appropriate medical services are unlikely to increase equality in accessing healthcare (194).

The aim of this review is to map the reported barriers to healthcare access for ethnic minority children with chronic or mental health conditions, as to my knowledge this has not been

investigated in children. The second aim is to map the different types of interventions that have been devised or piloted aiming to improve access to healthcare services for ethnic minority children with chronic or mental healthcare conditions. The included papers reporting barriers to accessing healthcare in the review also highlighted the role of facilitators and ideas for interventions to improve access; these data have also been extracted and synthesised from the papers and included in the review.

The specific review research questions were:

1. What does the evidence tell us about the barriers ethnic minority children and adolescents with chronic or mental health conditions face when accessing specialist medical services?
2. What interventions have been used to improve access (reduce barriers) to specialist healthcare services for paediatric patients from ethnic minority communities?

The HCAB model (182) has previously primarily been used in the literature to measure barriers for adults, as adults would typically access healthcare services on behalf of children and adolescents, therefore adult barriers may also be relevant. I applied it in this review as the basis for extraction and analysis as it provides a comprehensive tool to capture barriers for children and adolescents as identified in the papers.

3.3 Methods

3.3.1 Rationale for Systematic Review

For this thesis, to understand the results from the qualitative projects, I needed to review the literature around access to healthcare for ethnic minority children with chronic or mental health conditions globally, along with interventions that have been piloted to improve access and reduce barriers. Initially, a literature review on ethnic minority children and CFS/ME was considered and preliminary searches were ran, but there is a lack of research on children and there has been limited work since a 2009 systematic review (168). Through the preliminary literature searches, only one paper was identified that has looked at the barriers to accessing specialist CFS/ME services for ethnic minority patients and this was looking at the barriers for adults with CFS/ME (22).

Therefore, I decided instead to run a systematic review focussing on ethnic minority children and barriers to accessing healthcare for all chronic or mental health conditions, due to their hidden and stigmatised nature (211–213). Alongside looking at literature related to barriers (the barriers literature also included facilitators), a second strand of the review incorporated interventions that aim to reduce the barriers to accessing healthcare through a description of the interventions, any effectiveness measures along with barriers for implementation of the intervention. Through combining these two strands of the review, an overview of the barriers and ideas to reduce them will be demonstrated and can be incorporated into the results from the quantitative and qualitative work in this overall thesis to form the ideas for interventions that form the output from this PhD work.

For this research, a systematic mapping review was conducted. Systematic mapping reviews synthesise research findings by providing an overview of the literature on the topic (204). Whilst a systematic search is carried out, a systematic mapping review is not intended to be exhaustive and does not assess the quality of evidence (214), instead providing a descriptive synthesis of the findings and highlighting potential research gaps (204).

A systematic mapping review was selected as the systematic review methodology for this work as the evidence and research studies vary widely in terms of country, ethnicity, age, and healthcare condition studied. In addition, most of the included studies did not have enough information to use traditional quality of evidence assessors. Furthermore, the aim of this review is to provide an overview of both the barriers and interventions, to enable readers to see the areas of work that have previously been carried out, any successes or challenges, and where future research could be directed. Therefore, a systematic mapping review was decided as the most appropriate option to present the data collected from the varied papers in a synthesised way.

3.3.2 Searches

To perform the search and to ensure no relevant literature was disregarded, a detailed systematic literature search was developed in consultation with a systematic review specialist at the University. Preliminary searches identified mental health as being a common theme in

the literature identified and therefore terms related to mental health were incorporated in the search strategy.

The final search was based on specific terms (keywords and MESH headings) related to:

1) Black, Asian and Ethnic Minority individuals;
2) Children and adolescents.
3) Mental / Chronic health services
4) Health inequalities/healthcare access OR interventions to improve access to specialist healthcare services;
5) Secondary/specialist mental health OR chronic health services;

The final search strategy developed and ran is included in the Appendix. Six databases were searched in July 2018:

- MEDLINE
- EMBASE
- PsychInfo
- ASSIA
- CINAHL
- The Cochrane Library

To ensure that all relevant studies were identified and included, I also hand searched the reference lists of relevant studies for further literature, but no additional literature was identified.

3.3.3 Inclusion / Exclusion criteria

The following was the inclusion (Table 7) and exclusion (Table 8) criteria when reviewing identified literature.

Table 7: Systematic Review Inclusion Criteria

	Inclusion Criteria
Participants	• children who identify as ethnic minority (BAME) in the country in which they reside • aged between 5 and 18 old, along with parents/family members/key informants/clinicians if the child was the focus of the paper.
Context	• studies were included if they were published between 2008-2018, due to the implementation of the UK Government's Department of Health Race Equality Scheme (2005-2008) (215)
Study Type	• Studies were included if they reported empirical data that described barriers faced by ethnic minority children or interventions targeting ethnic minority children to improve access to specialist healthcare serves. • This includes data from qualitative studies and questionnaires.

Table 8: Systematic Review Exclusion Criteria

	Exclusion Criteria
Population	• Studies were excluded if they addressed only prevalence differences between populations, or differences in healthcare usage, and not barriers to healthcare access or interventions to improve access.
Language	• Papers were excluded if they were not in English due to resource limitations.
Context	• Papers were excluded if they were published pre-2008

3.3.4 Screening

References identified from the database searches were de-duplicated using Endnote (216) and then uploaded to the specialist systematic review platform Rayyan (217) for title and abstract screening.

To assist with carrying out the systematic review, eight individuals joined the review team to assist with screening and data extraction (Contribution Statement). The individuals who assisted were: second year Undergraduate Psychology students; Masters Psychology students; PhD students and a Paediatric trainee with an interest in research.

Myself and a second person from the review team independently screened papers using the pre-defined inclusion and exclusion criteria. Studies that were identified as potentially

relevant at the abstract/title screening stage were taken to full text review and all papers were screened independently by myself and another reviewer in Covidence (218) software. Any disagreement between myself and another reviewer at both title and abstract stage and full-text screening was highlighted on the software and was resolved through meeting, reviewing the paper and discussing if it met the criteria.

Hierarchy of full text exclusion:

- Duplicate
- Wrong context: before 2008
- Wrong population: not specifically looking at ethnic minority children (or their parents/family members views)
- Wrong paper type: protocol, abstract or presentation
- Wrong population: focus of paper not on child/adolescent aged 5-18
- Wrong intervention: not targeting ethnic minority child/adolescent
- Wrong population: parents access to healthcare

3.3.5 Data Extraction and Synthesis – Barriers

When the paper included White ethnicity along with data from ethnic minority individuals, data were only extracted from ethnic minority participants. If the paper included a chronic/mental health condition, along with a more general discussion on accessing all health care, only relevant data on chronic/mental health was extracted. If a paper included the views of those aged over 18, the data were only extracted if it related to adolescent healthcare.

Myself and another reviewer independently extracted data from all papers into a purpose designed database, designed specifically for this data extraction (see Table 9 for data extracted). Any disagreements between myself and another reviewer were resolved through discussion. Categories for data extraction were based on the Health Care Access Barriers (HCAB) Model (182) with an additional box for 'other barriers' if any barriers identified in the paper did not map onto the HCAB Model categories.

Table 9: Barriers Data Extracted (based on the HCABM) (182)

Demographic Data	Year Country Ethnicity Condition Study Design Sample Size Age (minimum and maximum) Population consulted
Structural Barriers	Availability of medical care Transportation to health care facility Telephone access to providers Lack of child care resources Street safety Waiting time Multiple locations for tests and specialists Continuity of care Multi-step care process Opening hours of health care facility
Financial Barriers	No health insurance Under insured
Cognitive Barriers	Knowledge barriers Awareness of prevention facts Awareness of health resources Health literacy Understanding of diagnosis Understanding of treatment Communication barriers Availability: interpreter services Language concordance of signage Availability: cross cultural communication skills Availability: translated materials Racial/ethnic concordance of provider
Other	Other barriers reported in the paper Facilitators reported in the paper Ideas for interventions reported in the paper

Using the HCAB Model (182) grounded the data extraction in existing and validated theory. However, the use of additional inductive coding of barriers and facilitators meant that this review was not constrained by the model and ensured that the findings were driven by the data in the papers. During the data extraction, qualitative data were extracted related to participant ideas for interventions. Quotes were extracted and synthesised into categories/ themes on discussion.

During the review, I had planned to use the exact categories in the HCAB model (182) for data extraction, however when piloting the extraction template new categories were devised (culture, stigma and trust), based on the above, but more able to capture the data in the included papers.

3.3.6 Data Extraction and Synthesis – Interventions

For the interventions extraction, a purpose designed database was used to capture descriptive details along with the design of the intervention and any results (Table 10). In addition, any barriers to implementing the intervention reported in the paper were extracted.

Table 10: Interventions Data Extraction

Demographic Data	Authors Country Year Ethnicity Condition Study Design Sample Size Age Minimum Age Maximum
Intervention Design	Type of Intervention Barrier(s) Addressed Intervention aimed at / target Setting
Intervention Results	Outcomes Effectiveness Barriers to implementation

All titles and abstracts and full text 'interventions' papers were double screened by a second screener from the review team. In total, 50% (11 out of 22) of the intervention studies were double data extracted for data verification and to check for accuracy in the extracted data.

3.4 Results: Barriers

The search identified 5994 papers (after de duplication) (Figure 6: PRISMA Diagram).

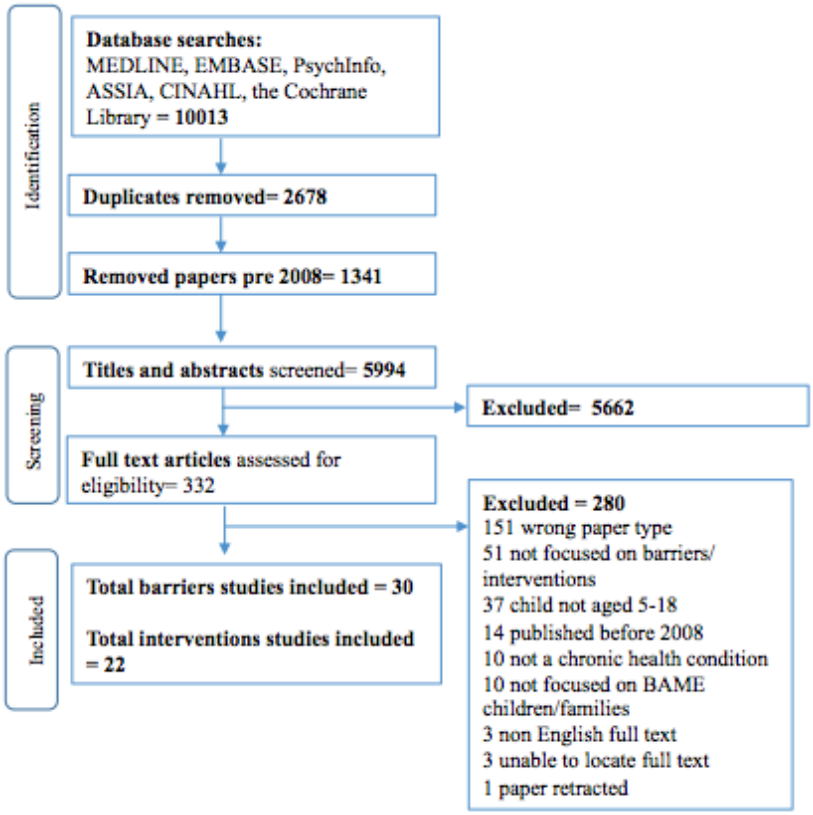

Figure 6: PRISMA Diagram of the Review Process

5662 papers were excluded from the review during title and abstract screening and 332 papers were taken to full text screening. The most common reason for papers excluded during full text screening was 'wrong paper type' for example a literature review paper or a conference abstract (n=151) and not focused on barriers/interventions, for example a discussion of differences in prevalence (n=51).

In total 30 'barriers' papers were included in this mapping review with a total of 2038 participants.

The HCAB model (182) was found to be too limited for the papers included; therefore on discussion with the research team, I added the following categories:

- Culture,
- Stigma

- Trust

These categories were important to include as they were commonly found in the papers and did not neatly map onto an existing category. As the review aimed to ensure the barriers collected were indicative of the participants' own words and their personal descriptors of the barriers, it was important to add these new categories that the participants in the papers described as a barrier to accessing healthcare.

3.4.1 Study characteristics / description of studies

Country: Of the 30 studies, 17 were conducted in the USA, 5 in the UK, 3 in Australia with the remaining studies were conducted elsewhere in Europe and in New Zealand (see Table 11).

Table 11: Characteristics of Participants in Included Barriers Studies

Criterion	Characteristic	Number*
Year	2010	4
	2011	3
	2012	2
	2013	4
	2014	2
	2015	7
	2016	2
	2017	3
	2018 (June)	3
Country	USA	17
	UK	5
	Australia	3
	Netherlands	2
	New Zealand	1
	Norway	1
	Portugal	1
Diagnosed/ Personal Experience (With Condition)	No	17
	Yes	14
Informant	Parents / Carers	20
	Young People	14
	Healthcare Professionals / Staff	7
	Key Informant	3
	Teachers	1
Methodology	Qualitative Focus Groups	15
	Qualitative Interview	12
	Quantitative Survey	5
	Mixed Methods (Qualitative and Quantitative)	2
Condition	Mental Health	20
	ADHD	2
	Depression	2
	Mental Health and Healthcare	2
	Autism	1
	Mental Health / Suicide	1
	OCD	1
	Physical and cognitive impairments	1
Ethnicity	African American	8
	Latino	4
	Afghan	3
	Iranian	3
	Somali	3
	American Indian / Alaska Native	2
	Chinese	2
	Eritrean	2
	Indian	2
	Iraqi	2
	Minorities - not specified	2

	Moroccan	2
	Pakistani	2
	Turkish	2
	Aboriginal	1
	Angola	1
	Arab - not specified	1
	Asian - not specified	1
	Black African	1
	Black Caribbean	1
	Bosnian Refugee	1
	Cape-Verde	1
	Guinea-Bissau	1
	Hispanic	1
	Korean	1
	Liberian	1
	Malaysian	1
	Malaysian Chinese	1
	Mozambique	1
	Persian	1
	Refugee - not specified	1
	Serbian Refugee	1
	Sri Lankan	1
	Sudanese	1
	Taiwanese	1

*multiple reported in most papers

The studies varied in the informants they included (Table 11), with 20 papers including parental or carers views, 14 including young people, 7 including healthcare professionals/ healthcare staff, 3 including key informants (community members; refugee services; youth leaders) and 1 consulting teachers. Some studies (n = 11) included more than one participant type and in total 45 groups of informants were included in the 30 papers.

Most included studies employed qualitative methodology (15 using focus groups, 12 using interviews) with 5 papers utilising a quantitative survey and 2 papers mixing methods (Qualitative and Quantitative). Some studies used a combination of focus groups and interviews; these were recorded as separate methods.

Although the review aimed to include any chronic healthcare condition, all papers eligible for inclusion discussed barriers to accessing mental healthcare for ethnic minority children rather than physical health conditions.

Ethnicities were varied, with the highest proportion of participants identifying as African American (7), with Latino (4) second. I recorded participant ethnicities in the way that they described themselves, aiming to capture the terms used in the studies included in the review as closely as possible (see Table 11).

3.4.2 Barriers identified in the literature

The most prevalent barrier identified in the literature for ethnic minority young people accessing specialist healthcare services was knowledge of the condition, followed by cultural barriers, communication barriers, stigma and lack of awareness and understanding of healthcare services/resources (Table 12).

Table 12: A Count of Barriers Identified

Criterion	Characteristic	Number of studies*
Barrier identified	Service structure/accessibility	11
	Financial	10
	Transportation	8
	Lack of services	7
	Waiting Time	5
	Knowledge of condition	23
	Culture	22
	Communication	20
	Stigma	18
	Awareness and understanding of healthcare services / resources	15
	Trust	14

*multiple barriers in most papers

In terms of Knowledge, participants talked about differences in how conditions would be classified ("*White people generally know that it is depression but Pakistanis have different views"* (219)(p.39)). This is closely related to the barrier of Culture. Table 13 provides further qualitative illustrative examples of the barriers present in the papers in the participants' own words.

Table 13: Qualitative Examples of the Barriers

Barrier	**Example**
Transportation	"*It's really difficult for a lot of our families to get to and if there were more of these services in other areas of the city that would make things a lot easier*" (220)(p.476)
Waiting Time	"*If you try to get a child into adolescent mental health you have a 3-year waiting list*" (221)(p.604)
Financial	"W*hen I tried to find a psychologist for my son, all of them don't accept Medicaid*" (222)(p.1531)
Knowledge of condition	"*I think it is different when it is Pakistani and White people because White people generally know that it is depression but Pakistanis have different views*" (219)(p.39) "*The school said my son needs to see a psychologist, but I don't think that really treats my son's condition [depression]* " (223)(p.54)
Awareness and understanding of healthcare services / resources	"*(Mental health services) aren't advertised enough in this community, I mean if the point is for parents to know. People don't let you know, ''we have this service for the children.'' Or ''If you need help, then this is the number that you could call*" (224)(p.1123)
Communication	"*I am worried that I cannot communicate with a doctor due to English problems*" (223)(p.53)
Stigma	"*I saw children with mental problems and they are at home and the parents would not take them to a psychologist or a psychiatrist because it is a shame... and the family will be stigmatized*" (225)(p.29) "*Somali people are not really into the whole scientific stuff, like therapy and all that. They think you're just crazy*" (226)(p.801-p.802) "*people think others are crazy when they go to the psychologist*" (227)(p.687)
Culture	"*Talking to a therapist, that's something we laugh at in our culture because we're like . . . "why would you want to talk about your issues?" . . . Somali's don't seek therapy*" (226)(p.801)
Trust	"*I didn't say to anything about my problem, I didn't tell it to anybody, you know, because I don't trust anybody*" (228)(p.132)

Further analysis showed differences in the data, depending on who provided the data and where the study was conducted. In the data extracted from the six papers that solely included children/young people (219,228–232), no structural/financial barriers were described, the barriers reported were all cognitive level barriers (Knowledge of condition, Culture, Communication, Stigma, Awareness and understanding of healthcare services / resources,

Trust). All six papers reported communication, stigma and trust barriers. Five out of the six papers reported knowledge barriers and culture barriers (Table 14).

In the data extracted from papers that captured parent views, a more even spread of barriers is found, with structural barriers, such as service structure/accessibility present. (Table 14)

Table 14: Reported Barriers by Informant

Barrier	**Ps**	**YP**	**YP, Ps**	**HPs**	**YP, Ps, HPs**	**HPs, KIs**	**Ps, HPs**	**YP, Ps, Ts, HPs**	**KI**	**Ps, KI**
Lack of services	1		2	1		1		1		1
Transportation	4		1	2		1				
Waiting time	2			2			1			
Service Structure / Accessibility	3		1	1	2	1	1	1		1
Financial	4		2	1		1		1		1
Knowledge of condition	9	5	3	2	1	1		1		1
Awareness and understanding of healthcare services/ resources	7	2	2	1	2				1	
Communication barriers	5	6	2	2	1	1	1	1		1
Stigma	5	6	4	1				1		1
Culture	6	5	3	2	1	1	1	1	1	1
Trust	3	6	2	1		1	1			
Number of Papers	*10*	*6*	*5*	*2*	*2*	*1*	*1*	*1*	*1*	*1*

Key:

Ps = Parents / Carers; YP = Young people; HPs = Healthcare professionals; Ts = Teachers; KI = Key informants

Although financial barriers are not prevalent overall in the papers, 90% of studies that reported financial barriers were conducted in the USA, likely due to the healthcare system, (with one in Portugal); 9 out of 17 USA studies reported financial barriers. In all studies, cognitive level (such as knowledge, stigma, awareness) barriers were more commonly identified than structural level barriers (Table 15).

Table 15: A Count of Barriers Identified by Country

Barrier	USA	UK	Australia	The Netherlands	New Zealand	Norway	Portugal
Lack of services	5	1					1
Transportation	6	1	1				
Waiting time	2	1	2				
Service Structure / Accessibility	6	1	2			1	1
Financial	9						1
Knowledge of condition	14	3	2	2		1	1
Awareness and understanding of healthcare services/ resources	8	2	2	1	1	1	
Communication barriers	9	4	3	2		1	1
Stigma	10	4	1	2			1
Culture	12	4	3	1	1		1
Trust	7	3	3	1			
Number of papers	*17*	*5*	*3*	*2*	*1*	*1*	*1*

3.4.3 Facilitators Identified

Some 'barriers' papers (n = 5) described facilitators, defined as those factors that help improve access to care. Facilitators are summarised in Table 16.

Table 16: Facilitators Identified in the Literature

Providers being "*fluent in different languages*" (220)(p.477)
Providers being "*aware of different cultural practices*" (220,221)(219 p.477)
Religion: religion as a source of healing (226)
A close community can inform parents about their children's issues (226)
Friends being key sources of help (226)
Different referrals to mental health care: teachers, parents and primary care providers (227); schools and the juvenile court system (224)
Strong relationship with family (221)

3.4.4 Ideas for Interventions

Informants in the 'barriers' papers provided multiple ideas for improving access to healthcare, in particular improving trust (228,233) and reducing the taboo of the condition (234).

Table 17 captures the ideas from the informants. The most frequently discussed ideas for improving access addressed knowledge barriers and included specialist support workers from similar cultural backgrounds, and school-based education programs. Ideas on how to improve cultural competence were also discussed in multiple papers.

Table 17: Ideas for Interventions from Participants

Barrier	Ideas for interventions
Knowledge of condition	Information on risk factors (219) Community events to increase knowledge in the community (219,235) School based education programs (226,229) Peer mentor (236) / Role models (236) Involving family (226,234) Support groups for parents (235)
Culture	Incorporate local understandings of wellness (233) Culturally sensitive services (225) Specialist support workers from similar cultural background (221,222) Traditional ways of learning and teaching (233) Culturally sensitive education in community settings (223)
Service structure/accessibility	Building relationships between agencies e.g. school, social services (236) Out of hours services e.g. helplines (235) Offer services in community settings (224,229)
Awareness and understanding of healthcare services / resources	Information on available services - e.g. leaflets (219) Educate about the healthcare system (222,237)
Communication	Material translated (219)

3.5 Results: Interventions

The second part of the systematic review included published papers that had devised (through model development) or piloted interventions aiming to reduce barriers and improve access to specialist secondary services for ethnic minority children globally. The inclusion of interventions captured data on effectiveness or acceptability to provide context for intervention ideas resulting from this PhD thesis.

When extracting the interventions papers, I also captured data about any barriers the intervention was targeting. This enabled me to analyse whether interventions we targeting the most common barriers found in the first part of this review.

3.5.1 Description of Interventions

In total, 22 intervention studies (that aimed to reduce disparities in specialist secondary medical services access for ethnic minority children with chronic or mental health conditions) were included in this review.

The interventions identified covered a broad range of countries and aimed to reduce different barriers for different conditions, therefore this descriptive analysis does not aim to report on effectiveness of the interventions, but instead to map what interventions have previously been designed or tested.

The ethnicities of the participants in the papers were varied (Table 18), with the highest proportion of participants identifying as Latino (n=7), with African American (n=5) second. The ethnicities of the participants are recorded here in the way they were captured in the study papers.

Table 18: Characteristics of Participants in Intervention Studies

Criterion	Characteristic	Number*
Ethnicity	Latino	7
	African American	5
	Refugee	3
	Hispanic	2
	Refugee and Asylum Seekers	2
	Aboriginal Australian	1
	American Indian or Alaska Native	1
	Asian American	1
	Mexican	1
	Central American	1
	Chinese	1
	Filipino American	1
	Maori	1
	Mi'kmaq (Canadian First Nations)	1
	Mixed race	1
	Refugee (Africa)	1
	Refugee (Asia)	1
	Refugee (Balkans)	1
	Refugee (India)	1
	Somali and Somali Bantu	1

*multiple reported in most papers

Of the 22 studies, 14 were conducted in the USA, 5 in the UK, and 1 each in Australia, Canada and New Zealand. Most studies were aimed at general Mental Health (n=13), with 4 papers specifically looking at depression. Two papers were aimed at chronic healthcare conditions, as opposed to mental health, one paper looking at asthma and one paper looking at an intervention for obesity healthcare (Table 19).

Most studies were aimed at multiple groups of participants, with 16 studies aimed at young people and 9 were aimed at parents. The majority of interventions took place in a school (n=11) or in a community setting (n=7).

Table 19: Characteristics of Included Intervention Studies

Criterion	Characteristic	Number*
Year	2008	1
	2009	1
	2010	2
	2011	1
	2012	4
	2013	1
	2014	2
	2015	2
	2016	4
	2017	4
	2018 (June)	0
Country	USA	14
	UK	5
	Australia	1
	Canada	1
	New Zealand	1
Study Design	Intervention Development	8
	Model development	5
	Pilot	4
	Evaluation of service delivery	2
	Initiative	2
	Intervention	2
	Cluster randomised control	1
	Evaluation of service model	1
	Evaluation of workshop	1
	Instrument Development	1
	Model	1
	Pilot evaluation	1
	Quasi-experimental design	1
	RCT	1
Condition	Mental Health	13
	Depression	4
	Anxiety	1
	Autism Spectrum Disorder (ASD)	1
	Asthma	1
	Disruptive Behaviour Disorders (DBD)	1
	Obesity	1
	Post-Traumatic Stress Disorder (PTSD)	1
	Suicide Prevention	1
Aimed at	Young People	16
	Parents	9
	Family	5
	Community	3

	Teachers	2
	Healthcare Professionals	1
	Health System	1
Setting	School	11
	Community	7
	Home	3
	Clinic	2
	Flexible locations	2
	Primary care clinic	1

*multiple reported in most papers

The most prevalent barrier interventions aimed to address was culture (n=15), followed by stigma (n=13), language (n=11) and trust (n=8) (Table 20).

Table 20: Barriers Addressed in Interventions

Barrier	**Count**
Culture	15
Stigma	13
Language	11
Trust	8
Knowledge	7
Financial	5
Service Structure	4
Engagement with services	3
Concerns accessing treatment could affect asylum application	2
Transport	2
Accessibility of services	1
Availability of services	1
Awareness of prevention facts	1
Childcare difficulties	1
Cost	1
Difficulties accessing services	1
Health Insurance	1
Health Literacy	1
Lack of access to health services	1
Lack of services in neighbourhood	1
Less likely to present to health services	1
Phone/ internet access	1
Piecemeal service plans	1
Poorly trained staff	1
Scheduling	1
Service Availability	1
Symptom Recognition	1
Treatment Engagement	1
Waiting Lists	1

The following table (Table 21) provides a comparison of the barriers identified in the first part of this review with barriers aimed to be addressed in the intervention studies. As can be seen from the table, culture features highly along with stigma in both 'barriers' papers and where 'interventions' papers have been targeted.

Table 21: A Comparison of Barriers Identified and Barriers Addressed

Ranking	Barriers Papers	Interventions Papers
1.	Knowledge of condition	Culture
2.	Culture	Stigma
3.	Communication / Language	Communication / Language
4.	Stigma	Trust
5.	Awareness and understanding of healthcare services / resources	Knowledge
6.	Trust	Financial
7.	Service structure/accessibility	Service Structure
8.	Financial	Engagement with services
9.	Transportation	Concerns that accessing treatment could affect asylum application
10.	Lack of services	Transport

3.5.2 Types of Interventions Overview

This review found different types of intervention studies (Table 22), which can be summarised into five groups as follows:

1. Delivery in Different Location Interventions
2. Improving Access Interventions
3. Prevention Interventions
4. Awareness Interventions
5. Screening Interventions

Table 22: Count of Type of Intervention

Type of Intervention	Number
Delivery in Different Location	8
Improving Access	5
Prevention	4
Awareness	3
Screening	2

3.5.2.1 Delivery of Interventions in Different Locations

The first type of intervention, found in eight out of 22 papers, is the delivery of specialist chronic or mental health services in different locations. In the interventions included in this review, the locations were: school, community, or online. Table 23 summarises Delivery of Interventions in Different Locations

Table 23: Delivery of Interventions in Different Locations

Reference	Country	Condition	Type of Intervention	Setting
(238)	USA	Mental Health	Step-Up – "*a high school based mental health service delivery model*" (238)(p.175)	School
(239)	USA	Mental Health	FACES (Family, Adult, and Child Enhancement Services) – "*a community based mental health program*" (239)(p.121)	Community
(240)	UK	Mental Health	The Haven: provides therapeutic support in schools	School
(241)	USA	Depression	Rise Above (Siempre Sale el Sol) "*Web based, self-help depression intervention for Latina/o adolescents*" (241)(p.37)	Web-based
(242)	UK	Mental Health	An early assessment and intervention school based service "The Haven Project"	School
(243)	USA	Depression, PTSD	Project SHIFA: includes, "*school-based early intervention groups for at-risk students, and direct intervention*" (243)(p.129)	School
(244)	UK	Mental Health	School based mental health service	School
(245)	UK	Mental Health	School based mental health service	School

All studies were on mental health conditions, even though the search was for mental and chronic health, with 6 out of 8 located in schools; 1 web based intervention and 1 community based. The aims of the interventions were to reduce the stigma, cultural barriers and language barriers of traditional mental health services by offering diagnosis and treatment in different settings.

The provision of school based mental health services was found to be acceptable and effective for young people. In one UK study, 40 qualitative interviews were carried out with refugees who had attended mental health services integrated within a school setting, to understand their experiences of attending the service (245). Two thirds of the adolescents preferred to be seen at school, due to the perceived familiarity and safety of receiving mental health care in a school setting (245). In addition, the young people described that the contact between teachers and the mental health service, in terms of referral and collaborations, was important (245). A further exploratory study of a school-based mental health service in the UK for refugee children found improvements in the 47 refugee children who completed the study in both the hyperactivity and emotional symptoms scale on teacher-completed Strengths and Difficulties Questionnaire (SDQ) (244).

Two further papers from the UK reported on creating of the Haven Project in Liverpool, funded by CAMHS, to provide early mental health assessment and intervention in schools for refugees and asylum seekers (242). The project team were integrated into the schools, providing therapeutic work and group interventions for refugee and asylum seeking children (242). Questionnaires and interviews with school staff reported positive feedback (242) and the report on the Haven Project states that:

"*a school based mental health provision for asylum and refugee children appears to provide timely and appropriate intervention to a population of young people who do not traditionally access mental health services*" (242)(p.225)

A service review of the Haven Project indicated that "*refugee children are more likely and prefer to access a school based mental health service than a CAMH clinic*" (240)(p.164), with reports of mental health improvements in the children who took part in the project, based on outcome measures from the group sessions; but findings are limited by the small number of cases included in the project (42 young people) (240).

Further results looked at delivering mental health services in schools, through the Step-Up program, to African American and Latino youth (238). The collaboration between schools and the Step-Up program is vital, as school staff identify students who would be eligible for the program (238). The program consisted of a flexible model of varied group and individual sessions for the young people, aiming to build life skills (238). The program also included a family intervention component, recognising that the young people may not need, or be ready to access, formal mental health care, or formal mental health care may not meet the needs of the young people (238). The program had high levels of engagement, with 81 students continued with one or more components of the program, with a retention rate of 89% (238).

One paper reported on Project SHIFA, a multi-tiered program that combines prevention, community resilience building, school-based early intervention groups, and direct intervention (243). The program involved Somali clinicians in the school based groups, and of those referred for further care, a Somali cultural broker was involved and accompanied the clinician; all clinicians involved also received information in delivering services to refugees (243). 30 Somali and Somali Bantu refugee youths in the USA were enrolled and there was 100% treatment engagement for those referred for higher levels of care and improvements in mental health for those in the program (243).

One community based mental health program for refugee children used the FACES program (International Family, Adult and Child Enhancement Services) (239). The program used ethnic minority health workers and was delivered at convenient locations for the participants, including at home, community or in school to reduce stigma (239). Longitudinal data analysis on 68 program participants showed improvements, and language match between the provider and the participant was associated with the participants remaining in treatment for longer (239).

The final paper reported on the development of a web-based, self-help intervention for depression in Latino/a adolescents and interviewed providers on the feasibility of the intervention (241). 75% of 33 respondents thought a web-based invention would increase treatment engagement through the incorporation of culturally appropriate features, for example Spanish language, and 56.3% of respondents thought the intervention could increase mood and knowledge of depression and be particularly valuable for individuals not familiar with mental health disorders (241).

3.5.2.2 Improving Access Interventions

The second type of intervention (Table 24) involved specific individual healthcare services in a given location altering their working practice in order to improve access. Five studies were found

Table 24: Improving Access Interventions

Reference	Country	Condition	Type of Intervention	Setting
(246)	Canada	Asthma	Five focus groups; introduced to findings from previous intervention; groups explored issues associated with implementation	Community
(247)	USA	Obesity	Improving access to the Families in Training Program, family-weight management clinic; employed a bilingual case manager and used Spanish language in the clinic; culturally sensitive retention strategies were developed	Clinic
(248)	USA	ASD	Family peer advocate; randomised to either the family peer advocate group or a community care control group	Community
(249)	New Zealand	Mental Health	Evaluation to assess service acceptability (Te Tomo mai survey developed and used to assess the acceptability of CAMHS delivery)	Clinic
(250)	Australia	Mental Health	Model of engagement for Aboriginal youth incorporating: location of therapy; including cultural norms; the use of a cultural consultant	Flexible

These five interventions provided descriptors, models or ideas of how specific services had reduced their access barriers in ethnic minority young people (246–250) with a variety of countries, ethnicities and conditions. One intervention was for asthma (246), one for obesity (247), one for ASD (248) and two for mental health (249,250).

Three out of the five interventions were targeted for health in indigenous youth: one in Canada for Mi'kmaq, First Nations (246); one intervention from New Zealand for Maori young people (249) and one in Australia for Aboriginal Australian young people (250). The

remaining two interventions were in the USA targeting Latino young people (247) and African American or Hispanic young people (248).

For specialist obesity health services for Latino young people, a bilingual case manager was employed and a Spanish language division of the clinic was created, along with culturally relevant and sensitive retention strategies, leading to an increase in Spanish speaking families beginning treatment, along with higher retention and program completion among Spanish speaking families (247).

To improve access for African American or Hispanic young people with suspected autism spectrum disorder (ASD) to specialist services, a randomised controlled trial allocated families of 39 children with ASD to a 'peer advocate' group to facilitate engagement and access to healthcare, or a community care control group (248). Despite there being no change in the healthcare utilisation of ASD healthcare services for the two groups, those who received the intervention reported significantly increased knowledge of ASD and lower stress levels, measured on the Parenting Stress Index (Short Form) (248). However, this study excluded non-English speaking families who may have different needs and barriers than English speaking families (248).

A mental health service evaluated their service delivery and developed an instrument to assess the acceptability of the services for Maori young people (249). Four factors were identified to improve acceptability of child and adolescent mental health services (CAMHS) delivery: "*cultural sensitivity, satisfaction, appropriateness and access*" (249)(p.101) with a desire for therapeutic models that incorporate culture and spirituality in delivery to Maori young people (249). Similarly the final improving access intervention developed and piloted a model of engagement with mental health services for Aboriginal Australian youth (250). The model incorporated: the location of the services, the use of Aboriginal cultural norms and using an Aboriginal cultural consultant (250), with the model effective in engaging 97% of the Aboriginal youth taking part, with only 3 Aboriginal youth not engaged (250).

One improving access intervention focussed on intervention preferences for asthma in Mi'kmaq young people (246). Face-to-face interviews were conducted with Mi'kmaq children with asthma and their parents, followed by an 'asthma camp' intervention in the first two phases of the intervention (246). In phase 3, 22 healthcare professionals were recruited

to focus groups for their perspectives on interventions and indicated that increased information for asthma awareness is needed and schools need to be involved in terms of school-based asthma education (246). In addition, health interventions were needed (e.g. support groups, education nights) but a lack of cultural competence and parents experiencing racism in health care settings, may make engagement challenging (246).

3.5.2.3 Prevention Interventions

Four papers (Table 25) focussed on mental health and prevention in ethnic minority children to reduce the barriers to accessing specialist services (251–254).

Table 25: Prevention Interventions

Reference	Country	Condition	Type of Intervention	Setting
(251)	USA	Anxiety and Depression	Prevention - school based mental health EHC (Emotional Health Curriculum)	School
(252)	UK	Mental Health	"Tree of Life" groups for parents and children in schools - develop empowering stores about their lives rooted in their culture; strengths based approach	School
(253)	USA	Mental Health	School based curriculum	School
(254)	USA	Mental Health	Intervention development – piloting of a faith based program in faith settings	Community (church)

Two papers focused on school based curriculums in the USA involving just the young person (251,253) and one UK intervention involved parents and children in groups in schools (252). The final paper from the USA took the form of intervention development which provided recommendations and the piloting of a faith based program in the community in a church setting (254).

One school based Emotional Health Curriculum (EHC) for Hispanic young people found: decreases in child reported depression and anxiety, decreases in teacher reported anxiety and high satisfaction (89.7%) with the curriculum (251). The EHC was culturally adapted to the

community, through the use of metaphors and the inclusion of both Spanish and English language and retention rates were high at 94% (251).

A further school based curriculum was adapted for ethnic minority youth and found a significant increase in internal resilience and the curriculum was a way to de-stigmatise mental health issues (253), but this pilot study is limited by a lack of a control group and the results could "*potentially reflect natural improvement of the students*" (253)(p.235). Pre- and post-surveys given to students showed low attendance for those completing the program (100 students completed the survey at the first session; 60 completed the survey at the last session) potentially reflecting differences in the students who completed the program (253).

The UK prevention program involving refugee parents and children, focussed on culture and found children developed their self-confidence through sharing stories of their lives (252). Participants attended a 'Tree of Life' group as an alternative to traditional mental health services, which can be difficult to access due to: stigma, a lack of knowledge of what is offered, and a lack of cultural considerations (252). The groups focussed on a strengths based approach and explored difficulties specific for the refugee experience and despite not evaluating effectiveness, teachers reported more positive behaviour in the children who had attended the groups (252).

The final prevention program took the form of intervention development to prevent mental health disparities for Filipino-American youth (254). Focus groups and interviews were held with stakeholders (including young people and their parents) to produce recommendations for interventions (254). Based on the recommendations a parenting intervention was piloted using a faith-based approached as focus groups and interviews highlighted "*faith settings as a community-identified and culturally appropriate strategy*" (254)(p.316) for Filipino-Americans to reduce mental health disparities (254). Further intervention ideas included a collaboration with churches to reduce the stigma of mental health (254).

3.5.2.4 Awareness Interventions

Three interventions situated in the USA aimed to raise awareness of mental health / suicide and available healthcare for Chinese (255) and Latino (256,257) young people (Table 26).

Table 26: Awareness Interventions

Reference	Country	Condition	Type of Intervention	Setting
(255)	USA	Suicide Prevention	Education and Awareness Initiative: workshop involving vignette case discussions and culturally relevant presentation of mental health education	Community
(256)	USA	Mental Health	e-health information intervention: to increase awareness of mental health and services	Community
(257)	USA	Mental Health	Culturally relevant education and engagement - Todas a bordo (All Aboard)	Flexible

One study involved workshops and culturally relevant presentations focussing on education and awareness of suicide in Chinese parents (255), one involved an e-health information intervention (through a website) to increase awareness of mental health in Latino children and service utilisation (256) and the final one involved a culturally relevant video, shown by health workers to parents, to educate Latino parents in child mental health care (257).

None of the three awareness interventions measured effectiveness and this needs to be further evaluated (257):

"*as with all suicide prevention initiatives that focus on education and awareness, it is hard to gauge the effectiveness of the parental workshops*" (255)(p.30).

Despite this difficulty in gauging effectiveness, 10% of parents in one workshop did seek consultation and seemed receptive to the idea of counselling (255).

3.5.2.5 Screening Interventions

The final type of intervention is screening interventions (Table 27), involving universal screening in a particular setting.

Table 27: Screening Interventions

Reference	Country	Condition	Type of Intervention	Setting
(258)	USA	Disruptive Behaviour Disorders	Integrating Care - Screening for mental health in primary care	Primary Care Clinic
(259)	USA	Depression	Universal mental health screening in a school based mental health service	School

In this review, two screening interventions situated in the USA (258,259) specifically looked at integrating universal screening as a method to reduce barriers for ethnic minority children accessing mental health care. One intervention (258) did not measure effectiveness but described an intervention that will be piloted to screen for mental health illness in primary care clinics, as well as integrating mental health providers in different healthcare facilities, improving existing services and improving training on mental health to clinical staff.

The other intervention (259) was designed as a cluster randomised control intervention to investigate universal depression screening in schools with predominantly Latino and Asian American students to improve healthcare access for depression. Although the universal screening successfully identified students who may have not received a routine referral, referrals initiated from the universal screening were less likely to lead to caregiver / parental consent for mental health treatment compared to the routine mental health referrals (259). Caregiver consent was obtained 36.7% of the time, with a lack of family engagement and parental mental health literacy as reasons for lack of consent for further treatment (259). Furthermore the intervention did not lead to a significant reduction in ethnic disparities (259). The authors concluded that:

"Mental health screening alone is not sufficient in improving the use of School Based Mental Health Services (SBMHS) for Asian American or Latino students. Although universal depression screening may have improved problem detection as shown by an increase in referral following administration of PHQ-A (Patient Health Questionnaire), screening

appeared to have had limited impact on parent perceptions and responses to identified problems." (259)(p.532).

3.5.3 Outcomes Reported

In terms of outcomes reported, most did not report statistical effectiveness or present outcome data of the interventions. 16 out of 22 papers did report some effectiveness data, mostly descriptive data, not formal outcomes or effectiveness. The following table (Table 28) presents the descriptive outcomes of the papers that did report data.

Table 28: Intervention Outcomes Reported

Reference	Type of Intervention	Effectiveness
(238)	Delivery in Different Locations	Completion of High School: 81 completed the program; 27 graduated from high school within 1 year; 18 transferred to another school or program; 36 currently completing high school
(239)	Delivery in Different Locations	Participants improved on CAFAS over time.
(240)	Delivery in Different Locations	Program succeeded in reaching those who are likely to disengage with mental health treatment Schools recognised the benefits of CAMHS in the school
(242)	Delivery in Different Locations	Positive feedback from schools; helped children settle in to school and build relationships The school based assessment and intervention service provided was appropriate and timely for children who do not usually access mental health services
(243)	Delivery in Different Locations	Improvements in mental health; significant improvements in PTSD and depression symptoms 100% treatment engagement in young people referred for higher levels of care
(244)	Delivery in Different Locations	Improvements in hyperactivity scale and emotional symptoms scale
(245)	Delivery in Different Locations	2/3 of young people preferred to be seen in school; majority found intervention helpful; teachers played a valuable role in supporting contact with the mental health team
(246)	Improving Access	Increased levels of community support and awareness of the chronic disease; enquires about running another community event

(247)	Improving Access	13 Hispanic families began treatment (compared to 1 family before the intervention); 16% of patients Spanish speaking; 70% of families successfully completed the program, and significantly fewer families withdrawing (at 4 months)
(248)	Improving Access	Significantly increased knowledge of ASD; no change in the utilisation of ASD services
(250)	Improving Access	Effectively engaged 97% of Aboriginal youth (n=108), 3 participants not engaged.
(251)	Prevention	Decreases in child reported depression and anxiety; significant decreases in teacher reported depression; children overall satisfied (89.7%)
(252)	Prevention	Groups enabled children to develop pride in their culture; develop self-confidence; offer support to others
(253)	Prevention	Overall internal resilience scores significantly improved; way to de-stigmatise mental health issues
(255)	Awareness	10% of the parents involved in the workshops did seek a consultation for their adolescents and the parents seemed receptive to seeking counselling
(259)	Screening	Did not have a statistically significant different on ethnic inequalities to access despite an increase in referrals; Screening "*less likely to result in parental caregiver consent compared to routine referrals*" (259)(p.523) Universal screening had a limited impact on parental perception of mental health and mental health treatment

3.5.4 Barriers to Implementation of Interventions

Table 29 captures the barriers to the implementation of interventions as described by authors in the papers. The most common implementation barrier described was cultural competence (of the provider) (n=6), followed by engagement / recruitment into the intervention or service (n=5).

Table 29: Barriers to Implementation of Interventions

Barrier	Count
Cultural Competence	6
Engagement / recruitment to intervention	5
Communication with different services	2
Funding for intervention	2
Internet access to complete intervention	2
Language barriers	2
Healthcare staff knowledge of the condition	2
Privacy concerns	2
Availability of staff	1
Childcare	1
Community stigma	1
Consistency of the intervention	1
Providing food	1
Implementing in an under resourced school	1
Increased staff workload	1
Management of intervention	1
Parents mental health literacy	1
Physical space to hold intervention	1
Pre-existing class dynamics	1
Shortage of services	1
Stigma	1
Teacher support	1
Transferability in a new setting	1
Transportation	1

3.6 Discussion

This is the first systematic review describing the barriers experienced by ethnic minority children across a variety of health care settings for a variety of conditions, along with ideas for interventions from the participants and a descriptive synthesis of interventions that have been devised or piloted.

3.6.1 Barriers

In terms of barriers papers, all of the issues described were for mental health conditions, suggesting that these conditions may have been more widely researched than chronic health with a lack of research into barriers to accessing specialist healthcare services for ethnic minority children with chronic health conditions.

Overall, knowledge was the most common barrier reported and most barriers identified in this review were at the cognitive level: knowledge, awareness, communication, stigma and trust. This is logical as if an individual does not know about the condition, they will not know about the specialist services available to them. This is consistent with a non-ethnic minority specific systematic review looking at parental views on barriers and facilitators, which highlights that parental knowledge and understanding of mental ill-health and how to access services, along with views and attitudes towards treatment are the key barriers to seeking psychological treatment for mental health problems (260).

Young people did not describe structural or financial barriers unlike parents, focussing on cognitive barriers. This could be because they were not aware of these barriers, or did not feel they were important. Cognitive level barriers can also be incorporated into participant ideas for interventions, as one paper described religion as a source of healing (219) therefore suggesting facilitators in this realm would be valuable. Future interventions targeting barriers experienced by young people should therefore consider cognitive level barriers.

Children and parents had different views on the barriers, with children describing cognitive level and a more even spread of barriers were reported by parents / carers and included structural barriers, such as service structure and accessibility. Parents are more likely to organise their children's medical care and therefore parents are more affected by structural barriers as they act in the 'gatekeeper' role for the children's access to treatment for mental

health problems (260). This suggests that future interventions to address access to specialist healthcare services for children and adolescents with mental health problems should consider both structural and cognitive level barriers.

Cultural constructs of specific illnesses can determine how individuals classify symptoms and some cultures may perceive symptoms of mental health conditions as somatic in nature (261). During data extraction using the HCAB model (182), some papers did not neatly fit into the pre-defined categories. Most of the papers in this review were qualitative; this enabled close review of the themes identified from reports of participants' experiences and illustrative quotes presented. During extraction, the screening team identified new codes in the data that could not be accurately captured in the HCAB model (182) so added the following three categories: Culture, Stigma and Trust. We felt these categories merited inclusion due to being commonly reported in many papers.

3.6.2 Ideas for Interventions

In this review, study participants provided numerous ideas for interventions to reduce barriers. The most frequently discussed ideas from the papers were improving knowledge of healthcare conditions and included support workers from similar cultural backgrounds, and school based education programs.

Global interventions aimed at reducing mental health related stigma describe short term benefits at the population level for attitude changes, but there is less evidence for knowledge improvement of the condition (262). In particular, in schools, there is limited evidence on how effective school based interventions are in reducing the stigma of mental illness (263). Historically the UK has also experienced stigma as a barrier and interventions have aimed to reduce the stigma around mental illness, such as the Time to Change program (264,265), which proved successful in reducing stigma (266), with greater knowledge and attitudes at a population level (267,268). This is important for future interventions aiming to reduce barriers to accessing mental health services to take into account. Although knowledge and awareness are important factors, stigma and cultural barriers need to be addressed as well. Stigma and knowledge can be interlinked, with stigma being associated with a lack of knowledge (269). Therefore, future health literacy interventions could give information to improve knowledge and awareness in a way that is culturally sensitive and reduces stigma, as

even if you target cognitions you also need to challenge the stigma. This finding shows that for example, solely offering leaflets might not work to improve access and a more rounded approach is needed for all identified cognitive barriers. This should be combined with providing parents with more support to overcome structural barriers.

3.6.3 Interventions

This review found five types of intervention studies: awareness; delivery in different locations; improving access; prevention; awareness and universal screening. Promising interventions to improve access to care for ethnic minority populations are multifaceted (181) as interventions that modify a single access barrier are unlikely to bring about the desired change (194). This was demonstrated by a study that found although universal mental health screening in schools was successful in identifying young people who might not otherwise have been identified by routine screening, there was low caregiver consent to subsequent mental health treatment due to parental perception and responses to the identified mental health issue (259). This universal screening intervention suggests that by just removing one structural barrier (referral) without considering cognitive barriers (such as knowledge, trust, stigma) the intervention did not have the anticipated outcome (259).

In order to develop an effective intervention for removing health care access barriers for ethnic minority individuals it is important for the targeted group to be actively involved in designing the intervention from the start (181) with a continued on-going relationship throughout (193). This was mirrored in the ideas for interventions results, which found cultural factors were important to participants in designing interventions that would be acceptable.

When comparing the barriers found in stage one of this reviews to the barriers the interventions in stage two aimed to modify, there was a broad overlap with culture, communication/language and stigma common on both. However, knowledge was the most prevalent barrier overall in the literature; and was the most common idea for intervention (in terms of knowledge building) but was only the fifth most prevalent barrier in interventions piloted or devised. Despite increases in knowledge and awareness being difficult to quantify and measure in interventions in order to gauge effectiveness, future work should focus on knowledge building to reduce barriers to accessing healthcare for ethnic minority children.

3.6.4 Strengths and Limitations of the Systematic Review

This review took a systematic approach to mapping the evidence for barriers that may be preventing ethnic minority children from accessing specialist healthcare services and any interventions aimed at improving access. A systematic approach ensured no relevant literature was missed through: close consultation with a systematic review specialist, testing the search strategy before the final search and by using second screening, to ensure no potentially relevant papers identified were discarded. In addition, the search terms were broader than the HCAB model (182) to ensure no potentially relevant literature was missed, but data were extracted according to the model as it assisted with making sense of the literature. What was identified during the searches fits with the model rather than the search strategy being based on the model, to ensure all relevant literature was located.

Some of the studies included in the intervention section of this review would be considered at the development stage as they were in the process of community engagement and model development to plan an effective intervention to remove the barriers, whereas others provided outcome or effectiveness data. Therefore the analysis of the reviews was a descriptive synthesis in the form of a mapping review in order to provide an overview of work previously carried out in this area (204).

This systematic review was intentionally broad to ensure all issues were captured, but limited the included papers to those written in English due to resource limitations. All ethnicities were included, along with refugees. Refugee children and young people are particularly vulnerable, especially those who are unaccompanied and may lack an adult advocate for their health and other needs (270–273). Refugees can have specific, but diverse physical and mental healthcare needs and may face additional barriers in accessing healthcare, including more pronounced language barriers and also legal and bureaucratic barriers due to their status (274).

All the studies recruited in countries with well-developed but diverse healthcare systems. Over half the studies were conducted in the USA, which may have biased the results because of the financial barriers to healthcare present in the USA, which are not present in all countries.

Different professionals may or may not be considered specialists in certain countries; therefore the search strategy could be amended in future work to incorporate these healthcare structure differences. I included the opinions and views of parents and healthcare professionals who may have a different perspective on the barriers compared to young people who are suffering from the chronic/ mental healthcare condition. Despite this, I considered it important to incorporate these views as for younger children parents would make the decision to seek healthcare. Finally, this review did not assess the barriers for younger children accessing healthcare, in particular ages 0-2 is an important window for interventions to prevent long term ill health (275). Future work could focus on younger children (via their parents and carers) and the barriers they perceive in accessing healthcare.

Although my review did not formally assess the quality of evidence, as a mapping review was conducted to provide a descriptive synthesis of the findings and highlight potential research and mapping reviews do not assess the quality of evidence (204,214), methodological issues in the included studies limit this review. This includes small sample sizes in some studies and selection bias. Ethnic minority children and families are an underrepresented population in health care research (161,162,276). This could lead to selection bias of those who self-select to be involved in the studies/interviews included in this mapping review and may not be representative of the ethnic minority population in general. Furthermore this review aimed to investigate all chronic health conditions, but all barriers literature identified discussed mental health conditions, demonstrating a lack of research in ethnic minority access to specialists for chronic health conditions and an important gap to be filled by future research.

3.7 Conclusions

This review identified “Knowledge” as the most common barrier in the literature overall for ethnic minority children accessing specialist healthcare services, but the review also found “Culture” and “Stigma” to be important. Future work should aim to develop interventions that focus on improving knowledge, whilst also reducing stigma, in a culturally relevant way. Structural barriers also need addressing for parents. Schools are seen as very influential in providing information and could potentially be used to improve knowledge of mental health and available mental health services directly to young people, whilst reducing stigma (277),

but knowledge building also needs to occur as universal screening may not lead to an uptake in access to service use if other barriers are not considered, for example parental perceptions and knowledge (259).

Overall the systematic mapping reviews provide an overview and an insight into the barriers ethnic minority children globally face when accessing healthcare services for chronic/mental health conditions, along with a descriptive synthesis of interventions aimed at improving access and interventions that have been devised or piloted, along with barriers to implementation of the interventions. To conclude, knowledge gaps need to be identified and addressed and interventions need to be multifaceted. Interventions that solely target structural barriers without addressing cognitive barriers are unlikely to be effective in eliciting change and improve access.

This review highlights the urgent need for research looking at barriers and facilitators to accessing healthcare services for ethnic minority children suffering from chronic health conditions. The following studies in this thesis aims to investigate this.

Main Findings:

- Parents and children highlighted different barriers to accessing healthcare services, therefore intervention planning should be aware of the different perceptions of barriers and tailor recommendations and interventions accordingly
- Globally, culture, stigma and trust are important barriers that need to be incorporated into any model of help seeking for ethnic minority children
- There is a lack of research for ethnic minority children with chronic healthcare conditions accessing specialist medical services – all barriers literature in this review focused on mental healthcare conditions, with asthma and obesity included in interventions studies.

Chapter 4: Methodologies

4.1 Overview of Chapter

This chapter outlines the aims and research questions in this thesis and the different methodologies employed to answer them. This chapter provides a rationale for the different methods used and provides justification for this thesis being multi-method. The methods used for each of the studies are detailed within the chapters where their related findings are presented (Chapter 3 for the systematic review, Chapter 5 for the quantitative work and Chapter 6 for the qualitative work).

4.1.1 Overall Aims and Research Questions of the Thesis

As presented in Chapter 1, the overarching aim of this thesis is to:

Understand the barriers and facilitators experienced by children from ethnic minority communities to improve access to specialist CFS/ME services.

This multi-method thesis is comprised of three interrelated projects; the results of the individual projects combine to fulfil the overarching aim of the thesis in the following ways.

The objective of Project 1 (Systematic Review) presented in Chapter 3 was to review and synthesise the existing evidence on the barriers experienced when ethnic minority children access specialist services. The systematic review also highlighted the importance of facilitators. The inclusion of the systematic review is to illustrate what the 'known' barriers and facilitators are, and any interventions that have aimed to improve access.

The objective of Project 2 (A descriptive statistical analysis of children in CFS/ME specialist services) was to determine the characteristics of individuals currently in CFS/ME specialist paediatric services to investigate if CFS/ME is different in ethnic minority children who access specialist care.

The objective of Project 3 (A qualitative investigation of patient, family, community, community leader and medical professional views) was to understand patient, family, community and medical professional views on the barriers (and facilitators) they perceive in ethnic minority children accessing specialist CFS/ME services. Qualitative interviews with patients, families, community leaders and medical professionals, and focus groups with Somali community members allowed an understanding of their experiences.

The combination of these projects investigated the barriers and facilitators from multiple perspectives to provide ideas for improvement that could help improve care for ethnic minority children with CFS/ME. This chapter describes the overall methodologies used in the thesis.

4.2 Ontological and Epistemological Considerations

When designing a research study, the methodology chosen depends on ontological and epistemological considerations, and the approach taken frames the research design (278); both the philosophical and the practical elements of a study are vital in designing a study (279).

There is a difference between ontology and epistemology. Ontology refers to the nature of reality (280–283) – what actually exists (283,284). The ontological assumption therefore asks 'what' it is possible to know (285). In contrast, epistemology refers to understanding the nature of knowledge (280,282,283) - how we acquire knowledge of what exists (284). The epistemological assumption questions 'how' to find out (285). The theoretical perspective taken grounds the study methodology in a philosophical stance (281).

Thematic analysis is a qualitative analysis method used for "*identifying, analysing and reporting patterns (themes) within data*" (286)(p.79). Thematic analysis is widely used and is a foundational method of qualitative analysis (286). A benefit of thematic analysis is that it is not linked to a specific theoretical framework (286). Both the qualitative interviews and the focus groups in this thesis were analysed using thematic analysis (see section 6.2.3 for detail of the analysis procedure used in the qualitative work).

4.3 Multi-Methods Design

Multiple methods (or a multi-methods approach) is defined as "*two or more complete projects attached to an overall inductive aim*" (287)(p.3). Each project in a multi-method study has a different research question and is a separate study (287) and there is less dependency on the other components as compared to a mixed-methods study design with one complete project that is "*not comprehensive enough to stand alone*" (287)(p.3-4).

Multi-methods is further differentiated from mixed-methods research in that there is not a requirement to have at least one qualitative and one quantitative method in the research project (288–290). Instead, different methods are used for the different goals of each project, with the most appropriate method selected of all possible methodological combinations available (289,291). Therefore, in a multi-methods project, complementary, but separate, research questions are used for each component (287). Due to the different nature of studies conducted in multi-methods research, integration of the projects is not required as opposed to mixed-methods research where integration is essential (290–292).

The use of multi-methods in this thesis is in keeping with the pragmatic approach taken to investigate access to specialist CFS/ME services for ethnic minority children. The research methods used in this thesis were selected to achieve the objectives of the different projects through the use of: a systematic mapping review, statistical analysis of CFS/ME trial data, and qualitative interviews and focus groups, attached to the overall aim of the thesis. I reflect on the use of multi-methods, and alternatives, in the Discussion of this thesis.

The following diagram (Figure 7) illustrates the patient pathway to the CFS/ME service. The various elements of this thesis aimed to explore different aspects of this patient pathway and due to the difficulties in accessing specialist CFS/ME services for ethnic minority children, a multi-method approach was the most appropriate.

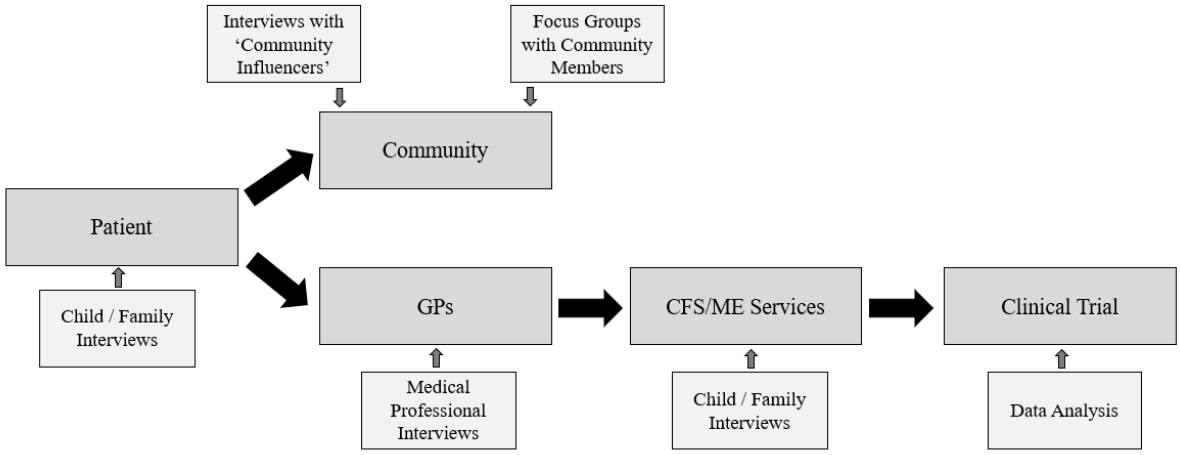

Figure 7: The Patient Pathway to the CFS/ME Service

This thesis used a multi-methods approach to understand the barriers and facilitators for ethnic minority children accessing specialist CFS/ME services, with different research questions for the different components of the thesis. The systematic review was conducted to understand existing evidence in this topic area, quantitative work was conducted to understand who is affected and accessing services, and qualitative methods were used to investigate the different experiences and perspectives of affected groups.

I thought it was likely there would be different barriers and facilitators experienced by those who were successful and those who were unsuccessful in accessing specialist CFS/ME medical services. I interviewed children and families who had been successful in accessing CFS/ME services, because it was felt likely that they would have an insight into the barriers and facilitators experienced at different stages of the patient pathway. However, because these families were successful at accessing CFS/ME services, I also needed insights from those who may be aware of the barriers experienced by families who were not successful at accessing services. Previous work in this topic area, conducted with ethnic minority adults with CFS/ME (22), highlighted the importance of community and cultural factors in accessing primary care and managing fatigue symptoms. In order to access information about such factors, I interviewed community influencers in different migrant communities (please see Section 4.6.1 for the rationale of using qualitative interviews). The views of community leaders may have been different from the families of children with fatigue. I was unable to recruit these families however community led focus groups enriched my understanding of access to care (please see Section 4.6.2 for the rationale for using focus

groups). I also interviewed medical professionals for their views on CFS/ME in ethnic minority children. Finally, I wanted to investigate the clinical features of those accessing services and I used data from trials (see Section 4.5 for more details, Section 5.2.4 for the rationale of using the individual data sets, and Section 7.10.2.3 for limitations of this).

The following table (Table 30) illustrates when the different elements of the thesis were conducted. The systematic review findings informed the qualitative interviews and focus groups (see section 6.2.1.7 for a description of how 'facilitators' were an important addition to the qualitative work). The data analysis was conducted at the end of the PhD because recruitment to one of the clinical trials continued throughout the PhD (293–295) and I wanted the largest sample size possible. During recruitment to the qualitative interviews with young people and their families from the CFS/ME service, I recognised there were few ethnic minority children in the CFS/ME service and therefore I conducted the statistical analysis later than anticipated to ensure the largest sample size possible in the FITNET-NHS trial.

Table 30: When the Elements of the Thesis Were Conducted

Year	Month	Systematic Review	Qualitative Interviews	Qualitative Focus Groups	Statistical Analysis
2017	October				
	November				
	December				
2018	January				
	February				
	March				
	April				
	May				
	June				
	July				
	August				
	September				
	October				
	November				
	December				
2019	January				
	February				
	March				
	April				
	May				
	June				
	July				
	August				
	September				
	October				
	November				
	December				
2020	January				
	February				
	March				
	April				
	May				
	June				
	July				
	August				
	September				
	October				
	November				
	December				
2021	January				
	February				

4.4 Rationale for the Systematic Review (Project 1)

The rationale for the systematic review was to understand what work had been conducted in this topic area previously and therefore what was known about access to healthcare for ethnic minority children. A preliminary literature search revealed a lack of published research on the barriers for ethnic minority children with CFS/ME. I considered that the barriers experienced by ethnic minority children and CFS/ME might be similar to other chronic long term health conditions. Whilst I was conducting the systematic review, I realised there was data on both barriers and facilitators. I therefore conducted a broader systematic review investigating barriers, facilitators and interventions for ethnic minority children accessing specialist secondary healthcare for any chronic or mental health condition. The systematic review (presented in Chapter 3) found that there are numerous barriers to accessing specialist health care services.

The systematic review took a broad global perspective (by the inclusion of international studies) when mapping previous work in this topic area. However, the UK is a country with a unique healthcare model (296,297) and we do not know if the results from the systematic review will align with the results from the present studies.

In the UK, healthcare is free at the point of access to all citizens/residents who are eligible and need to receive it, through the NHS (296,297). Even though healthcare is free at the point of access to all who are eligible, there is not equity in coverage (157,298); the NHS and the UK Department for Health have introduced reports, ideas and initiatives to try and improve equal access to healthcare services for ethnic minority individuals (202,299).

The systematic review made important contributions to this thesis in the following ways: firstly it highlighted the role of facilitators, and therefore the qualitative work captured this from participants. Secondly the systematic review provided background context by illustrating the barriers that had been identified in the literature previously. Finally, it found that most work is carried out on mental health, not chronic health, conditions; this was an unexpected finding and suggests that less research has been conducted in to the barriers and facilitators in accessing healthcare services for chronic physical conditions. Please see section 7.2.1 for a discussion on the findings of the systematic review and how they relate to the wider thesis.

4.5 Rationale for the Quantitative Work (Project 2)

To improve access to specialist CFS/ME services for ethnic minority children, it is necessary to understand if the demographic details and symptoms are different to those who do not identity as an ethnic minority (White) children, so services can be adapted to suit their needs. Statistical analysis was performed with the aim of investigating the characteristics of ethnic minority children attending specialist CFS/ME services, to understand if CFS/ME presents in different ways.

I was not able to use symptom data and patient reported outcomes from NHS clinics to compare symptoms and patient reported outcomes between those who identify as from an ethnic minority background, and those who do not identify as an ethnic minority. I therefore used clinical data collected in three randomised controlled trials. The quantitative project was not able to investigate if the illness is different in ethnic minority children, as data were only from those who presented to specialist CFS/ME services, have successfully navigated the system, and consented to take part in research. As highlighted in Chapter 2 there are numerous barriers to accessing healthcare for ethnic minority individuals and a lack of ethnic minority participants in research (161,162). This may have biased the results.

4.6 Rationale for the Qualitative Work (Project 3)

To my knowledge, there has been no research on the barriers for ethnic minority children accessing specialist CFS/ME services. Neither has there been research on facilitators and ideas to improve access. I chose to do qualitative work to investigate this. Qualitative work has been carried out in ethnic minority adults to investigate the barriers to accessing specialist CFS/ME services (22), but not children.

When considering study design, quantitative surveys were considered, but I decided that qualitative data would give a detailed and in depth understanding of the barriers for accessing specialist services for CFS/ME. The use of qualitative methods would capture the participants' situation, views and experiences (300), as using qualitative methodologies allows an understanding of unique experiences, with the individual and society as co-constructors of reality (278). This enabled the work to focus on barriers, facilitators and ideas to help with accessing specialist services.

4.6.1 Rationale for Qualitative Interviews

I decided that a qualitative semi-structured interview method was the most appropriate to explore the views and experiences of families, community influencers and medical professionals. I aimed to recruit different groups of participants to take part in a semi-structured interview.

This thesis used interviews in order to gain a rich insight in the participants' own words into how they make sense of their reality and experience events. Qualitative methods enhance understanding of events, and the context of them, by providing rich descriptions from participants (301,302). In qualitative methods, the emphasis is on the life experiences of those being interviewed, the meaning behind those experiences, and how they perceive the world (302,303). The purpose of a qualitative interview is to "*explore the views, experiences, beliefs and/or motivations of individuals on specific matters*" (304)(p.292).

Semi-structured interviews are the most frequently used method in qualitative research generally (302) and in health care (304) and health services research (303). Semi-structured interviews gathers "*information from key informants who have personal experiences, attitudes, perceptions and beliefs related to the topic of interest*" (303)(p.2). During a semi-structured interview, several key pre-determined, open ended questions are asked, based on previous knowledge (304,305), with other questions asked depending on the participant discussion (302). This flexibility of qualitative interviews (305) is a key strength, as the topic guide provides guidance on what to discuss, but is not aimed to be followed strictly (305) and the discussion can be guided by elaboration on what is important to a participant (304).

4.6.2 Rationale for Qualitative Focus Groups

Part of this section has previously been reported and published (1)

The second qualitative method used in this thesis was focus groups. This was for research I carried out during the PhD, using a Community Based Participatory Research (CBPR) approach, on Mental Health in the Somali community in Bristol. This paper has been published in the International Journal for Equity in Health (1). As part of my attempt to use

community contacts (the second recruitment method), I was introduced to two members of the Somali community who discussed with me their concern about rising suicide rates amongst Somali community members in Bristol. I offered to design and run a study as I realised that this would be a good methodology to a) work with the Somali community and b) enrich my sample size as I was struggling to recruit.

I was not able to recruit any ethnic minority children suffering from disabling fatigue who had not accessed medical care. As I was running focus groups on mental health and experiences of accessing healthcare with community participants for an ancillary study during the summer, I expanded the focus group schedule to include points for discussion relating to experiences, or perceptions, of fatigue symptoms. These data collected from the focus groups added to and enriched the data collected during interviews as participants discussed access to healthcare, and community barriers/ influences on accessing care.

However the focus groups were held with a different group of participants (Somali community members drawn from a multi-ethnic neighbourhood), and therefore did not solve the issue of not being able to recruit children with disabling fatigue who had not successfully accessed specialist services. However, the participants did provide an important perspective and enriched the data by sharing their perspectives of fatigue and pathways to care (please see section 4.6.3 for a discussion on using focus groups in this thesis). The focus group work encompassed the results that will be presented in Chapter 6.

4.6.2.1 Rationale for CBPR Methodology

An approach to enabling participation in research studies uses CBPR (Community Based Participatory Research) (306). Through a process of mutual respect and co-learning, CBPR bridges the gap between researchers and community members, along with community engagement in a process where community partners contribute their unique strengths to enhance understanding (307–309). Recruiting co-researchers from a community can lead to trust, build partnerships and reduce stigma and thus enable recruitment to research studies (29) through engaging the community early in the research process, and by using appropriate communication methods (29). Successful research partnerships, using a CBPR approach, has the potential to improve ethnic minority health through community-based interventions (310,311). A CBPR approach was chosen for the focus group work, to allow for community

members knowledge and experience to be combined with my (and the wider project teams) experience in study design and qualitative research methods (312,313).

Qualitative focus groups were chosen to explore the communities collective opinions (314) and provide insights into how different beliefs and knowledge operates within the community and the community structures (315). Focus groups were selected as the most appropriate method for this work, as they are useful for intervention development, particularly in multicultural populations (314). In addition, due to the sensitive and stigmatised topic area, the community partners advised that individuals would not be receptive to attending an individual interview, due to the perceived formality and isolation of interviews (315). Focus groups were chosen to encourage contributions from everyone in the group and to capture exchanges between participants, who might not take part in an individual interview, but would be encouraged to discuss a topic in a group setting (315).

4.6.3 Rationale for Interviews and Focus Groups

Two qualitative data collection methods were used in this thesis and the data analysis and findings are presented together in Chapter 6 (please see section 6.2.3.3 for a description of how data analysis was conducted).

Interviews with community influencers highlighted the role of cultural factors and community perspectives on accessing healthcare and fatigue symptoms. Although I had interviewed children and young people (and their families) who had been successful in obtaining a referral to a specialist CFS/ME paediatric service, the experiences of those who had been unsuccessful may have been different. For example, they may be unaware of the availability of services or may not see fatigue as a problem amenable to medical intervention. In the absence of data from families and children who had not, or had not been able to, access specialist services, it was important to try and explore access to care from another angle.

Many of the community leaders discussed families that they were aware of whose child had disabling fatigue, but none of these families agreed to take part in an interview. It is possible that families did not take part because they perceived an "interview" as being too formal (see Section 4.7.6) or because of low English language fluency. To address this lack of data, I

took a pragmatic decision to expand the scope of a planned focus group study on perceptions of mental health and access to healthcare, to include points for discussion relating to experiences or perceptions of fatigue symptoms. The focus group data added to and aided interpretation of my findings by providing a lay perspective from adults who were neither community leaders nor parents who had accessed services; this merited the inclusion of relevant focus group data in this thesis and enhanced my understanding around pathways to care.

It has been argued that data collected from focus groups and interviews are different, and the different data collection methods "*defy direct comparison*" (316)(p1117). However, despite the differences between interviews and focus group data, they can be usefully combined in a multi-method study (317). A combination of interview and focus group data can add to and provide complementary views of a phenomenon, enhance data richness, and contribute to a more complete understanding (317,318), through the addition of a different perspective (319). The aim of this thesis was to understand barriers and facilitators to accessing specialist CFS/ME services for ethnic minority children, therefore a pragmatic decision was taken to include relevant data from the focus groups to enhance understanding around access to care. The limitations of using these different methods (interviews and focus groups) are discussed in Section 7.10.2.4.2.

4.7 Reflexivity

Reflexivity is critical to qualitative research and can be defined as: "*the process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome*" (320)(p.220).

Reflexivity was an important part of my research process, including acknowledging the role and influence of myself on the process and the results (316) and how knowledge was co-constructed between myself and the participant (321). This section details my reflections on the research process, highlighting any challenges and my attempts to mitigate these and my reflections on the PhD are also further considered in the Discussion (section 7.13).

4.7.1 Trust and Recruitment

I found recruitment to the community leader qualitative interview study resulted in limited participants and low interest in the study. The first strategy I trialled of emailing organisations, did not work, on reflection, for numerous reasons. I then focussed on building trust and understanding within the community. I worked on becoming visible presence within the Bristol Somali community by volunteering at a mother and child activity group once a week from January 2019 – March 2020 (paused because of the COVID-19 Pandemic). This meant I built relationships with the community and they started to trust me (322). This resulted in recruitment of individuals who might not have engaged with the study. One participant said to myself "*you are part of the community now*" and I would often be recognised walking around the local area by different residents, who wanted to stop and have a discussion about the project and how the research was going. As soon as trust started forming, participants were keen to be involved and would introduce various individuals who they thought could help with the project.

I reflected on this Inside-Outside status (323) in the research process and my own ethnicity; I identify as White British. This had advantages and disadvantages when it came to recruitment and also during interviews. Previous work has stated that a researchers "*gender and racial identity can and does affect the research process*" (324)(p.285) and toolkits for researchers engaging with ethnic minority participants in health research emphasise using ethnic minority researchers (who are familiar with the participants' language and culture) and also using relevant community groups and organisations to help develop appropriate recruitment strategies, are important (28). Participants may not talk about sensitive topics with those viewed as being outside of their community, potentially due to trust and fear (314,325). However, focus group participants did discuss high levels of stigma from within their community, so from being from outside the community could have been a strength to enable discussion, as participants might not have wanted to talk with their own community about this sensitive issue. Through the partnership with community organisations, I was able to build trust and understanding in the community with the project as the community researchers acted as gatekeepers in the process (322).

I supervised two undergraduate student placements, assisting with this project. The first student, an Undergraduate Medical student, was tasked with recruiting and interviewing community leaders. This student was provided with full training and supervision in order to

broaden their research skills. The medical student provides the following self-description: "*I was born and raised in Bristol, my family are originally from Libya (ethnically Arab).*" In contrast to myself, the medical student found recruitment relatively easy through personal and family connections and through cultural groups. I met with the medical student regularly to discuss potential suitable participants and to ensure a range of participants were interviewed and included. The second student assisting with this work was an Undergraduate Psychology student, who provided support to the focus group project. This student identifies as Chinese and therefore during the focus groups, neither primary university researcher was Somali, but there was a range of ethnicities in the room.

4.7.2 Participants not wanting to speak for their 'community'

The first organisations approached to take part either declined or did not follow up on interview requests. These organisations had wanted an introductory chat and I met with four separate community groups, who ultimately declined to be interviewed for the project. Two groups were from the East Asian community and spoke informally about doctors and medical professionals being very highly respected in their cultures and not wanting to disagree with their views. The community leaders from these groups did not want to officially be interviewed as they did not want to comment on medical care that they, or others, had received in the UK. The community leaders also informally said that they did not feel it was appropriate to speak generally on the attitudes and beliefs of those they knew within their community for confidentiality reasons and they did not want to be the "voice" of their community. Even on subsequent interviews, some participants made it clear that they were talking generally, not about all community attitudes. I reflected on this, as I was not sure who I would identify as my community leader and who could speak for me.

Throughout recruitment to this project, there was caution around the word "community". The use of this term can imply a homogeneity and social cohesion that might not be present (29). Previous work (22,326) has typically used the phrase "*community leader*" in recruiting to studies aiming to gain a broad community based view. In this study, those identified as community leaders expressed unease at the phrase as they felt they could not speak for their community. Therefore the term community leader was not a useful tool in approaching and recruiting participants, perhaps due to other connotations with the phrase and participant discomfort of being assigned a label by an individual from outside their community.

Potential community participants who wanted to meet face to face to discuss the study before deciding whether or not to take part, felt uneasy with being asked to speak for their community. This was an interesting discussion point, that had not been previously considered and therefore during qualitative interviews with community leaders the participant was asked if they thought of themselves as a community leader and what they would be comfortable being referred to as. This unique insight into how terminology can hinder recruitment will be presented in Chapter 6: Qualitative Project and discussed in detail in Chapter 7: Discussion.

4.7.3 Power dynamics between the researcher and participants

I was very aware of the potential dynamics between the interview participant and myself (300). In terms of the children and young people interviewed who had been diagnosed with CFS/ME, I made it clear that I am a researcher, not a medical professional, and could not offer advice on medical symptoms, and instead was there to capture ideas and experiences. Age appropriate terminology was used when talking with the young people to ensure understanding of the topic and the questions asked. I also made clear that the participants' medical care would not be affected in any way by choosing, or declining, to take part in an interview. In terms of the community participants, I took care to build understanding by explaining the topic of discussion prior to the start of the interview and made sure participants knew of the goals and motivations and what the output would be.

4.7.4 Stigma of hidden health conditions

Hidden illnesses can be stigmatised (211), including stigma surrounding mental illness (212,213) and CFS/ME stigma (22,40,49). Health related stigma was a recruitment challenge. Individuals may not want to openly admit that they are suffering from a hidden illness, or could be concerned that symptoms could be due to mental health conditions. I made clear that the interview process was anonymous and that any data, or any quotes published, would not be able to be linked back to the participant.

4.7.5 Contribution to the research

Some participants were concerned that they could not contribute to the research, as they did not know what CFS/ME was. I assured participants that I was interested in their views and

understanding, whatever they might be, and that it was valuable to know whether they did or did not understand about the condition.

4.7.6 Terminology

Terminology was also important when inviting participants to take part. Participants did not like the word "interview" and I realised after a few interviews had taken place that inviting "Community Leaders to an Interview" was perhaps the least likely phrasing to get responses. At the end of one of the first interviews conducted with a community leader the participant asked myself "*is that it*?" in terms of they expected a more formal encounter that what had taken place. Upon realising that terminology was of vital importance to the success of recruiting to this project, on discussion with the supervisory team, "community leaders" were referred to as "community influencers" and "interviews" were referred to as a "chat". This new *rebranding* from "interview with a community leader" to "chat with a community influencer" increased recruitment .

4.8 Summary of Methodologies Used

This chapter has presented and described the thesis methodologies. Quantitative analyses, of CFS/ME trial data, was designed to investigate the characteristics of those who access specialist CFS/ME services. Qualitative interviews and focus groups used thematic analysis to investigate the barriers and facilitators to accessing specialist CFS/ME services, along with ideas to improve access, from different perspectives (patients and families, community leaders, medical professionals, community views).

The next Chapter (Chapter 5) presents the quantitative work conducted for this thesis (methods, analysis, results and key results). Chapter 6 presents the qualitative work conducted for this thesis (methods, findings (1) barriers to accessing CFS/ME services, findings (2) improving access, and a summary of key findings). Chapter 7 provides an overall discussion, presenting all thesis findings, contextualises the findings within the wider evidence base, my reflections on the PhD, the implications of the findings for policy and practice, and future research and concludes the thesis.

Chapter 5: Quantitative Project (Project 2)

5.1 Overview

This chapter presents the methods and findings for the quantitative study which aimed to understand the characteristics of ethnic minority children diagnosed with CFS/ME who accessed specialist CFS/ME services. The methods, analysis, results and a brief discussion of key findings are contained within this chapter. Further discussion of this study, including the strengths and limitations, and how this study fits into the wider thesis, are presented in the Discussion chapter of this thesis.

5.2 Methods

5.2.1 Research Question

What are the clinical/demographic characteristics of ethnic minority children compared to those who do not identify as an ethnic minority (White) children who access specialist paediatric CFS/ME specialist services?

5.2.2 Objective

To investigate and describe the baseline characteristics of children (those who identify as ethnic minority and those who do not) with regards to demographic and clinical characteristics: co-morbidities; fatigue score; pain score

5.2.3 Study Design

Quantitative analysis was performed on data collected from the following CFS/ME trials: SMILE, MAGENTA and FITNET-NHS. These data sets provide detailed data from trials that recruited regionally and nationally in the UK. Each data source included demographic data, data on fatigue, disability, anxiety, depression and pain.

The SMILE trial has data on 100 children randomised to Specialist Medical Care or Specialist Medical Care plus the Lightening Process (327,328).

MAGENTA has data on 220 children randomised to Graded Exercise Therapy or Activity Management (329).

FITNET-NHS has data on 314 children randomised to online CBT or Activity Management (293,294).

The Statistical Analysis Plan that I followed was uploaded to the University of Bristol PURE system and can be found at: https://research-information.bris.ac.uk/en/publications/statistical-analysis-plan-understanding-whether-bame-children-hav

5.2.4 Rationale For Using The Individual Data Sets:

The three data sets were chosen to address the research question (What are the wider characteristics of ethnic minority children compared to non-ethnic minority (White) children who access specialist paediatric CFS/ME specialist services?).

The advantage of these data sets were that they included data on symptoms, as well as patient reported outcome measures (pain, fatigue and mental health), from participants. They therefore provided rich data on patient characteristics which were not easily and consistently available in routinely collected NHS data. As I did not have access to routinely collected NHS data for analysis and the trials were large, with high recruitment rates of eligible children and young people, I considered that it was likely that participants recruited to the clinical trials would be similar to those seen routinely in specialist CFS/ME clinics. In the absence of clinical data, the data sets were therefore helpful to see the wider characteristics of ethnic minority and non-ethnic minority (White) children.

In addition, the FITNET-NHS trial recruited from throughout the UK (295). I thought that it was likely this data set would have a higher number of ethnic minority children and young people, compared to clinical data from children and young people recruited from the Bath area, due to the fact that the trial recruited participants from more diverse regions in the UK.

However, when I came to the analyses, there were fewer cases of ethnic minority children than expected. This low power in the data sets limited the analyses that could be performed and prevented me from answering my research question. In addition there are further

limitations (discussed in full in Section 7.10.2.3) with using these data sets, such as the selective nature of the data collected and volunteer bias; ultimately the data sets did not include the data needed the address the research question. My thoughts on how I would do this in the future (for example exploring the data prior to analyses) can be found here (Section 7.13.2).

The next sections detail the specifics of the individual data sets included in this study:

5.2.4.1 MAGENTA

The MAGENTA trial recruited participants from three specialist NHS CFS/ME services in Bath, Cambridge and Newcastle (329) between September 2015 and March 2018. Young people were screened for eligibility at their initial clinical assessment at the CFS/ME clinic and were not eligible if they were severely affected (329,330). Pilot feasibility results showed 80 out of 161 (49.7%) of those eligible were recruited into the trial (330). The main reasons for families declining to participate were: preference for a particular study arm, and perceived study burden (including travel to the service to take part) (330).

5.2.4.2 SMILE

The SMILE trial recruited 100 patients from the Bath/Bristol paediatric CFS/ME service between September 2010 and September 2013 (328). Participants were excluded if they, or their parents, did not have sufficient English language skills to understand the patient information sheet and consent form, or to take part in the trial or research interviews, or if the child was too severely affected with CFS/ME (331). Potential participants were identified at the initial clinical assessment (331). Of the 631 eligible to take part in the trial, 136 consented to receiving further information and 100 were randomised (328); findings from the feasibility stage showed participants declined to participate due to not being interested, or the trial would be burdensome (327).

5.2.4.3 FITNET-NHS

As presented in Chapter 2 (Literature Overview), there are only 12 specialist CFS/ME services that paediatric patients in the UK can be referred to (112), with wide disparities in coverage meaning most UK children (aged 11-17 years old) do not have access to local

CFS/ME services. FITNET-NHS aimed to deliver CFS/ME management via the internet, reducing the barriers of lack of access to services and also travel barriers, which can further affect access (114).

Eligibility criteria for recruitment into the FITNET-NHS trial included having no access to a local CFS/ME paediatric specialist service, defined as more than 1 hours journey, or the specialist service having a waiting list longer than 6 months (293–295). Therefore, the trial aimed to recruit those who would not typically be able to access specialist CFS/ME management due to lack of services. The main benefit of FITNET-NHS is the ability to access management for CFS/ME without travel and those recruited came from a wide range of locations in England (295). The pilot phase of the trial recruited participants between November 2016 - October 2017 (295) and the full trial closed for recruitment in November 2020.

An internal pilot for the first 12 months of FITNET-NHS found that 89 out of 150 potentially eligible referrals for the trial (59.3%) were recruited, with 75 out of 89 (84.2%) providing 6-month outcome data (295). Reasons for not participating in FITNET-NHS included: 24 out of 150 (16%) or potentially eligible participants preferred travelling to the hospital for standard management, instead of taking part in the trial; 8 out of 150 (5.3%) experienced symptom improvement and declined; 5 out of 150 (3.3%) received a referral from Wales where there was no funding arrangement and patients could not participate; and 3 out of 150 (2.0%) declined due to perceived study burden, or an unwillingness to use Skype (295).

Most participants were positive about taking part in the trial and referred to it as a "*lifeline*" or felt "*lucky*" to participate as there was "*absolutely no treatment*" available in their local area (295)(p.6). However, families reported difficulties with a diagnosis before receiving a referral and becoming eligible to participate in the trial (295). Therefore, this data set was viewed as appropriate for investigating the ethnic characteristics of the participants as it recruited extensively from large cities in the UK and was hoped to have a diverse sample.

5.2.5 Outcome Measures

The following outcome measures were used in the analyses (Table 31):

- Baseline assessment form: symptoms, co-morbidities, time since onset, school attendance
- Short Form 36 Health Survey Questionnaire (SF-36) physical function subscale (332)
- Chalder Fatigue Scale (333)
- Spence Children's Anxiety Scale (334,335)
- Hospital Anxiety and Depression Scale (HADS) (336)
- Revised Children's Anxiety and Depression Scale (337)

Table 31: Statistical Analysis Outcome Measure

Measure	SMILE	MAGENTA	FITNET-NHS
SF-36 Physical Function	X	X	X
Chalder Fatigue Score	X	X	X
Pain Visual Analogue Scale (VAS)	X	X	X
School Attendance	X	X	X
Hospital Anxiety / Depression Scale (HADS)	X	X	
Spence Children's Anxiety Scale	X	X	
Revised Children's Anxiety and Depression Scale (RCADS)			X

The data sets were categorised based on ethnicity categories collected in the SMILE trial, MAGENTA and FITNET-NHS (Table 32) as follows:

Table 32: Ethnicity Categories in the Data Sets

SMILE	MAGENTA	FITNET-NHS
British English Irish Scottish Welsh Any other White background White & Black Caribbean White & Black African White & Asian Any other mixed background Indian Pakistani Any other Asian background Caribbean African Any other Black background Chinese	British English Scottish Welsh Any other White background White and Black Caribbean White and Asian Any other mixed background Any other ethnic group	White White/ Multiple ethnic groups (White and Black Caribbean/ White and Asian/ White and Black African/ Other Mixed) Asian/ Asian British (Indian/ Pakistani/ Bangladeshi/ Chinese/ Other Asian) Black/ African/ Caribbean/ Black British Arab If any other ethnic group please specify (in box below)

Two variables were created from the ethnicity data captured in the trial data (Table 33) for analyses:

- 1 = children who do not identify as an ethnic minority (White)
- 2 = children who do identify as an ethnic minority

Table 33: Coding of Ethnicity Data

SMILE	Code	MAGENTA	Code	FITNET-NHS	Code
British	1	British	1	White	1
English	1	English	1		
Irish	1	Scottish	1	White/ Multiple ethnic groups (White and Black Caribbean/ White and Asian/ White and Black African/ Other Mixed)	2
Scottish	1	Welsh	1		
Welsh	1	Any other White background	1		
Any other White background	1				
		White and Black Caribbean	2		
White & Black Caribbean	2	White and Asian	2		
White & Black African	2	Any other mixed background	2	Asian/ Asian British (Indian/ Pakistani/ Bangladeshi/ Chinese/ Other Asian)	2
White & Asian	2				
Any other mixed background	2	Any other ethnic group	2		
Indian	2				
Pakistani	2			Black/ African/ Caribbean/ Black British	2
Any other Asian background	2				
Caribbean	2			Arab	2
African	2				
Any other Black background	2			If any other ethnic group please specify (in box below)	2
Chinese	2				

5.2.6 Analysis

The data were anonymised and MAGENTA and SMILE were data cleaned by a statistician before it was provided for analysis. By definition, data cleaning is the "*process of detecting, diagnosing, and editing faulty data*" (338)(p.1). Data cleaning involved removing missing variables, database cleaning, and database validation. Validated methods were used to input missing items in partially completed scales. FITNET-NHS is ongoing, and the database is designed to do checks (e.g. range checks) on the data. Analysis was conducted using the Stata Statistical Software, Release 15 (339).

Firstly I categorised the data sets based on the ethnicity categories collected in the SMILE trial, MAGENTA and FITNET-NHS to create the ethnicity variables.

Patient characteristics were described at first assessment at the clinic using the following categories:

- Age
- Gender
- Pain score
- Fatigue score
- School Attendance
- Co-morbid disorders (Depression and Anxiety, using Spence Children's Anxiety Scale, Hospital Anxiety and Depression Scale and Revised Children's Anxiety and Depression Scale)
- Severity of illness (SF-36 physical function subscale)

The above categories of patient characteristics were described in terms of the ethnicity variables created (those who identify as an ethnic minority and those who do not). The prevalence of those who identify as an ethnic minority and are accessing specialist CFS/ME services and have been recruited into a trial, and summary statistics of the baseline characteristics are presented in the next section of this chapter.

5.3 Results

5.3.1 Overview of Quantitative Results

To improve access to specialist CFS/ME services for ethnic minority children, we need to understand if their needs are different to non-ethnic minority children so services can be adapted to suit their needs. I aimed to investigate the prevalence and describe the characteristics of ethnic minority children attending specialist CFS/ME services.

5.3.2 Categorisation of Data

Prior to starting analysis, the data available for analysis from three CFS/ME trials (SMILE trial, MAGENTA and FITNET-NHS) was looked at to categorise ethnicity and codes were attached as 1 = non-ethnic minority (White) and 2 = ethnic minority.

5.3.3 MAGENTA Results

In total for the MAGENTA trial, there were 240 participants at baseline: 235 participants selected an ethnicity, and 5 participants did not select an ethnicity (this was classified as missing data).

As can be seen in Table 34, the majority of participants identified as 'British' (N = 145, 61.7%), with 'English' the second most commonly selected ethnicity (N = 77, 32.77%).

In terms of ethnic minority children, all those who selected an ethnicity were from a mixed background: 'White & Black Caribbean', 'White & Asian' and 'Any other mixed background'. Two participants (0.85%) selected 'any other ethnic group'.

Table 34: Frequency and Percentage of Ethnicity Data in MAGENTA

Ethnicity	**Ethnicity (frequency)**	**Ethnicity (percentage)**
British	145	61.7
English	77	32.77
Scottish	1	0.43
Welsh	1	0.43
Any other White background	2	0.85
White & Black Caribbean	3	1.28
White & Asian	1	0.43
Any other mixed background	3	1.28
Any other ethnic group	2	0.85
Total	*235*	*100*

The ethnicity categories were recoded into a new variable: 1 = non-ethnic minority (British, English, Scottish, Welsh or any other White background) and 2 = ethnic minority. Table 35 shows that 226 (96.7%) participants were coded 1 (non-ethnic minority - White) and 9 (3.83%) participants were coded 2 (ethnic minority).

Table 35: Frequency and Percentage of Ethnicity in MAGENTA

Code	Frequency	Percentage
Non-Ethnic Minority	226	96.17
Ethnic Minority	9	3.83
Total	*235*	*100*

There was insufficient statistical power to look at differences between the groups as the ethnic minority group was too small (N = 9). Therefore, summary statistics of the baseline characteristics of the samples was produced and a descriptive synthesis as follows (Table 36).

5.3.3.1 Baseline Summary Characteristics (MAGENTA)

Age

For both non-ethnic minority (White) children and ethnic minority children, ages ranged from 8-17 years old. The mean age of ethnic minority children (M = 13.44, 95% CI [11.37, 15.52]) was slightly younger than non- ethnic minority (White) children (M = 14.27, 95% [CI 13.98, 14.57]).

Gender

73.45% of the non-ethnic minority (White) children were female (N = 166) compared to 77.78% of the ethnic minority children (N = 7). 26.55% of the non-ethnic minority children were male (N = 60) compared to 22.22% of the ethnic minority children (N = 2).

Pain Score

Non-ethnic minority (White) children had higher mean pain scores (M = 45.25, 95% CI [41.52, 48.98]). Ethnic minority children had lower mean pain scores (M = 36.57, 95% CI [13.02, 60.12]).

Fatigue Score

Non-ethnic minority (White) children had higher mean fatigue scores (M = 24.34, 95% CI [23.71, 24.96]). Ethnic minority children had lower mean fatigue scores (M = 21.56, 95% CI [15.78, 27.34]).

Physical Function

Non-ethnic minority (White) children had higher mean physical function scores (M = 54.82, 95% CI [51.73, 57.92]) than ethnic minority children (M = 48.19, 95% CI [20.92, 75.47]).

Depression Score

Ethnic minority children had a higher average mean depression score (M = 8.86, 95% CI [4.57, 13.14]) than non-ethnic minority (White) children (M = 7.37, 95% CI [6.85, 7.89]).

Anxiety

When looking at the HADS Anxiety Scale, non-ethnic minority (White) children have higher mean anxiety scores (M = 8.96, 95% CI [8.34, 9.58]) compared with ethnic minority children (M = 6.14, 95% CI [3.40, 8.89]).

When looking at the Spence Children's Anxiety Scale, the mean anxiety score of ethnic minority children (M = 33.71, 95% CI [15.44, 51.06]) and non-ethnic minority (White) children (M= 33.25, 95% CI [31.25, 36.16]) are very similar.

Table 36: Means and Standard Deviations of Ethnicity Data in MAGENTA

Variable	Non-Ethnic Minority (White)	Ethnic Minority
Age	N = 226 M = 14.27 (SD = 2.23) 95% CI [13.98, 14.57] Range = 8 - 17	N = 9 M = 13.44, (SD = 2.70) 95% CI [11.37, 15.52] Range = 8 - 17
Gender	Female N = 166, (73.45%) Male N = 60 (26.55%)	Female N = 7 (77.78%) Male N = 2 (22.22%)
Pain score	N = 206 M = 45.25 (SD = 27.16) 95% CI [41.52, 48.98] Range = 0 - 100	N = 7 M = 36.57 (SD = 25.46) 95% CI [13.02, 60.12] Range = 7 - 70
Fatigue Score	N = 225 M = 24.34 (SD = 4.77) 95% CI [23.71, 24.96] Range = 3 - 22	N = 9 M = 21.56 (SD = 7.52) 95% CI [15.78, 27.34] Range = 5 - 31
SF-36 Physical Function	N = 226 M = 54.82 (SD = 23.61) 95% CI [51.73, 57.92] Range = 0 - 100	N = 8 M = 48.19 (SD = 32.62) 95% CI [20.92, 75.47] Range = 5.56 - 85
HADS Depression	N = 198 M = 7.37 (SD = 3.70) 95% CI [6.85, 7.89] Range = 0 - 18	N = 7 M = 8.86 (SD = 4.63) 95% CI [4.57, 13.14] Range = 2 - 14
HADS Anxiety	N = 198 M = 8.96 (SD = 4.44) 95% CI [8.34, 9.58] Range = 0 - 20	N = 7 M = 6.14 (SD = 2.96) 95% CI [3.40, 8.89] Range = 2 - 9
Spence Anxiety	N = 226 M = 33.71 (SD = 18.72) 95% CI [31.25, 36.16] Range = 1 - 99	N = 8 M= 33.25 (SD = 21.30) 95% CI [15.44, 51.06] Range = 10 - 78

School Attendance

The same ethnicity categories were used to investigate school attendance (non-ethnic minority and ethnic minority). As can be seen in Table 37, 33.33% of ethnic minority children were not attending school at baseline, and no ethnic minority child was attending school full time. 12.33% of non-ethnic minority (White) children were not attending school and 12.79% were attending school full time.

Table 37: School Attendance in MAGENTA

Attendance	Non-Ethnic Minority	Ethnic Minority
None	27 (12.33%)	3 (33.33%)
About 10%	19 (8.68%)	-
About 20%	13 (5.94%)	1 (11.11%)
About 40%	33 (15.07%)	1 (11.11%)
About 60%	41 (18.72%)	2 (22.22%)
About 80%	56 (25.57%)	2 (22.22%)
Full time (100%)	28 (12.79%)	-
N/A	2 (0.91%)	-

Summary of MAGENTA Results

The vastly unequal sample sizes meant no comparisons between group tests could be performed; instead descriptive statistics in the form of means and standard deviations were used.

Non-ethnic minority (White) children had higher mean scores for: pain; fatigue; physical function.

Ethnic minority children had higher mean scores for: younger; lower physical functioning; depression.

5.3.4 SMILE

I had aimed to analyse the data collected from the SMILE trial. When investigating ethnicity in the data set, all participants (100%) selected either 'British', 'English' or 'Welsh' as their ethnicity. Therefore no analysis was undertaken on the SMILE trial data, as no participants identified as an ethnic minority in the SMILE trial data set.

5.3.5 FITNET-NHS

In total, 314 participants were enrolled in FITNET-NHS on the 10th February 2021. 299 participants selected an ethnicity, 2 chose '*I do not wish to answer this question*' and 13 participants did not select an ethnicity

After the first 65 participants were recruited into FITNET-NHS, the ethnicity categories changed. The breakdown of the first ethnicity categories are as follows (Table 38):

Table 38: Frequency and Percentage of Ethnicity Data in FITNET-NHS (1)

Ethnicity	**Ethnicity (frequency)**	**Ethnicity (percentage)**
British	39	60.00
English	23	35.38
Any other White background	1	1.54
White & Asian	1	1.54
Pakistani	1	1.54
Total	*65*	*100*

The breakdown of the subsequent ethnicity categories are as follows (Table 39). One participant selected both British and White. This was recoded into 'White' and included in the following summary:

Table 39: Frequency and Percentage of Ethnicity Data in FITNET-NHS (2)

Ethnicity	**Ethnicity (frequency)**	**Ethnicity (percentage)**
White	224	95.73
White / Multiple ethnic groups	8	3.42
Asian / Asian British	2	0.85
Total	*234*	*100*

The following table (Table 40) shows the ethnicity, as combined from the two ways of measuring. As can be seen in the Table, the majority of participants identified as 'White' (N = 224, 74.92%), with 'British' the second most commonly selected ethnicity (N = 39, 13.04%).

Table 40: Frequency and Percentage of Ethnicity Data in FITNET-NHS (Combined)

Ethnicity	**Ethnicity (frequency)**	**Ethnicity (percentage)**
White	224	74.92
British	39	13.04
English	23	7.69
White / Multiple ethnic groups	8	2.68
Asian / Asian British	2	0.67
Any other White background	1	0.33
White & Asian	1	0.33
Pakistani	1	0.33
Total	*299*	*100*

The ethnicity categories were recoded into a new variable: 1 = non-ethnic minority (British, English, any other White background, or White) and 2 = ethnic minority. Table 41 shows that 287 (96%) participants were coded 1 (non-ethnic minority - White) and 12 (4%) participants were coded 2 (ethnic minority). This is similar to the results presented for MAGENTA where 226 (96.7%) participants were coded 1 (non-ethnic minority - White) and 9 (3.83%) participants were coded 2 (ethnic minority).

Table 41: Frequency and Percentage of Ethnicity in FITNET-NHS

Code	**Frequency**	**Percentage**
Non-ethnic minority (White)	287	96
Ethnic minority	12	4
Total	*299*	*100*

5.3.5.1 Baseline Summary Characteristics (FITNET-NHS)

As with the MAGENTA data there was insufficient statistical power to look at differences between the groups as the ethnic minority group was too small (N = 12). Therefore, summary statistics of the baseline characteristics of the samples was produced and a descriptive synthesis as follows (Table 42).

Age

The mean age of ethnic minority children (M = 13.67, 95% CI [12.75, 14.58]) was slightly younger than non-ethnic minority (White) children (M = 14.21, 95% CI [14.01, 14.40)].

Gender

62.72% of the non-ethnic minority (White) children were female (N = 180) compared to 83.33% of the ethnic minority children (N = 10).

37.28% of the non-ethnic minority children were male (N = 107) compared to 16.67% of the ethnic minority children (N = 2).

Pain Score

Non-ethnic minority (White) children had higher mean pain scores (M = 48.82, 95% CI [45.62, 52.01]). Ethnic minority children had lower mean pain scores (M = 41.67, 95% CI [22.87, 60.47]).

Fatigue Score

Fatigue scores were similar for non-ethnic minority (White) children (M = 36.02, 95% CI [35.43, 36.60]) and ethnic minority children (M = 36.25, 95% CI [33.37, 39.13]).

Physical Function

Similar physical functioning scores were found for non-ethnic minority (White) children (M = 19.66, 95% CI [19.13, 20.18]) and ethnic minority children (M = 20.58, 95% CI [17.06 – 24.11]).

Table 42: Means and Standard Deviations of Ethnicity Data in FITNET-NHS

Variable	Non-Ethnic Minority	Ethnic Minority
Age	N = 287 M = 14.21 (SD = 1.69) 95% CI [14.01, 14.40] Range = 11 - 18	N = 12 M = 13.67, (SD = 1.43) 95% CI [12.75, 14.58] Range = 11 - 16
Gender	Female N = 180, (62.72%) Male N = 107 (37.28%)	Female N = 10 (83.33%) Male N = 2 (16.67%)
Pain score	N = 287 M = 48.82 (SD = 27.53) 95% CI [45.62, 52.01] Range = 0 - 100	N = 12 M = 41.67 (SD = 29.59) 95% CI [22.87, 60.47] Range = 0 - 80
Fatigue Score	N = 287 M = 36.02 (SD = 5.02) 95% CI [35.43, 36.60] Range = 20 - 44	N = 12 M = 36.25 (SD = 4.54) 95% CI [33.37, 39.13] Range = 30 - 43
SF-36 Physical Function	N = 287 M = 19.66 (SD = 4.52) 95% CI [19.13, 20.18] Range = 10 - 29	N = 12 M = 20.58 (SD = 5.55) 95% CI [17.06, 24.11] Range = 14 - 29

School Attendance

The same ethnicity categories were used to investigate school attendance. As can be seen in Table 43, 33.33% of ethnic minority children were not attending school at baseline, and 16.67% of ethnic minority children were attending school full time. 23.34% of non-ethnic minority (White) children were not attending school and 3.14% were attending school full time.

Table 43: School Attendance in FITNET-NHS

Attendance	Non-Ethnic Minority	Ethnic Minority
None	67 (23.34%)	4 (33.33%)
About 10%	24 (8.36%)	-
About 20%	25 (8.71%)	1 (8.33%)
About 40%	35 (12.20%)	-
About 60%	47 (16.38%)	1 (8.33%)
About 80%	55 (19.16%)	2 (16.67%)
Full time (100%)	25 (3.14%)	2 (16.67%)
N/A	9 (3.14%)	2 (16.67%)

5.3.6 Percentage of Ethnic Minority Children in the Trials

The following table (Table 44) presents the average percentage of ethnic minority children in the three trials combined. As can be seen from the table, including the SMILE trial where 100% of participants identified as 'British', 'English' or 'Welsh', on average 2.61% of children identified as being from an ethnic minority background across the three trials.

Table 44: Overall Percentage of Ethnicity Data Combined (MAGENTA, SMILE and FITNET)

Trial	non-Ethnic Minority (White) (%)	Ethnic Minority (%)
MAGENTA	96.17	3.83
SMILE	100	0
FITNET-NHS	96	4
Average	*97.39*	*2.61*

In terms of frequency of ethnicity in the data sets, the following table (Table 45) presents the count of ethnicities in the MAGENTA and FITNET-NHS trial combined, excluding the SMILE trial. 96.07% of participants were not coded as an ethnic minority in the analysis. 3% of participants identified as mixed ethnicity (16 out of 534). In individuals who identified as an ethnic minority, 76.19% identified as mixed ethnicity (16 out of 21).

Table 45: Frequency and Percentage of Ethnicity in MAGENTA and FITNET-NHS combined

Ethnicity	Frequency	Percentage
Non-Ethnic Minority (White)	513	96.07
Mixed ethnicity	16	3.00
Asian/Asian British or Pakistani	3	0.56
Any other ethnic group	2	0.37
Totals	*534*	*100.00*

5.4 Chapter Summary

This short quantitative chapter has four key findings that are important to this thesis. Firstly, ethnicity was not accurately recorded in the trial data, with multiple options for participants to choose from. Secondly, all analyses found a lack of ethnic minority children in trials recruiting from specialist CFS/ME services. Thirdly, in analyses undertaken, 33.33% of ethnic minority children were not attending school, found in both MAGENTA and FITNET-NHS data, and finally 76% of children who identified as an ethnic minority, identified as 'mixed ethnicity'.

Both MAGENTA and FITNET-NHS are large randomised controlled trials with different recruitment methods: the FITNET-NHS trial was open to the whole of the UK and MAGENTA participants were mostly recruited from the South West of England. Given the different recruitment methods into the trials, I was surprised that there were not differences in the results. I had expected to see more children from ethnic minority backgrounds in FITNET-NHS which recruited extensively from Birmingham and other large cities and was the only CFS/ME management available.

The following chapter (Chapter 6) presents the qualitative project conducted for this thesis, including the methods and findings on the barriers to accessing specialist CFS/ME services for ethnic minority children and also improving access to services (including facilitators).

Chapter 6: Qualitative Project (Project 3)

6.1 Chapter overview

Presented in this chapter is the qualitative component of the thesis (Project 3) that was conducted with the aim of understanding barriers and facilitators to accessing specialist CFS/ME services for ethnic minority children. The chapter starts with a description of the methods used and then presents the findings from the qualitative work in two sections: the findings in terms of barriers to accessing specialist CFS/ME services are presented in section 6.3 and the findings in terms of improving access (including facilitators) are contained in section 6.4. The chapter ends with a summary of key results, including how the findings specifically relate to ethnic minority children with CFS/ME. How the results fit into the wider body of evidence is contained in the Discussion of this thesis and the strengths and limitations of the qualitative work are contained in section 7.10 in the Discussion.

The qualitative project presented in this chapter encompasses two different qualitative methods: semi-structured interviews and focus groups. The following section presents the methods used for the qualitative project conducted for this thesis.

6.2 Methods

6.2.1 Qualitative Methods – Interviews

This section presents the design of the qualitative interview study, the recruitment strategy and the interview procedure. Justification for using a qualitative methodology in this thesis is contained within Chapter 4 (Section 4.6). Approval for the qualitative interview study (REC Reference 18/SW/0120) was obtained from the Health Research Authority (HRA) (Dated 21 August 2018) and NHS Research Ethics Committee (REC) (Dated 19 July 2018).

6.2.1.1 Study Design

I decided that a qualitative semi-structured interview method was the most appropriate to explore the views and experiences of the participants. I aimed to recruit different groups of

participants to take part in a semi-structured interview: ethnic minority young people with CFS/ME, their families, community influencers and medical professionals.

6.2.1.2 Setting

The qualitative interview study was located in Bristol in the South West of England. Bristol has a population estimate of 463,400, with individuals who identify as being from an ethnic minority making up 16% of the total population of Bristol, an increase from 8.2% in 2001 (340). The ethnic minority population in Bristol is much younger than the Bristol population as a whole, with 28% of children aged 0-15 identifying as belonging to a ethnic minority group, 15% of those aged 16-64 identifying as ethnic minority and 5% of those aged 65 and over (340). In 2011, Somalia was the second most common country of birth for Bristol residents, after Poland, with India, Jamaica and Other European Union (EU) countries also in the top five (340). 'Somali' is not a separate ethnic group on the 2011 Census, but recent estimates put the Bristol Somali population at 10,000 individuals (340,341) and over 5% (1 in 20) of all school children in Bristol are now of a Somali ethnic heritage (341).

I chose to limit the location of all participants to the Bristol/ Bath area, as this is the catchment area for the paediatric CFS/ME service; if I was introduced to a child with disabling fatigue who wanted to access specialist health care services, the CFS/ME clinic would be available for them. As discussed later in the chapter, this was an important ethical consideration. The community leaders and medical professionals were also selected from this geographic location in order to provide continuity in the study.

6.2.1.3 Public and Patient Involvement and Engagement (PPIE)

I recognised the importance of using Public and Patient Involvement and Engagement (PPIE) throughout the study, so incorporated it within all elements of planning and design. I met with the leader of an ethnic minority community group when designing the interviews, who observed that it was an important study to carry out, but I needed to be aware of the following two issues: firstly ensuring that participants who do not speak English as a first language understand what disabling fatigue and CFS/ME is, and secondly participants may fear judgement from the community so anonymity needs to be made clear and ensured.

6.2.1.3.1 PPIE – Study Materials

Detailed PPIE was used for the design of study materials. The information sheets, consent to contact and consent forms were adapted from previous studies with young people with CFS/ME, all of which have had significant input from the CFS/ME Patient Advisory Group. The information sheet for under-14s was reviewed by a young person to check understanding, and the information sheet for adults was reviewed by a 23 year old female from an ethnic minority background to ensure understanding and cultural sensitivity.

For the interviews with young people, the study materials and the topic guide were developed with input from an existing Young Persons Patient and Public Involvement and Engagement (PPIE) group, comprised of young people living in the Bristol area aged between 13 and 17 years old, interested in research. I consulted this group, gave an overview of the topic, presented preliminary interview question ideas, and asked for feedback on if the questions were acceptable and understandable. This PPIE group provided valuable feedback on the questions and helped refine the topic guide and information sheets by suggesting language changes to make the materials more age appropriate. The PPIE group also suggested that a picture of myself should be put on the information sheets, along with a brief biography including my interests and hobbies, in order to look more approachable to potential participants. This feedback was incorporated into the design of the study materials.

6.2.1.4 Recruitment

I aimed to include as many views as possible in the qualitative interview study, to triangulate viewpoints and understand the participant journeys holistically and from multiple perspectives. In order to gain this understanding of the barriers and facilitators to accessing CFS/ME paediatric services, I aimed to recruit four separate groups of participants to take part:

1. Clinic Participants and their parents/carers
2. Children suffering from disabling fatigue and their parents/carers
3. Community Leaders
4. Medical Professionals

Recommendations for the number of participants for qualitative studies ranges depending on study methodology used, but for in depth interview studies, saturation can occur within the

first 12 interviews with meta-themes present after the first six interviews (342). The initial study sample size was aimed to be up to 40 participants overall: 25 participants ultimately took part and this was supplemented with focus groups to gain perspectives from Somali community members.

6.2.1.5 Sampling

For the qualitative interviews, I intended to recruit a purposeful sample of young people with CFS/ME, with a range of ages, ethnicities and CFS/ME illness duration. Purposeful sampling is defined as sampling participants based on the qualities they possess (343) and occurs by interviewing those who have experiences of the concept the study is exploring (344,345). Purposeful sampling aims to recruit a small number of participants that will provide in depth information on the topic (345).

However, due to the limited number of ethnic minority children referred to the specialist CFS/ME service, convenience sampling was ultimately used and I recruited all ethnic minority children I was able to from the clinic. Convenience sampling recruits participants based on accessibility, and recruitment can use existing relationships, or can focus on recruiting participants from specific locations or settings (280,346,347). I recognise that by using convenience sampling, the participants recruited may not be representative of the population and could have relied on self-selection, or clinician selection, of those who chose to take part in the research (280,343,346,347). Please see section 7.10.2.4.1 for a discussion on data saturation.

6.2.1.5.1 Clinic Participants

Ethnic minority young people from the CFS/ME clinic (aged 11-18), and their families, were recruited through clinicians working in the clinic. Clinicians in the service identified eligible participants and discussed the study with them and their families during a routine clinic appointment. If the family was interested in taking part, they were given an information sheet to read and signed a consent to contact form. If I received a consent to contact form I contacted the potential participant to discuss taking part in the study.

6.2.1.5.2 Young People Suffering from Disabling Fatigue

I attempted to recruit young people (aged 11-18) suffering from disabling fatigue who had not been diagnosed with CFS/ME, and their families. I contacted relevant community and social groups and I met with two different activity groups for adolescents, to explain the study and what taking part would involve, and asked if anyone was suffering from disabling fatigue: no one wanted to talk to myself about this. Snowball sampling was also trialled, and three families told community contacts that they were willing to take part, but ultimately did not respond to contact from myself and did not make further inquiries with the community contacts in regards to the study. Therefore, despite some interest, no adolescents suffering from disabling fatigue, or their families, took part in an interview.

6.2.1.5.3 Community Leaders

Previous work researching CFS/ME in ethnic minority adults highlighted the importance of community and religious leaders in accessing specialist services (22). Therefore a sample of community leaders were recruited through contacts, word of mouth, snowball sampling and contacting community groups and organisations. At the start, I emailed organisations and community leaders to invite them to talk part. This was only minimally successful (four wanted to meet to discuss the study, and 0 agreed to take part). I then developed a new recruitment strategy, through personal contacts and building relationships, with a community partnership and CBPR approach (see 4.5.1: Study Design). In addition, a medical student completed a placement under my supervision assisting with the community leader interviews. The medical student sampled her own contacts and snowball recruited through community organisations.

6.2.1.5.4 Medical Professionals

A sample of medical professions were recruited through contacts, contacting GP practices and word of mouth. Potential participants were given information about the study and invited to participate. I attempted to recruit GPs from a range of practices in the Bristol/Bath area who had experience of working with ethnic minority young people. GP practices contacted did not express interest in taking part in the study, therefore personal contacts and snowball sampling was used to recruit medical professionals.

6.2.1.6 Inclusion and Exclusion Criteria

For the qualitative interviews, I aimed to recruit an ethnically diverse sample. Ethnicity is taken to represent self-claimed or subjective identity related to common descent or shared ancestry (348,349) and the projects conducted for the PhD thesis asked participants to self-identify their ethnicity. In the UK, there is no widely accepted protocol for the collection of ethnicity data, but the National Statistical Institute (NSI) has proposed measures to classify individuals ethnic group identification which are widely used in surveys and Census collections (348). Any data reported in this thesis will use the participants' own words to describe their ethnicity. For this study, 'ethnic minority' was defined as individuals who self-identify as any ethnicity apart from White British. A range of ethnicities was aimed to be included in the study.

The following table (Table 46) details the inclusion and exclusion criteria for taking part in the qualitative interviews:

Table 46: Qualitative Interviews Inclusion and Exclusion Criteria

Participant Group	Inclusion Criteria	Exclusion Criteria
Clinic Participants	• Diagnosed with CFS/ME and attending specialist services • Aged between 11-18 years old • Self-identify as being from an ethnic minority background • Must provide consent to take part in the study • Must live in the Bristol area	• Severely affected patients too unwell to participate (housebound)
Non-Clinic Participants	• Not diagnosed with CFS/ME but suffering from disabling fatigue • Aged between 11-18 years old • Self-identify as being from an ethnic minority background • Must provide consent to take part in the study • Must live in the Bristol area	• Too unwell to participate
Parent/Family Participants	• Have a family member suffering from CFS/ME or disabling fatigue • Must provide consent to take part in the study • Must live in the Bristol area	
Community Leaders	• Work closely with an ethnic minority community • Must provide consent to take part in the study • Must work in the Bristol area	
Medical Professionals	• Qualified medical professional • Have experience of working with ethnic minority children / adolescents • Must provide consent to take part in the study • Must work in the Bristol area	

6.2.1.7 Development of the Topic Guides

The topic guides were developed based on a review of the literature (including the Healthcare Access models as presented in Section 2.4 of the Literature Overview), the aims of the study, and the inclusion of PPIE input (as detailed in section 6.2.1.3). In addition to the PPIE input on the topic guides, and the inclusion of questions based on a review of the literature,

CFS/ME specialists and experts in qualitative research also provided insights and feedback on the topic guide for all groups of participants.

After the topic guides were drafted, they were checked and piloted with an ethnic minority adult to ensure cultural sensitivity (303). The involvement of the advisory group and specialists was to ensure that the questions asked in the interview allowed for rich information and meaningful responses (350).

In addition, the development of the topic guides was iterative; if themes emerged from initial interviews, these were then explored in more detail in further interviews. The systematic review results provided further insights into the general barriers identified in the literature, this was also included in the interview discussions, by asking about barriers, facilitators and ideas which could help improve access.

My PhD originally aimed to understand the barriers to accessing specialist CFS/ME services. The systematic review highlighted the importance of facilitators (what 'did' help). The first interviews also covered ideas for interventions, what did and did not help, and what could have helped in gaining access to the specialist CFS/ME service. Therefore, following my systematic review, all groups of participants were asked in interviews about both barriers and facilitators: 'what did help' or 'what could help'. My rationale was that if there were facilitators to access that families viewed as helpful, it is important to understand these.

6.2.1.8 Interview Procedure

I took advice from multiple sources on interview technique to ensure that I conducted interviews in a way that all participants had the chance to freely explore the topic area without closed or leading questions (285). I sought opportunities for feedback on interview technique from supervisors and the CFS/ME research team, especially after the first few interviews, to ensure the best interviews possible were conducted with participants. To enhance my skills and learning, I attended relevant training courses to improve my qualitative interview technique and qualitative analysis skills.

The interviews followed a semi-structured method (302,304) using the topic guide. Prior to the start of the interviews, participants were briefly told the main aim of the interview, which

was to understand their perspectives on CFS/ME and disabling fatigue in ethnic minority children along with a discussion of access to medical care more generally. The first question asked of those who had not been diagnosed with CFS/ME was "do you know what CFS/ME is?" This initial question was used to establish the baseline of the participants' understanding of the condition and lead to further questioning about the level of understanding the participant had about the illness. After a discussion about CFS/ME, disabling fatigue and personal or community views on tiredness, questions related to general access to healthcare were asked. This was asked to encourage participants to discuss any barriers or enablers they perceived for themselves, or their community, in accessing healthcare. Finally, participants were asked if they had any ideas as to what could help young people with CFS/ME or disabling fatigue to access medical care. Interviews with GPs and healthcare professionals followed a similar thread but also covered how regularly they saw adolescents with CFS/ME from ethnic minority backgrounds (a Topic Guide example is included in the Appendix).

The qualitative interviews were arranged at a convenient location and time for the participants (303,304) and the participants were able to ask any questions before informed consent was taken. All young people recruited from the CFS/ME clinic were asked to be interviewed separately from their parents/family members, but were given the option of being interviewed with their parents/family present and all participants chose this option; no young person chose an individual interview. Consent was obtained to record the interviews on a voice recorder. All interview participants chose to express themselves in English language. Participants were ensured of anonymity and were assigned a code for data storage of the audio recordings and transcripts. During the interview, participants were asked how they refer to themselves (in terms of ethnicity/culture/background) and this was recorded. I transcribed verbatim the majority of the audio recordings, but the medical student who assisted with the community leader interviews on summer placement transcribed their own interviews. Any information that could identify a participant in the transcript (for example: names, ages, locations) were deleted and replaced with a general summary or a reason for deletion, e.g. "*school name*", "*participant name*".

6.2.2 Qualitative Methods – Focus Groups

Part of this Methods section has previously been reported and published (1) - *please see the following publication for more detail:*

Linney C, Ye S, Redwood S, Mohamed A, Farah A, Biddle L, Crawley E. "Crazy person is crazy person. It doesn't differentiate": an exploration into Somali views of mental health and access to healthcare in an established UK Somali community. International Journal for Equity in Health. 2020 Dec;19(1):1-15.

The second qualitative method contained within the qualitative work is focus groups. This study received ethical approval from the University of Bristol Faculty of Health Sciences Research Ethics Committee (FREC).

6.2.2.1 Study Design and PPIE

A community-based participatory research (CBPR) approach was used for the focus groups, by co-producing this research with two Somali co-researchers from community organisations (351). This collaboration with the Somali co-researchers was used in all aspects of the research, with the Somali co-researchers involved in the research design and planning, producing materials (information sheets, consent forms, topic guides), recruitment to the study, analysis of the data, and contributing to the published journal article. In addition, a second year Psychology undergraduate assisted to gain research experience in this area; I supervised the student providing guidance and feedback.

6.2.2.2 Recruitment

The Somali co-researchers recruited participants to the study, though advertising and word of mouth. It had been said informally that "*Somali's do not like paperwork*"; the Somali language is a verbal language and was only converted to written text in 1972 (352) based upon the Latin alphabet and literacy levels are low in Somali individuals. Therefore, information sheets, in both the Somali and English language, were advertised, and individuals were spoken to when they used community facilities. Potential participants were asked if they knew anyone else who might be willing to take part, in an attempt to reach out beyond uses of the community centre and to include a wider sample of participants, although most participants were regular users of the centre. Recruitment aimed to bring together a diverse sample of participants (in terms of gender, age, time resident in Bristol, English language

ability, and number of children) to ensure different perspectives could be explored during the focus group discussions (315).

6.2.2.3 Participants

It was important for participants who attended the focus groups to have confidentiality in this close community and anonymous numerical codes were given to participants. To ensure anonymity and avoid potential identification, exact participant demographic details were not collected. On discussion, before the focus groups began, participants informally stated that their ages varied from late 20s to 60s, with the majority of participants between the ages of 30 to 45 years old. The majority of those who took part in the focus groups had at least one child, but this varied in terms of the number and ages of children participants had. I did not formally assess the English language skills of the participants, but offered the information sheet and consent form in either English or Somali. Participants had been living in Bristol for between less than a year, to over 20 years.

6.2.2.4 Data Collection

The four focus groups were conducted at a community centre in Bristol, due to it being a neutral location that was convenient and socially acceptable to the study participants (314), with a private room booked for the groups. Participants who took part in the focus groups were not given any contribution for their time, but refreshments (tea, coffee, snacks) were provided during the group.

The whole study team, including the Somali community research partners collaborated to produce the study documents (participant information sheet, consent form and topic guides). During the production of study materials, drafts were circulated for comments on how to make them easy to understand and culturally sensitive, before new drafts were produced. After finalising the study materials, the Somali community research partners translated the participant information sheet and consent form that had been produced in English, into the Somali language. The Somali community research partners took responsibility for focus group recruitment and providing Somali-English interpreter services for the groups.

The whole study team worked collaboratively to produce a topic guide, based on previous literature and the aims of the study. The topic guide consisted of broad questions that served

as discussion prompts during the groups to stimulate conversations. The topic guide was reviewed after each focus group, and revised if necessary to ensure focus group discussions covered all relevant topics to the study area.

Relevant to this thesis, in the topic guide, questions to prompt discussion were on hidden health conditions and fatigue and further discussion explored if participants would access medical care for fatigue. One section in the topic guide was focused on accessing healthcare and included questions on: factors influencing healthcare seeking, relationship with GP / medical services; and seeking help from places other than the GP. The final section in the topic guide was related to information about the community and included a discussion on community barriers / influences around accessing healthcare. Please see Section 4.6.3 for the rationale for interviews and focus groups, Section 6.2.3.3 for the analysis of both the interview and focus group data for this thesis, and Section 7.8 for a discussion on project integration.

Myself, and the undergraduate Psychology placement student, took informed consent from the participants at the beginning of the focus groups. Participants were provided with a choice of the English language or Somali language versions of the information sheet and consent form, or could request both versions. The community research partners checked understanding in Somali with all participants, as all participants spoke Somali as a first language. At the beginning of the groups, participants were informed in English and Somali of their anonymity and that they could leave the group at any time without having to give a reason.

The Somali community research partners advised that it was culturally appropriate to hold separate focus groups for male and female participants to enable open discussion of the topic area. Participants were thus invited to one of four focus groups with 5–6 people per group (2 female groups were held and 2 male groups). The focus groups lasted between 33 and 50 min and were run by myself and the undergraduate psychology student (with the student note taking (314)). During the focus groups, strategies were used to encourage discussion and to ensure all voices were heard, and to engage those who seemed more hesitant, including direct questioning where necessary.

To ensure that language was not a barrier, and everyone could take part in the focus group discussions, interpreters were present in all groups to provide continuous Somali-English translations throughout: a male Somali interpreter in the male focus groups and a female Somali interpreter in the female focus groups. Most participants chose to express their thoughts in the Somali language. Participants who spoke English confirmed after translation that the interpreter had correctly relayed their own (or others) thoughts into English. On a few occasions, study participants themselves translated into English what others had said in Somali, so I sought confirmation from the interpreter that this was an accurate translation. This cross-checking between participants and the interpreter, of what was said in Somali, meant I was confident in the English translations received during the focus groups (353).

6.2.3 Qualitative Data Analysis

Part of this Methods section has previously been reported and published (1)

For both interviews and focus groups, the discussion was recorded on an encrypted voice recorder and transcribed verbatim. During transcription of all data, any personal information, was removed to preserve anonymity and replaced with an anonymous summary, for example [name], [location].

I transcribed the majority of the interviews, but the medical placement student transcribed their own interviews (n=8) and the Psychology summer placement student assisted myself with transcribing the four focus group recordings. For the focus groups, myself and the summer placement student transcribed verbatim the English language translations provided by the interpreter in the focus groups, or the participants' words if they expressed their views in English.

Thematic analysis was used for data analysis (286,354) for both interview and focus group data, using Braun and Clark's Thematic Analysis guidelines (286). This involved initial coding, the forming and refining of categories, searching for negative evidence and constant comparison (355) across the data sets at each stage of the analysis. Constant comparison was used to explore similarities and differences in the views of individuals emerging during interviews and focus groups (356,357). This enabled key themes and cases of divergence to be identified.

6.2.3.1 Analysis Procedure – Interviews

For the interview analysis, the transcripts were coded inductively from the data, using the participant views to form the initial codes and then the themes. To ensure coding reliability, half of the transcripts of the qualitative interview study were double coded by another member of the CFS/ME research group. All focus group transcripts were double coded. Any conflicts between codes or theme development were discussed between researchers to resolve. There was the option of assistance in resolving conflicts from the CFS/ME research group, or supervisory input, but this was not needed during data analysis and conflicts were resolved through careful re-reading of transcripts and listening to audio-recordings if necessary.

Braun and Clarke's six steps of thematic analysis (286) were used for the analysis for the individual data sets as follows:

1. Phase 1: Familiarisation with the data

I conducted interviews with 17 out of the 25 qualitative interview participants and transcribed the interviews that I carried out. To ensure accuracy in the transcripts and familiarity and immersion with the data, I listened to the audio-recordings multiple times, along with multiple re-readings of the transcripts. After the data were anonymised, the transcripts were printed and any initial thoughts on the data, or any additional contextual information that could be useful for analysis, was noted in the margins, such as the participant tone of voice (e.g. a positive or a negative tone).

2. Phase 2: Generating initial codes

When I was confident that I was familiar with the data, the transcripts were read again and on the printed copy, line-by-line comments were made. I transferred these brief comments onto the NVIVO computer program (358) and these formed the basis of the initial codes. The participants' own words were used as much as possible for the initial codes and they were intentionally kept broad, with some excerpts coded in multiple ways.

3. Phase 3: Searching for themes

After all the data had been coded and the broad codes were inputted onto NVIVO (358) a long list of the codes was produced. These codes were sorted into groupings of what could combine to form the basis of an overarching theme. I used mind maps to sort codes into

patterns. Initial thoughts on themes were discussed with supervisors and other members of the CFS/ME research team and the initial coding frame was drafted.

4. Phase 4: Reviewing themes

The themes that had been generated were then refined by paying close attention to what had been sorted into these themes through the NVIVO software (358). It became apparent that some potential themes did not have enough data to support them. I also re-listened to the recordings to check if what was thought of as a key theme was actually emphasised as important by the participant, or was merely a passing comment.

5. Phase 5: Defining and naming themes

When I was confident that the themes devised accurately represented the data, I conducted further refinements by defining the theme, in terms of what the theme covered and that the individual themes ensured a coherent account amongst the data extracts. I named the individual themes and ensured that they fitted together to form a broader narrative with sub-themes included.

6. Phase 6: Producing the report

The final stage of qualitative data analysis was writing the report (see section 6.3 and section 6.4). Descriptive interview excerpts were included as evidence of the themes, and were chosen to provide illustrative examples and to allow the participant experiences and voices to be included.

6.2.3.2 Analysis Procedure - Focus Groups

Part of this Methods section has previously been reported and published (1)

For the focus group data analysis, initially the entire data set was transcribed and analysed. A similar analysis procedure was conducted for the focus group transcripts, using thematic analysis (286), but with additional input from the study partners. After the first two focus groups interviews, myself and the summer placement student each read the transcripts multiple times, independently, annotating the margin with general ideas, then draft ideas for 'codes' and then worked to group the 'codes' into broader 'themes'. We discussed and refined our initial thoughts, and the codes and themes were agreed with the Somali community researchers. From this agreement, a thematic coding framework was drafted,

which was then discussed with the wider University of Bristol study team. NVivo software (358) was used for data management, and new codes from the final two focus groups were added to the coding framework. During this process, the coding framework was revised, merged and refined to develop a coherent thematic summary, which was discussed and agreed with the community partners. During coding, any links between codes was explored along with any negative evidence or contradictory aspects of the themes. After the thematic summary was devised, myself and the placement student, and the Somali community researchers met to discuss the findings and the recommendations for action from the results. Please see the next section (Section 6.2.3.3) for analysis and triangulation of interview and focus group data for inclusion in this thesis.

6.2.3.3 Analysis and Triangulation of Interview and Focus Group Data

The qualitative findings presented in the next section of this chapter are based on the analysis of multiple qualitative data sets obtained via multiple methods with the following participant groups:

1. young people with CFS/ME and their families (family interviews)
2. community influencers (interviews)
3. medical professionals (interviews)
4. Somali community members (focus group discussions)

Each data set was analysed separately using Braun and Clarke's (2006) six steps of thematic analysis (286) (please see section 6.2.3.1 for details of interview data analysis). Thematic analysis was the method selected for data analysis and was used across all data sets to identify patterns of meaning. Thematic analysis was an appropriate analytic tool because of its breadth of application to different qualitative data types and its independence from epistemological or theoretical approaches (286). At Phase 3 of analysis (searching for themes) an initial coding frame was drafted and this was refined as more data were collected and analysed.

For the focus group data analysis (as presented in section 6.2.3.2) initially the entire data set was transcribed and analysed using thematic analysis (286). I was therefore familiar with the focus group discussions as a whole. I then extracted and thematically analysed (286) relevant data for inclusion in this thesis, i.e. those in response to the following focus group discussion

points a) experiences, or perceptions, of fatigue/tiredness symptoms, b) accessing healthcare services, and c) community context and community barriers / influences on accessing health care. I excluded data related to attitudes to and perceptions of mental health conditions as CFS/ME is not a mental health condition, and mental health is not a focus of this thesis.

I triangulated the themes generated from data obtained from the interview data sets (interviews with young people with CFS/ME, their families, community influencers and medical professionals) and the focus group data (relevant data from the focus group discussions with Somali community members). It was evident that there were data related to the conceptualisation of fatigue symptoms, barriers to accessing healthcare, and cultural factors that were similar in both the interview data and from my analysis of the focus group data. A pragmatic decision was taken to include these relevant focus group data in this thesis to enhance my knowledge and understanding of access to care. During the process of triangulating and interpreting my findings I paid careful attention to divergent views or misalignments between data sources and different perspectives within and between the different participant groups.

Data collection and analysis for this thesis were iterative and interviews continued after the focus groups were conducted (Table 30). Therefore, although the data sets were analysed separately, the overall coding framework was applied to both interview and relevant focus group data and the final set of themes presented in this chapter includes data from both interviews and focus groups. I have considered the different methods of data collection and their impact on the data collected (please see Section 7.10.2.4.2 for a recognition and discussion of the differences between focus group and interview data, and the limitations of this approach of using both methods).

6.2.4 Ethical Considerations

Ethical issues were considered very carefully due to the sensitive subject matter and the stigma of hidden illnesses (211,212). Participation in this study was voluntary and no financial incentives were provided to study participants. The following ethical considerations and mitigation strategies were identified:

6.2.4.1 Accommodating paediatric patients with fatigue

As this study aimed to be as inclusive as possible, I predicted that a range of severity levels would be encountered and the effort required from the participants with CFS/ME was carefully considered when planning the interviews. Children and their families were able to schedule interviews at a time and place that suited their needs, including remotely if that was more suitable for the child's illness. Participants were informed that they could stop the interview at any time, or they were given the option of scheduling a series of shorter interviews if more appropriate. No participant chose to schedule multiple interviews. Severely affected patients were excluded for the child/adolescent interviews, due to placing demands on participants that could have been detrimental to their overall health: one child was too unwell to take part in an interview, but their mother did take part.

6.2.4.2 Data management

Data management was carefully considered to ensure confidential data were (and continue to be) securely stored. Participants were ensured of the confidentiality of their personal data and any recordings or transcripts made.

Interviews and focus groups with study participants were recorded using an encrypted and password protected voice recorder. The audio files were stored as password protected audio files on a password protected University of Bristol computer, in a locked office. The audio recorder was taken straight to the office once the interview or focus group was concluded, transferred to the computer and deleted from the voice recorder.

Interviews were transcribed verbatim into a Microsoft Word document, which was saved using a numerical code assigned to each participant. A master Excel spread sheet, listing participant names, contact information and the corresponding numerical codes was stored as a password protected document on a password protected computer in a locked office and this was stored in a separate folder to the transcripts.

All consent forms were stored in a locked filing cabinet, in a locked office, in a key code access only building. Printed copies of anonymised transcripts were kept in a folder, in a locked cabinet, in a locked office, different to the locked filing cabinet where the consent forms were kept.

6.2.4.3 English Language Ability

This study aimed to be as inclusive as possible and encountered a range of English language abilities. I ensured that participants had the ability to be able to consent to taking part in the study and they understood the topic of discussion and their rights. For the qualitative interview study, all participants were fluent and comfortable conversing in English, but if English was a participants' second or third language, I ensured a thorough understanding of the study and the consent process before commencing.

For the focus groups, most participants did not have sufficient English language skills to ask questions and read the English language consent form so a translated consent form and information sheet (into the Somali language) was also offered. A Somali language interpreter was used to ensure participants understood the study and the consent procedure. The interpreter assisted in ensuring participants understood about their rights to stop and withdraw consent. In the focus groups a few participants did speak English and they provided confirmation, along with the interpreter, that participants understood and consented.

6.2.4.4 Child is Identified with an Illness

During the course of the project, I carefully considered what would happen if a participant was identified as potentially having CFS/ME because of this study, due to being identified as suffering from disabling fatigue. In this situation, given the prognosis is much better with management; the participant is likely to benefit if they were referred to CFS/ME management. If this occurred, I would signpost (if requested) to the specialist services in Bristol. All participants were recruited in the Bristol area; therefore signposting to specialist paediatric CFS/ME services, which cover this area, would have been appropriate. This ethical issue was carefully considered during the application for ethical approval for the study, but ultimately this did not happen during the project.

6.2.4.5 Confidentiality

It was highlighted in all Participant Information Sheets that participation in an interview was confidential. Participants were informed that all names and places would be anonymised during transcription and that myself, or an external company with confidentiality agreements

with the University, was doing the transcribing. Ultimately the external company was not used to transcribe any interview or focus group recordings. The limits of confidentiality (the only time confidentiality would be broken and the supervisory team informed) was if there was concern about the risk of harm to a person. I did not have to break confidentiality during the course of the study.

6.2.4.6 Debriefing

After the interview, participants were debriefed. On occasion, participants wanted to keep talking about the study topic after the interview was concluded and they were asked, "*is there anything else you would like to add or discuss*?" On the occasions when the participants wanted to talk more about the research topic, permission was sought to turn the audio-recorder back on to capture these views. The interview participants granted this permission and this happened in two interviews.

Participants were asked after the interview if they were comfortable with how the conversation went and it was ensured that, as far as possible, the participant was in the same emotional/mental state as when they started the interview. Participants who had been diagnosed with CFS/ME verbalised after the interview that they were glad of someone to listen to their stories, experiences and feelings. Participants from community groups were thankful for taking the time to listen to their views.

No participant became emotional or upset during the interviews, but it had been agreed with the supervisory team that if a participant was to become distressed, the interview would be paused, the participant would be given a break, then asked if they wanted to continue. If they did not want to continue, the interview would be immediately stopped. This was also the case with all participants; the interview could be stopped at any point with the participant not having to give a reason.

6.2.4.7 Consent

Informed consent was sought from all study participants prior to taking part. Time was spent talking to each participant before the interview or focus group commenced ensuring the participant understood the topic of discussion and the study procedure. Written consent was taken on a consent sheet and participants were informed that they could withdraw from the

study at any point without having to give a reason and that they could withdraw their data up until any data they provided have been published. No participants have withdrawn thus far.

6.2.4.8 Researcher Safety: Lone Working

Although most participants chose to be interviewed in a neutral location, or a virtual interview, all interview participants were offered their own home as a choice of interview location. Some participants did choose to be interviewed in their home and in instances of entering a participants' house, I adhered to the lone working policy and took the following steps to ensure safety. Firstly I made the appointment with the participant and kept details of the appointment in a sealed envelope in a locked filing cabinet. I phoned a colleague from the research team before entering the house, and provided a time that the interview will be concluded by, and therefore when I would be leaving the house. I phoned the colleague when leaving, or if the time of the interview had changed for any reason (for example if the interview was longer than expected). If I did not phone the colleague at the pre-arranged time, the colleague would phone until I answered. If I did not answer the phone, the colleague would phone the police with the address where the interview was taking place.

6.2.5 Summary of Methods

This section has presented an overview of the study design, recruitment procedure, data analysis and ethical considerations of the qualitative component of this thesis. The next section (section 6.3) presents the qualitative findings (1) in terms of barriers to accessing specialist CFS/ME services for ethnic minority children and section 6.4 details the qualitative findings (2) in terms of improving access (including facilitators). This chapter finishes with a summary of qualitative findings in section 6.5.

6.3 Qualitative Findings (1) – Barriers to Accessing CFS/ME Services

This section presents the findings of the qualitative study on the barriers for ethnic minority young people with CFS/ME accessing specialist CFS/ME services. Thematic analysis was conducted on the data sets from different groups of participants and the barriers are presented in the form of themes derived inductively from the data. The data from the four different participant groups were analysed together, and this section describes themes that were similar

across the groups, but also differences. This produced three overarching 'barriers' themes, with subthemes (Table 47). In this section, the qualitative findings on barriers are presented, with a description of each theme and sub-theme, with participant interview excerpts to provide illustrative examples.

Table 47: The Key Qualitative Findings: Barriers to Accessing CFS/ME Services

Theme	**Sub-Themes**
1. Conceptualisation of CFS/ME	Lived Experiences of Fatigue Symptoms Understanding Awareness Stigma
2. Cultural Factors	Perceived Closeness to a Specific Community Close Communities and Families Alternative Sources of Help 'Respect for authority': Disagreeing with Medical Professionals
3. 'What's going on with the NHS?': Experiences of 'Going to the Doctors'	Factors Influencing Help-Seeking Behaviour General Medical Care Barriers CFS/ME Specific Experiences

6.3.1 Section Overview

This section (6.3.1) provides a breakdown of the sample included in the qualitative interviews and focus groups in terms of demographic details (section 6.3.1.1)

Section 6.3.2 details how the 'Conceptualisation of CFS/ME' can be a barrier to help seeking, in particular: (1) 'Understanding', for example if the term CFS/ME is not understood, or if there are alternative explanations that fatigue can be attributed to; (2) 'Awareness' of CFS/ME and how that impacts on help seeking; and (3) 'Stigma' surrounding CFS/ME and fatigue.

Section 6.3.3 details the participants' accounts of 'cultural factors' that may influence help-seeking for fatigue symptoms, encompassing community closeness, alternative sources of help, and cultural factors in medical consultations.

The final theme detailed (section 6.3.4) is barriers present when 'Going to the Doctors'. This theme considers help-seeking, in particular when a doctor would be consulted for fatigue

symptoms, along with more general medical care barriers that may be present when accessing healthcare (the role of ethnicity in medical care, getting an appointment, language barriers, relationship with GP). In addition, detailed accounts of children and young people with CFS/ME journeys to specialist CFS/ME services is included.

Section 6.4 presents the section overview for the Qualitative Findings (2) – Improving Access.

Section 6.5 provides a summary of the barriers and includes an illustrative diagram to highlight the different ways in which the barriers may interlink to limit access to CFS/ME services for ethnic minority children.

6.3.1.1 Demographic Details

The qualitative findings presented in this chapter are from the following participant groups, with a total of 48 participants: 25 interview participants and 23 focus group participants (Table 48 and Table 49).

Table 48: The Demographic Details of the Participants

Participant Group	Data Collection Method	Number of Participants	Anonymised Code
1. Ethnic minority adolescents diagnosed with CFS/ME	Qualitative interviews	3 Young People (aged 11-17)*	CYP (Clinic Young Person)
2. Parents / families of ethnic minority adolescents diagnosed with CFS/ME	Qualitative interviews	5 Parents/carers (4 Mothers, 1 Grandmother)	CP (Clinic Parent)
3. Community "Influencers"	Qualitative interviews	14 Community 'Influencers'	CI (Community 'Influencer')
4. Medical Professionals	Qualitative interviews	3 Medical Professionals	MP (Medical Professional)
5. Somali community member views	Four focus groups	23 Focus Group Participants	FG -P (Focus Group Participant)

*all young people chose to be interviewed together with their parent/carer

To protect participants' anonymity, due to low sample sizes, anonymised codes are not presented with demographic data, to avoid participant identification (Table 48 and Table 49). Table 50 presents the interview/focus group lengths and Table 51 details when data were collected.

Table 49: Further Participant Demographic Details

Participant Group	Ethnicity	Job	Gender
Ethnic minority adolescents and their parents/families	All young people self-describe as mixed-ethnicity	-	Female
Community 'Influencers'	Arab Somali Pakistani Bangladeshi Ethiopian Kurdish	Advocacy Worker Social Worker Founder/manager of a charity Founder/manager of a community group Medical Translator Program Worker Lead Muslim Chaplain Imam	8 Female 6 Male
Medical Professionals	Somali White British	GP Nurse	1 Female 2 Male
Community Members	Somali	Varied	12 Male 11 Female

Table 50: Interview/ Focus Group Lengths

Participant Group	Interview / Focus Group Length (Range)	Interview / Focus Group Length (Mean)
Adolescents and Parents/Families	26 minutes – 51 minutes	41 minutes
Community 'Influencers'	10 minutes – 62 minutes	31 minutes
Medical Professionals	18 minutes – 26 minutes	23 minutes
Community Members	33 minutes – 50 minutes	39 minutes

Table 51: Data Collection

Participant Group	Data Collection
Adolescents and Parents/Families	May 2019 – January 2021
Community 'Influencers'	March 2019 – December 2019
Medical Professionals	July 2019 – January 2020
Community Members	August 2019 – September 2019

The themes and subthemes are described and illustrated in the following sections using interview excerpts selected on the basis of providing detailed examples of the theme and participant discussion, and to ensure the participants' own voices are heard throughout the findings. To preserve anonymity, participants were given an anonymised code and any identifiable data (such as name, age, location) were removed and replaced with a generic descriptor, for example [location]. Excerpts are presented using codes that detail their participant group:

- CYP for Clinic Young Person
- CP for Clinic Parent/Family Member
- CI for Community Influencer
- MP for Medical Professional
- FG-P for Focus Group Participant

During recruitment and participant interviews, section 6.4.5.1 describes how 'Community Leader' was unacceptable to participants and therefore, this has been replaced by 'Community Influencer' in this presentation of results (see section 6.4.5: Ideas to Improve Recruitment to Healthcare Studies).

6.3.2 Theme 1: Conceptualisation of CFS/ME

The first theme was the conceptualisation of CFS/ME. This theme was identified across all participant groups and the theme encompasses four distinct subthemes: (1) Lived Experiences of Fatigue Symptoms; (2) Understanding; (3) Awareness; and (4) Stigma.

This first theme describes how CFS/ME might be understood. This is important because how CFS/ME is conceptualised, and what attributions are made about fatigue can determine how participants will present to medical care.

6.3.2.1 Sub Theme 1: Lived Experiences of Fatigue Symptoms

Many community participants had experience of fatigue symptoms (personally or within their family) illustrating how common the symptom is in the general population, including in ethnic minority individuals.

One community influencer spoke of their own fatigue symptoms and described how they are "*very tired*" (CI-012), with another discussing their children experiencing fatigue. One community influencer thought their child's tiredness could be mental health related: "*my daughter says she's feeling tired all the time and I put it down to depression*" (CI-008).

Other community influencers suggested that their child's tiredness was related to vitamin deficiencies. One community influencer stated that their child is: *"tired all the time, low energy, we thought maybe iron deficiency or vitamin deficiency*" (CI-004). Another community influencer also described their children as tired and attributed it to vitamin deficiencies: "*sometimes they take Vitamin D supplement and it's quite challenging, when I see them they are very tired"* (CI-001), with another commenting that their children were tired "*when they were young they were very tired, but um I didn't know what what causes the tiredness"* (CI-002).

No participants, apart from those recruited from the CFS/ME clinic, spoke about a formal diagnosis for the fatigue symptoms and no participant asked for advice or more information about CFS/ME.

6.3.2.2 Sub Theme 2: Understanding

Most individuals (from the following participant groups: young people with CFS/ME and their family members, community influencers, and medical professionals) discussed how understanding of CFS/ME is limited. Young people with CFS/ME discussed a lack of understanding from others, especially friends and social contacts at school, with only family members understanding the condition.

"some of my friends just don't understand what it is and they're always constantly asking me 'why are you never in?"" (CYP-003)

"*they keep asking, 'why are you always tired'?*" (CYP-004)

Parents also echoed this view of CFS/ME as "*not understood, people don't appreciate what it entails*" (CP-002) and "*people didn't understand what she was going through*" (CP-002). This lack of understanding was viewed as a key initial barrier in accessing medical care: "*I think initial barrier would be just a lack of understanding about the condition*" (CP-002).

Community influencers displayed varied understanding of the condition and the symptoms of CFS/ME. There was some understanding of the condition and the main symptom of tiredness and how CFS/ME "*causes more tiredness in a person than it would in someone who wasn't suffering from um from ME*" (CI-013), but there was a view that there was a lack of treatment for CFS/ME. If CFS/ME was viewed as having no available treatment, this could stop people accessing medical care and be a barrier for help seeking:
"*God forbid if any of us have chronic fatigue because I'm not sure what treatment there is. From what I understand there isn't really any treatment, you just kind of have to cope*" (CI-008)

Some community influencer participants discussed the legitimacy of the condition CFS/ME, expressing doubts about if it would be viewed by others as a medical condition. One community influencer stated that CFS/ME could be viewed by others as a "*new age kind of thing, almost like an excuse*" (CI-008) and people might question "*is it an official condition?"* (CI-008). This could be due to the term CFS/ME being viewed as *"a new term and so it's like a new-fangled thing*" (CI-008) highlighting some views that CFS/ME could be a Western biomedical construct and not universally recognised.

6.3.2.2.1 Terminology of the phrase CFS/ME:

Related to understanding the condition, community influencers and medical professionals discussed understanding the terminology of the phrase 'CFS/ME' and the negative connotations associated with it. Understanding was discussed by those with English as an additional language as "*quite a big challenge because this word is not part of our languages*" (CI-001) and community influencer participants commented that the individual words are understandable, but the meaning is not: "*I heard the words, but I don't understand what the meaning, what the meaning of that is, so completely new to me*" (CI-002).

A medical professional provided context of the difficulties understanding the phrase CFS/ME, due to language differences and cultural understanding: "*I've come to learn that there isn't a name for chronic fatigue […] in the Somali culture, sort of the East African, because it's not, not only is it not heard of, but also yeah there's not many, we don't really see many children or young people with chronic fatigue*" (MP-001).

Despite children and young people with CFS/ME not having visible signs and symptoms of the condition, there is some understanding of the term, especially the term ME (compared to CFS). ME was discussed as being more known amongst the Somali community as "*a condition that only affects older people. Because sometimes um you know, you see it in persons of older, adults, rather than young children, um and I think it's more sometimes, it's more known as chronic fatigue syndrome in young people*" (MP-001).

This lack of understanding of the terminology of CFS/ME could be a key barrier, and a medical professional proposed that if there was increased understanding and knowledge of the phrase CFS/ME, individuals may be more likely to seek help: *"if they know there's a name for a condition, they'd be more willing to get more medical help*" (MP-001).

6.3.2.2.2 Alternative explanations

Most community influencer participants discussed alternative explanations for the causes of fatigue in children. This is a barrier in help-seeking as depending on what the fatigue is attributed to, home remedies could be trialled, or medical care might not be sought if there is a view that the condition might not be treatable, or stigma surrounding the potential cause of fatigue.

Most participants recognised that there would be an underlying cause of tiredness in children, as "*it's not a cause by itself, it's related to something else happening to you*" (CI-012) with a view that tiredness needs a reason, "*I see them children saying 'I'm tired' but I don't know what they tired of, I don't know*" (CI-003). But there were divergent views as to what that cause of underlying tiredness could be, and this section explores alternative explanations given to the symptoms.

Some individuals may attribute CFS/ME symptoms as being caused by other health conditions as: "*with it sometimes being so subtle you know, the tiredness, the weakness, it could be so many other things that people assume first*" (MP-001). Due to a lack of understanding of CFS/ME, numerous alternative explanations could be considered before CFS/ME as discussed by a medical professional: *"I could just imagine a child from the Black and ethnic minority, the parents say 'I'm tired, I'm tired all the time' you know there's so*

many other things that could come through the parents mind rather than my child's got chronic fatigue" (MP-001).

Participants discussed medical causes and non-medical causes of fatigue, and this section details the participants' ideas as to what causes disabling fatigue in children.

Non-Medical Causes of Fatigue in Children

The symptoms of CFS/ME were described by some community influencers as being attributed by others to an individual's attitude, not an underlying health condition. Individuals with CFS/ME could be viewed by others as "*they aren't trying hard enough to take care of themselves"* (CI-008), they have a "*lack of will*" (CI-011) or they are wanting "*attention*" (CI-008). If fatigue is attributed to an individual's attitude, rather than a health condition, help-seeking could be less likely.

Lifestyle choices were also discussed as a cause of disabling fatigue and CFS/ME in children. There was a view shared by community influencers that others (including medical professionals) may think "*maybe it's just lifestyle choice that are creating it?*" (CI-008). Other community influencers discussed the particular lifestyle aspects that could cause the disabling fatigue symptoms, including a lack of "*sleeping"* (CI-011) and the education system in the UK, which causes children to be "*completely exhausted, they're really tired*" (CI-010) after the school day.

Divergent views were found regarding exercise; some participants thought that a lack of exercise causes fatigue in children, whereas others thought that too much exercise could be a cause. In terms of lack of exercise in children, "*not engaging with much activities which can make them feel tired*" (CI-006) with a medical professional discussing how they had heard parents talk about how their children "*need to go out there and you know increase their physical exercise*" (MP-001). Lack of exercise was discussed as related to overuse of technology, with a recognition that "*children are busy with their devices, so children doesn't have the physical activity in the home*" (CI-010). A lack of exercise could ultimately cause fatigue symptoms as "*you really need to train your body to be active and do things, then the more you do the less tired you get"* (CI-009). Other participants discussed how children doing too much exercise can cause fatigue and tiredness and *"your child needs to sit down*" (CI-003). One community influencer questioned whether tiredness in children could be "*are*

they really very tired because they have done something in the school or in the park or in the active?" (CI-001).

In addition, an uncommon explanation for tiredness and CFS/ME in children, shared by one community influencer, is that of a 'curse': "*there may be some, it's possible but I don't know, maybe more conservative, that might think there's a curse, yeah the curse, why has this happened to us*" (CI-011). In Theme 2: Cultural Factors, alternative sources of help are discussed by participants, therefore if a 'curse' is believed to be the cause of the fatigue, alternative help-seeking could be trialled.

Medical Causes of Fatigue in Children

In terms of medical causes of fatigue in children, participants provided explanations that could be causing tiredness, including: high blood pressure, hay fever, fibromyalgia and juvenile arthritis. These can be barriers to accessing help as if CFS/ME is conceptualised as another condition, individuals may be more or less likely to seek help, depending on if the health condition can be treated by home remedies, or any stigma surrounding the condition.

The symptoms of diabetes were well known, with awareness campaigns in medical settings leading to an increased knowledge of the condition. A medical professional discussed how in their experience, parents could attribute tiredness in their child to diabetes, due to diabetes getting "*promoted, you know, you see it on you know GP notice boards you know 'you're feeling tired, check this and check that'*" (MP-001) and community influencers agreed that if a child was complaining of tiredness, "*first thing I would think was 'does he have the diabetes' because I think that links into, I don't know, in my head that's what I would think*" (CI-003).

A further explanation attributed to fatigue was vitamin deficiencies, as discussed in Sub Theme 1: Lived Experiences of Fatigue Symptoms. Most community influencer and focus group participants were aware that a symptom of vitamin deficiency is fatigue. Participants discussed that if vitamin deficiencies were suspected, a doctor could be consulted and blood tests requested, as a parent might wonder "*is my child anaemic?"* (CI-014) with anaemia being "*the most common symptom they would be looking for, they would associate tiredness with*" (CI-014). With tiredness, individuals would "*straight away we could think of vitamins*" (CI-009) and they would advise others to seek medical care as "*anyone complains to me that,*

the first thing I would say is 'did you go to your GP and check all your vitamins are at the correct level?'" (FG1-P002).

Multiple community influencer participants spoke about how specifically Vitamin D deficiency can cause fatigue symptoms. Participants were very aware of how low Vitamin D can lead to "*muscle and joint pains*" (CI-001), with a recognition that Vitamin D is common: "*I see a lot of people, mainly parents actually, you know complaining about you know the vitamin D deficiency*" (CI-006). Additionally, multiple community influencer participants discussed the link between ethnicity and Vitamin D deficiency. Participants described the "*struggle with Vitamin D, because of the sun, the limited sunshine here in Bristol*" (CI-001) with "*little chance to get Vitamin D from sunshine, especially in this country*" (CI-007).

Medical professionals also talked about this understanding of tiredness being related to vitamin or mineral deficiencies, but suggested that home remedies may be trialled instead of medical care: "*with tiredness, people often assume it's low iron and obviously the first thing they do is go and get a pack of multivitamins from you know the local pharmacy*" (MP-001).

Related to the understanding of vitamin deficiency and fatigue symptoms was diet and "*not eating enough fruits and vegetables*" (CI-014) or "*not eating the right thing*" (CI-009), as with diet *"the children can get tired if they have an imbalance or not sufficient"* (CI-006) but how diet "*could be as a result of poverty"* (CI-006).

Mental ill-health was also a common explanation for fatigue and tiredness in children, specifically depression. Parents of young people with CFS/ME recognised this as with CFS/ME symptoms, "*people assume it's gonna be stress or, or emotion*" (CP-001). Community influencers and focus group participants also discussed how mental ill-health can cause disabling fatigue symptoms, such as "*if you are under a lot of stress*" (CI-012), or being "*stressed out, or she is feeling tensions about whatever it is*" (FG3-P001). Male focus group participants, when asked about the symptom of fatigue, stated "*that's depression isn't it?*" (FG2-P004).

Medical professionals discussed how fatigue and mental ill-health can be linked, but stigma around mental health could delay access to medical care:

"*parents could feel like it's because of their mental health, rather than their physical health, and that actually that could be the biggest stigma, them worrying about, um worrying about their mental health and then feeling like they need to keep it to themself and not actually go and seek help because they're worried about what people might think*" (MP-001).

There was an alternative view amongst some community influencer participants, with a discussion of how the GP may be quick to diagnose mental health issues when the patient is experiencing tiredness. A view was discussed that GPs "*tend to diagnose with the, with the mental issue or stress*" (CI-002) when seeing ethnic minority patients. Therefore concerns around a diagnosis of a mental health disorder is a barrier to help-seeking.

Various home remedies could be trialled for tiredness and fatigue symptoms, dependent on what individuals attribute the cause of the symptoms to. A clinic parent discussed how multivitamins were trialled for their child's initial tiredness symptoms, "*I just thought maybe because you know teenager and not eating properly, perhaps, I don't know but she did eat well, so I put her on multivitamins, you know the mum things that you do"* (CP-003). More exercise had been suggested to improve fatigue symptoms: "*the advice we had from some people like my in-laws, oh you just need to 'get her up, get her exercising, getting her doing stuff, don't let her stay in bed*'" (CP-002). With a focus on general lifestyle changes to try and alleviate symptoms, such as: "*trying to have a balanced diet, take them on outings and try their best*" (CI-008).

6.3.2.3 Sub Theme 3: Awareness

The third sub theme, in terms of 'Conceptualisation of CFS/ME' is that of awareness. As presented in sub-theme two ('Understanding'), participants' understanding of CFS/ME and what fatigue could be attributed to, was varied. This sub-theme found that if individuals had an awareness of CFS/ME, it held certain connotations. One parent of a paediatric patient from the CFS/ME clinic referred to CFS/ME as a "*posh persons flu*" (CP-003):

"*one of my friends 'oh that's like a posh persons flu' and I'm like really? Posh persons flu is not what it's called, um I never knew that. Yeah so they have like little terms for it*" (CP-003)

With another parent commenting that others "*tend to treat it a bit like yuppie flu*" (CP-005).

But all clinic families discussed how generally there was limited awareness of CFS/ME by others as "*the consultant didn't quite get it, and I suppose generally speaking Joe Bloggs*

everyday doesn't really get it either" (CP-002). Clinic participants discussed how "*people are very unaware of this"* (CYP-001) and acknowledged that before their diagnosis, "*I didn't have a clue what chronic fatigue was*" (CYP-001). This view of a lack of awareness before diagnosis was also echoed by another family as "*I don't think you hear a lot about it, it's not something people know about unless it happens to you*" (CP-003).

Community influencers also supported this view of a "*lack of awareness of things like CFS"* (CI-004) in the general population, with the condition "*definitely not known. I don't think you will find a Somali* [with CFS/ME]" (CI-001). In particular, community influencers discussed how they were not aware of ethnic minority individuals diagnosed with CFS/ME, as this interview excerpt illustrates:
"*I don't think I've heard about in the BME community the only people I've heard about it is on BBC or articles medical journals and things so I haven't heard any person first hand tell me, especially from an Asian community, a BME community, that they're suffering from chronic fatigue, it's not just a, I've never heard of it but I'm sure people must be suffering*" (CI-008).

Community influencers did recognise that due to a lack of awareness of CFS/ME, it is possible the some children have not been diagnosed: "*I've heard people say for example 'my child sleeps all the time', or 'they're lazy', or 'they're this', or 'they're that', and it is possible I'm thinking that they may have a condition like this and it hasn't um like picked up on"* (CI-011).

Medical professionals also echoed the lack of general public awareness of CFS/ME and how a lack of awareness of CFS/ME can lead to not presenting to medical care: "*probably they do have it and they're just not being assessed or because parents are not aware of the condition, they're not taking their child to be assessed*" (MP-001).

6.3.2.4 Sub Theme 4: Stigma

Most individuals (from the following participant groups: young people with CFS/ME and their family members, community influencers, and medical professionals) discussed stigma of both the symptom of tiredness, and of the condition CFS/ME, in detail; this is contained within this final sub theme 'stigma'. Most participants discussed a stigma surrounding the

condition, with a perception of CFS/ME as 'lazy' and if there is stigma, individuals may be less likely to seek healthcare.

Young people with diagnosed with CFS/ME spoke of the "*stigma*" (CYP-001) when experiencing CFS/ME with "*stigma around kids just trying to stay off school and things and this, like, it's really not like, I really actually can't get out of my bed today*" (CYP-001). Parents of children diagnosed with CFS/ME also discussed how CFS/ME is "*still a stigmatised illness*" (CP-001).

Community Influencers also recognised this "*stigma*" (CI-001) around tiredness, with a perception of "*lazy*" (CI-001). The term "lazy" was very common when discussing tiredness and CFS/ME, and most participants used this word. The notion of laziness was also found in clinic participants who had been diagnosed with CFS/ME, with CFS/ME sufferers viewed by others as "*just being lazy"*" (CYP-001). Most community influencers also associated the symptoms of tiredness and fatigue with "*generally laziness*" (CI-014) and a "*lazy person*" (CI-002). One community influencer spoke about gender roles and how girls are typically seen within their community as 'lazier': "*somehow girls are more lazier, tired. Like I don't know, they tired, but they just don't want to do stuff, so I don't know if it's this or not*" (CI-003).

Medical professionals also commented on the stigma surrounding tiredness, fatigue and CFS/ME. A medical professional recognised a stigma of CFS/ME, but discussed how adults may be more stigmatised: "*I think there is a stigma, I don't think of it quite so much with children for some reason, but yes I'm sure there is*" (MP-003). Additionally, a stigma from within the family regarding the condition could be a barrier to accessing medical care as "*it takes the child to report the problem, so there could be barriers around the child feeling stigmatised even within the family"* (MP-003).

Finally, a medical professional presented a view that a stigma could be related to CFS/ME being considered an "unworthy" condition to have, as this following interview excerpt illustrates:

"*It's certainly a hypothesis isn't it, that people wouldn't present with something through some sense that it was an unworthy thing to have, that it was a bad thing to have or be, some*

source or shame, some source of, you know it's only a hypothesis I couldn't say for sure" (MP-003).

6.3.3 Theme 2: Cultural Factors

The second theme is Cultural Factors, and how this can impact on help-seeking behaviour, and the interplay with the stigma of hidden health conditions. This was a recurrent theme for community influencers and community members, and participants described how cultural factors can affect openness about their child's health to others, and how cultural factors could impact seeking medical care. In addition, alternative sources of help that are viewed as traditional healing, or culturally acceptable, were discussed by participants. Cultural factors that can influence how appropriate it is to disagree with medical professionals were also discussed by participants, and how that influences help seeking.

The theme Cultural Factors is comprised of four sub-themes: (1) Perceived closeness to a specific community; (2) Close communities and families; (3) Alternative sources of help; and (4) Disagreeing with medical professionals.

6.3.3.1 Sub Theme 1: Perceived Closeness to a Specific Community

Prior to analysis, the data were explored to see how participants self-classify their ethnicity and if they relate to, or discussed, being part of a specific 'community'. All clinic participants described their ethnicity as 'mixed' (one White British parent and one Ethnic Minority parent). When interviewing clinic young people, ethnicity and 'community' was not mentioned (or was only mentioned in passing), as opposed to some parents who highlighted potential differences in how their child was treated when accessing medical care, due to their ethnicity (contained in Theme 3). Other families did not discuss ethnicity, and one stated that "*we don't really see race do we?*" (CP-005).

Some clinic parents discussed generational differences and understanding from family members. One clinic parent discussed a lack of understanding from older relatives about their child's condition, due to "*cultural*" (CP-003) factors:

"*we just couldn't be bothered to explain it* [CFS/ME], *because to them there is a little bit of cultural things to them being in a you know Indian background they are not very good with*

the mental illness, they don't look at it like it's an illness kind of thing, you know you're alright just buck up and get on with your life, be strong" (CP-003).

In contrast, most community participants (community influencers and community members) placed a strong emphasis on their cultural background, self-identifying as, for example "Somali". Community influencer participants spoke in depth about their community, and closeness to the community. Similar to the discussion by a clinic parent, community influencers also discussed generational differences, and a potential generational gap, with different understandings of hidden healthcare conditions. There was a differentiation between the "*older generations*" (CI-003) and the younger generation, which was attributed to education by one community influencer:
"*Everyone has that basic level of understanding now and because simply because more and more of the BME community is educated where the generation before was not*" (CI-014).

Medical professionals also spoke in depth about their experiences of closeness in ethnic minority communities. A medical professional discussed how they had observed more of a "*communal view*" (MP-003) on healthcare conditions and attributed this to the closeness of some ethnic minority communities. But the medical professional also recognised the generational gap and the stigma of hidden healthcare conditions. The following two interview excerpts illustrate both the closeness of ethnic communities, and the generational gap, from a medical professional perspective:
"*A curious thing about ethnic communities is that although they are societally isolated in some ways, in other ways they are more connected to each other than typical White British people are, so they have more of a sense of community and slightly more of a communal view on things*" (MP-003)

"*I think the new generation of Somali young people I think would be more immune to that sort of reflex prejudice* [for hidden health conditions]" (MP-003)

6.3.3.2 Sub Theme 2: Close Communities and Families

The second sub-theme identified under Theme 2: Cultural Factors is that of Close Communities and Families. This is related to sub-theme 1 (Perceived Closeness to a Specific Community). Individuals who did strongly identify with being a member of a "community"

spoke in depth about the role of the community, and how community closeness can affect the stigma of hidden health conditions and access to medical care.

Most community influencers discussed in depth their affiliation to a community and how a community closeness can lead to any illness being stigmatised. Community influencers discussed that with CFS/ME and fatigue, individuals would be "*embarrassed*" (CI-008), want to avoid "*pity*"(CI-009), worry that "*people with label them*" (CI-001) or "*everyone will talk*" (CI-009) and "*they don't know if anyone would believe it*" (CI-008).

In particular with CFS/ME, there was much discussion with community influencers about whether the condition would be considered a medical condition, with negative reactions from others. Some community influencers discussed how in the communities they have worked with, "*fatigue is not considered a condition or illness*" (CI-011), whereas other community influencers discussed how a "*certification from a very understanding doctor*" (CI-008) could lead to a recognition that CFS/ME is a medical condition amongst others. Due to concerns about negative reactions from others, potentially due to not categorising fatigue and CFS/ME as a medical condition, some families may "*hide it*" (CI-0009) to avoid "*blame*" (CI-011) and the child being perceived as "*a burden on the family*" (CI-008).

One community influencer spoke in depth about how due to stigma, a child suffering from disabling fatigue may be "*excluded from the activities*" (CI-009) in the community and how "*if he's got siblings, then the siblings will be excluded from getting involved in the community*" (CI-009). The stigma of CFS/ME could be long lasting and persistent in a close community, leading to one community influencer discussing a stigma later in life with regards to marriage:

"*There would be a stigma that maybe would always be attached to it and you know maybe when it would come to things like marriage et cetera, they would be hesitant to take the bride or groom suffering from such illnesses*" (CI-014)

"*It's just culture, you know, they wouldn't want their daughter or son to have the burden of someone who is sick*" (CI-014)

The following interview excerpts with community influencers summarises their views of the community, the importance of contributing to the community, and stigma and blame with

regards to chronic fatigue. In particular, the idea of 'weakness' is expressed in the excerpts, with individuals not wanting to feel "*weak in the community*" (CI-009);
"*In communities it's not individual society yeah? So everything's about the community and what you can bring to the community and how you how you help your parents and how you help others. So if you're fatigued you're not going to be able to do these things yeah? So people aren't going to look at that as an individual who's fatigued, there's going to look at that as somebody who hasn't got any kind of advantage to the community yeah?*" (CI-011)

"*They would be sympathetic if it was disease or something, but you know in the community like you know people don't want to feel like weak or something wrong then other people kind of pity them, they don't want feeling like weak in the community*" (CI-009)

"*Close communities, where everybody knows each other, everybody knows like each other's business, yeah um there's a bit of a culture of blame so you know it may um the mother didn't feed him properly or her or yeah they must be things, they're too late to watch TV because they have no control […] anything goes wrong or anything you have this thing about whose fault is it yeah looking for fault straight away*" (CI-011).

However, not all community influencer participants echoed this view that CFS/ME leads to stigma and blame from others. Divergent views were found with some participants discussing how "*the community will be sympathising"* (CI-009), and parents would not be seen "*in any negative way*" (CI-014) or would not be *"stereotyped if their child was suffering from something, I think there would be compassion once it had been diagnosed*" (CI-014).

Due to a recognition that there could be a negative reaction from some individuals, there was discussion with some community influencers about how the 'community' could do more to help those who are struggling, with a recognition that "*there isn't enough support, even from the community*" (CI-008). One focus group participant discussed the differences from traditional community structures: "*if you cannot help each other how used to be in traditionally, is for mothers used to get help, individuals used to support each other back then, that was the culture, but here there's not much help*" (FG2-P004), with ultimately a recognition that in terms of support "*we lack that in our community*" (CI-014).

6.3.3.3 Sub Theme 3: Alternative Sources of Help

Some community influencer and focus group participants discussed alternative sources of help that may be trialled if a child is experiencing fatigue symptoms. These alternative sources of help were discussed as traditional and culturally appropriate.

Herbal remedies and alternative medicine could be used for fatigue symptoms, such as a "*kind of tea*" (CI-009) that "*we learnt from you know grandparents or mums or dads back home they used to do this, if you are tired you do this*" (CI-009). This was an uncommon view but illustrates the different strategies used.

In contrast, the most common alternative source of help discussed by community participants was religion and faith healers. Religion, and religious and spiritual healing, was discussed as important by most community influencers and focus group participants and could take the form of "*reading the Qur'an to that person in Islamic way*" (FG1-P002) or some parents could consult "*a religious leader, an Imam, a leader of a Mosque to get more spiritual advice and support*" (MP-001). The following interview excerpt details how a medical professional might not be the first contact, and prayer could be trialled first by some individuals:
"*If a child was showing like symptoms like this they might be looking like to prayer for a kind of an answer maybe, rather than the looking to a medical professional"* (CI-011).

A medical professional also discussed alternative sources of help from their experiences. The following interview excerpt details how some Somali patients may choose to see a Somali doctor as a source of help. The medical professional discussed the downside of this being a lack of continuity of care, as they are not integrated into the UK healthcare system:
"*In the Somali community there's a tendency to see private GPs, particularly they go to* [location] *I think they may be Somali doctors, you know, I haven't found their input on the whole particularly helpful thus far, because they're not properly meshed into the system* […] *they don't communicate in writing with us so decisions are made and we're kind of in the dark*" (MP-003).

6.3.3.4 Sub Theme 4: 'Respect for authority': Disagreeing with Medical Professionals

The final sub-theme is that of disagreeing with medical professionals. Clinic parents spoke about how disagreeing with medical professionals may be unacceptable for certain cultures

due to a "*respect for authority*" (CP-002) with doctors viewed as authority figures. The following two interview excerpt provide context for this discussion of doctors as authority figures:

"*For our culture you would just say 'oh well they're a doctor, they're a GP or a consultant, they know what's what, they'll tell us what to do' and we'll do it because it's kind of a respect for authority as well involved in that, not everyone will question authority*" (CP-002)

"*You just believe them* [medical professionals] *and go with it, you don't try and find an alternative necessarily, and that's very prominent in certain cultures and communities*" (CP-002)

A medical professional provided an alternative perspective, specifically referencing the Somali community, and how within the community there can be a group discussion and consensus on healthcare conditions. This contrasts with the opinion from the clinic parent of believing an authority figure, and instead illustrates a more communal view on medicine and healthcare and also "*whether they trust what's being said*" (MP-003). The following interview excerpt details the medical professional's perspective on the communal view of healthcare and its relation with cultural factors and a potential suspicion of Western medicine:

"*I have been told on many occasions, that patients in the Somali community have an attitude to medical opinion which is that they don't believe it on face value, they like to go and talk about it and they'll even talk about it in community settings*" (MP-003)

Compared to White British communities, one medical professional noted that: "*White or certain middle-class British people, they don't meet and discuss things together in that way*" (MP-003).

This second theme derived from the data (Theme 2: Cultural Factors) has presented participants' perspectives on how cultural factors can interplay with CFS/ME, tiredness and medical care. The theme has described how some individuals perceive themselves as close to a 'community'. Community closeness can impact on help-seeking behaviour and also stigma of a chronic hidden healthcare condition. In addition, alternative sources of help that individuals discussed were presented, with a focus on religion and spiritual healing. Finally, the theme detailed cultural factors that may impact on a medical consultation and potential community consensus on conditions and trust with healthcare professionals.

6.3.4 Theme 3: 'What's going on with the NHS?': Experiences of 'Going to the Doctor's'

The final theme in terms of 'barriers' that participants described to accessing specialist CFS/ME services encompasses participants' experiences of 'going to the doctor's'. In this theme, participants discussed when a medical professional would be consulted, and difficulties with accessing services or gaining a referral to further specialist healthcare. In addition, this theme describes the specific experiences that ethnic minority young people with CFS/ME faced when accessing specialist CFS/ME services, with a presentation of the medical barriers they experienced when seeking healthcare.

6.3.4.1 Sub Theme 1: Factors Influencing Help-Seeking Behaviour

In this first sub-theme, participants discussed the factors influencing help-seeking behaviour, in terms of when a doctor would be consulted for fatigue symptoms. There were individual differences and divergent views amongst participants and this interlinks with Theme 2: Cultural Factors and Theme 1: Conceptualisation of CFS/ME. Some participants discussed taking a child to the doctor immediately, some discussed how a child may be hidden, and others discussed how home remedies might be trialled first before consulting medical care.

As discussed in Theme 2: Cultural Factors, some community participants explained that parents might try and "*hide*" (CI-009) fatigue symptoms in children due to social stigma from others. Despite parents wanting to hide fatigue symptoms, community influencers discussed how others would be sympathetic and: "*will push that mum to take her child to um the doctor and get the right hmm getting the right diagnosis*" (CI-009). Some community influencers provided another view that children would always be taken to the GP with fatigue symptoms as if a "*child is sick, first thing you think is always the doctor*" (CI-003). But this may depend on symptom severity and if the "*tiredness is very serious then maybe they would go*" (CI-001).

Related to Theme 1: Conceptualisation of CFS/ME, some community influencers discussed how "*changeable health situation is*" (CI-002) could be a factor in decided when to consult for fatigue symptoms. Home remedies for tiredness may be trialled before seeking medical care: *"I think they'd try everything you know that they could and then yeah eventually go to the doctors"* (CI-008) as: "*I'm sure they're* [medical professional] *going to wonder what*

have you done to help yourself" (CI-008). This trialling of home remedies could delay access to medical care depending on what is trialled.

A medical professional recognised these divergent views as to when a GP would be consulted. The following interview excerpt details a medical professional's understanding of the patient pathway and discusses the role of individual differences in consulting a medical professional, with variation in when patients might present:
"*some will come early, some will come late and that's, that can be down to the, partly the patient's motivation, partly their perception of severity of symptoms, um there's this kind of term 'activation' so the internal motivation of a patient to present, maybe more a paternalistic approach that a doctor will sort them out, others will be quite motivated to sort themselves out, they might do a bit more first, so everyone's a bit different*" (MP-002).
But medical professionals noted how there are some individuals *"who have chronic fatigue and haven't come to the doctor at all, so they'd be hard to reach*" (MP-003). This could be due to perception of symptom severity, trialling home remedies, concern about stigma when consulting a medical professional, or suspicion of Western medicine.

When it comes to children and medical care, parents usually have the final decision in deciding to seek help as "*children don't generally make their own appointments"* (MP-003). Therefore, parents have to recognise the symptom severity and decide to make the appointment: *"so it has to be foregrounded in the mind of the parents, then the parents have to think that it's worth making the appointment*" (MP-003).

In addition, a further consideration to making a GP consultation for a child with disabling fatigue is that there may be family dynamics that influence attending a GP practice and seeking medical care, for example one parent might not know about the symptoms, or the extent of the symptoms: "*I mean a barrier might be that mum actually knows what's going on but dad comes and doesn't know what's going on*" (MP-003).

6.3.4.2 Sub Theme 2: General Medical Care Barriers

Numerous general barriers to accessing medical care were discussed by all participants (young people with CFS/ME and their family members, community influencers, community members and medical professionals). These include being treated differently due to

ethnicity, the perceived availability of GP consultations, language and cultural barriers, and doctor-patient relationships. These barriers can interlink and delay or limit access to medical care for young people with disabling fatigue.

6.3.4.2.1 Treated Differently Due to Ethnicity?

Some participants discussed the role of ethnicity in accessing healthcare, with a clinic parent discussing if her child's ethnicity played a role in accessing CFS/ME services and if their child would have been treated differently if they were a "*White patient*" (CP-001). The parent questioned of their experiences: "*Are there factors that are assigned to race that are unconscious in the process?*" (CP-001) and whether a "*White women*" (CP-001) would have a different experience:

"*You do wonder if it was, I don't know, if there's any difference for White patients getting access into the service, but I could understand there'd be a more sympathetic view to a young frail White women than an outspoken mixed-race girl like yourself.*" (CP-001).

Some community influencers also described a feeling in the community of being treated differently due to their ethnicity, or cultural background, which could reduce people taking their child to the doctors. Firstly, some participants discussed how some ethnic minority individuals are perceived as "*accessing the GPs kind of like above the norm*" (CI-011) with others discussing a stigma with ethnic minority individuals "*maybe they don't take care of themselves maybe they are a bit lazy"* (CI-008). Some community influencers described individuals being treated differently because of their ethnicity "*because we, we're different, we're not from this country, that's why they treat us different*" (CI-013). Others have a perception that medical professionals hold "*stereotypes, that do still exist*" (CI-014) about different ethnicities: "*I think the medical profession feels sometimes that the Asian community, the ethnic community, exaggerates their illnesses and sometimes they think that it's in their mind*" (CI-014).

One community influencer did perceive that individuals from an ethnic minority could be treated differently within a healthcare consultation but acknowledged that "*I have no way to prove it, I just have this feeling"* (CI-008). Another community influencer described how they personally had not received different care or discrimination, but knew of others who had

"*I never been treated, treated different here, but I have some friends they said yeah" (CI-013).*

6.3.4.2.2 Perceived Availability of GP Consultations

A further key barrier to receiving medical care was the availability of GP consultations and most participants discussed a lack of available appointments. Community influencers did not report an issue with specific doctors, but instead with the overall UK healthcare system: "*I don't think it's the doctors that we have a problem with, it's the system*" (CI-003). This was attributed to population density and "*lack of staff*" (CI-003) in certain areas: "*they don't have a lot of staff to deal with how many people are living in this place*" (CI-003). This population density and lack of appointments was discussed as a particular issue in cities:
"*inner city overcrowded, GP practices are overcrowded, so there's no, you cannot get an appointment when you need*" (CI-004).

Some community influencers discussed how over time, it has become increasingly difficult to get a GP consultation, and questioned why this was: "*what's going on with the NHS? Why are we are not getting the appointment with the GP easily as you used to get it before?*" (CI-004).

Other community influencers recognised that a lack of access to a GP was a population wide issue, that was not specific to ethnic minority individuals, the following two interview excerpts detail this:
"*My wife she's not Asian she's from British born, from* [location], *and she's originally from English family, she got the same experience she doesn't get the appointment easily so is not actually difference everybody getting the same experience*" (CI-010)

"*They are not happy about the delay in the appointments but like I keep telling this is the way the country is run so it's not because you're Syrian but because this is the way of the NHS*" (CI-012)

A lack of understanding of the current UK NHS healthcare system can lead to 'frustration' with waiting times as "*these families come from a culture where you're seen by a doctor instantly or you can pay extra money and you can be seen by a consultant*" (CI-014), so there

is a need to "*manage expectations*" (CI-014) as "*the NHS is struggling, and they are overworked*" (CI-014).

Medical professionals also recognised that a key healthcare barrier is "*generally it's an inability to book a GP appointment, it's a capacity issue*" (MP-002) with this being "*a nationwide problem with access*" (MP-003). Some medical professionals also discussed how some patients "*seem to get a disproportionately large number of appointments"* (MP-003) due to understanding the healthcare system and knowing when appointments are released, and therefore when to phone the GP surgery to book an appointment.

Due to difficulties with getting a GP consultation, some community influencers discussed how individuals who can, will seek out private healthcare in the UK or abroad. Community influencers recognised that individuals who do this are "*fortunate*" (CI-014) to have the ability to travel abroad for treatment and choose this option "*because it's cheaper and it's very quick for them to be able to receive the care that they need*" (CI-014). No participant with CFS/ME reported going abroad, but this is included here to illustrate the options that some individuals have for healthcare.

6.3.4.2.3 Language and Cultural Barriers in the GP Consultation

Language was a commonly discussed medical care barrier by community influencers but this was not described by clinic participants and their parents. Community influencers talked about language barriers, which could impact an individual's ability to "*explain generally about things*" (CI-001) and "*express themselves*" (CI-012) in the medical consultation, in addition to the ability to "*call a GP to speak to book appointments*" (CI-007).

Furthermore, "*terminology and medical language*" (CI-006) can be a language barrier. The ability to understand the terminology around a diagnosis can be a barrier to medical care as "*parents might not even have, cannot grasp, or might not even have an understanding which can affect how they can support their child*" (CI-006). This is particularly relevant to CFS/ME as in Theme 1: Conceptualisation of CFS/ME, there was much discussion from participants as to understanding of the phrase 'chronic fatigue syndrome'.

Medical professionals also recognised the role of language, with a medical professional recognising that "*the biggest barrier is language and also awareness*" (MP-001) as "*if you don't know how to describe your child's symptoms, that is the worst thing"* (MP-001) with some parents "*they learn to live with their child's tiredness which obviously in the long run is not good*" (MP-001). Therefore, parents may not go back to medical care if they do not feel they can explain the symptoms to the GP. A further impact of language barriers is the potential for misdiagnoses:
"*we get trapped with the words, the person might not actually ever use the word fatigue for instance, or tiredness even, they might just say well like I, it could be misdiagnosed as depressed for instance*" (MP-003).

In addition to language barriers, cultural barriers were also discussed by community influencers, in terms of how individuals from different cultures may express symptoms, or due to cultural factors, there may be a preference to see a certain gender of doctor, for example women "*ask for the woman doctor*" (CI-009). This preference to see a certain gender can be a medical care access barrier, as if there are limited appointments available with that doctor, waiting times can be increased.

Community influencers described strategies individuals may use to gain access to appropriate medical care, due to language and cultural barriers. One community influencer discussed how in their experience, some individuals may bypass the GP and go to a hospital for care instead due to a perception of the availability of interpreters. Or some individuals may stay living in a particular area because services provided are not available elsewhere.
"*I can only talk about my area, like at the GPs what they have is interpreter that works days.* […] *always there helping people to interpret if anyone needs it. But there are some areas that they don't have that, so that's why a lot of people struggle to move some areas to another area, that's why they live in overcrowded houses because they feel like if they leave here, they won't get the help*" (Cl-003).

Even in areas with interpreter availability, there are still cultural differences and challenges when using interpreters, for example "*sometimes people will describe symptoms in a cultural way*" (CI-011) which can provide challenges for interpreters when there are multiple interpretations of the description. Additional challenges participants discussed with using interpreters include: if there isn't "*the equivalent of* [the word] *in English*" (CI-012) and

using interpreters takes more time in medical appointments and "*prolongs the situation*" (CI-004). In the following interview excerpt, a medical professional describes their experience of working with interpreters, including the variation in quality of interpreters and the patients concern that the consultation will not stay private:

"*when they get to the appointment, they have to have a doctor who's willing to shut up long enough for the parents to be able to speak of the problem and that is potentially not in English, so that's a barrier. It's a funny thing how it plays out with the interpreters because first of all the interpreters themselves vary from truly superb to apparently doing the dishes while consulting with someone in the background, you know like it can be an absolute joke, and I've had to complain, make formal complaints in the past about interpreters, but that's uncommon but you know if you have an interpreter in the room, because we do have that at* [location] *that is not altogether straightforward, because even if the person comes from outside the area the fear is that something will be disclosed to the community that will be harmful to the family or to the child so you've got a whole bunch of problems there um, that said most people with young or children are English speakers, it's just the way it works, the non-English speakers*" (MP-003)

6.3.4.2.4 Doctor-Patient Relationships

A further general medical care access barrier is that individuals might not have a good relationship with a GP, so could be reluctant to seek care for their family. Multiple community influencers discussed this based on their own experiences, or those they knew, as "*a lot of people are complaining from the GPs saying that 'they don't do anything'*" (CI-002). This was attributed to GPs being "*overworked*" (CI-008) and *"tired"* (CI-008) and therefore "*seem to have an exasperated reaction to what you're asking*" (CI-008).

A consequence of not feeling that the GP helps, is that "*they feel they have to constantly go to visit doctors in order for them to receive some kind of attention*" (CI-014). This is a medical care barrier, as some individuals may not seek future medical care if they do not think the GP will help them:

"*sometimes it can get frustrating for parents I think that keep constantly going back to the GP*" (MP-001).

One community influencer spoke of the concern amongst some of their contacts of how going to the doctor's might have repercussions, in terms of welfare checks for children. As discussed in Theme 1: Conceptualisation of CFS/ME, participants proposed multiple alternative explanations for disabling fatigue in children, and Theme 2: Cultural Factors, there could be stigma and blame. Therefore, a view shared by a participant was that parents may have concerns with going to the GP if the fatigue is attributed to another factor: "*she don't want to go* [to the GP] *because she has a couple of people once and they involve the family they come home check the kids* […] *and she heard about the people what happened to them and that's why she said I don't want to be involved*" (CI-013).

However, multiple community influencers described a good relationship with their doctor, but recognised that relationships with GPs are varied: "*there is people who have problems with their GPs and people who have very good relationship with their GP*" (CI-002). Having a good relationship with a GP was important to participants, and increase the likelihood of presenting to the GP with a child suffering with disabling fatigue.

6.3.4.3 Sub Theme 3: CFS/ME Specific Experiences

"*You're physically drained but it's like also like, it's hard to explain, it's like a mental prison as well*." (CYP-001) - Young Person describing living with CFS/ME

Although there was a small sample size for interviews with clinic participants and their families, the interviews resulted in rich data, with participants discussing their experiences in depth. This section in Theme 3: 'What's going on with the NHS?': Experiences of 'Going to the Doctor's', details the specific journey and the experiences of the clinic patients who had accessed paediatric CFS/ME services, along with medical professionals' views of CFS/ME.

6.3.4.3.1 Family and Medical Professionals Perceptions of Diagnosing CFS/ME

In terms of diagnoses, clinic young people received other interim diagnoses that "*ended up masking the primary symptoms*" (CP-001) of CFS/ME, with medical professionals attributing symptoms to: stress, depression, a virus, joint pains caused by growing, or asthma. Not having a diagnosis of CFS/ME was viewed as the key barrier in accessing specialist CFS/ME services for ethnic minority children, and this occurred "*at a GP level*" (CP-001), but

difficulties with diagnosis were recognised as "*chronic fatigue it itself is just hard to diagnose*" (CYP-001).

Most young people with CFS/ME and their parents reported attending multiple medical appointments with fatigue symptoms. Some families reported going to the GPs "*once a week*" (CP-003) and seeing multiple doctors, "*we've been to like loads of different ones many times*" (CYP-001) with fatigue symptoms, with a parent categorising the experience of multiple appointments as: "*constantly going to doctors, you know, like almost like a paranoid mum"* (CP-003).

Medical professionals discussed the challenges with diagnosing suspected CFS/ME and how this can impact access to medical care. In terms of multiple appointments, they may be necessary as "*you have to rule out everything else*" (MP-001). But barriers were recognised with multiple appointments, as medical professionals discussed the importance of having an overview of the patient's health, rather than the symptoms the patient is presenting with in each appointment: "*there's the barrier of the GP putting the pieces together and thinking oh this might be chronic fatigue syndrome*" (MP-003). This following interview excerpt from a medical professional details the clinical reasoning process with CFS/ME and how a lack of continuity and overview of the symptoms can mean that each appointment is dedicated to a single symptom, rather than a holistic view of a patient's health:

"*there's a focus at each appointment on that one symptom, maybe it's a sore throat, maybe it's a bit of fatigue and then they come again* […] *just sometimes there's a lack of a step back*" (MP-002).

Clinic parents also recognised that it took one doctor to get "*to the bottom of it*" (CP-001) and suspect that the symptoms were due to CFS/ME. This lack of a "*holistic overview*" (CP-001) could be due to the "*changed*" (CP-001) role of the GP over time:

"*in the 70s we'd see the same doctor over and over and over again so they had a holistic view of your family let alone just you, whereas now people are picking up notes and not necessarily linking in things*" (CP-001).

With medical professionals also echoing this view of the changing health system as "*lots of communities are more detached nowadays compared to days gone by when the GP was kind of integral to the community"* (MP-002).

Medical professionals discussed in detail their experiences with CFS/ME. Some medical professionals spoke about their knowledge of "*a steady stream of people who present with* [CFS/ME]*"* (MP-003) but due to the perception of CFS/ME, some individuals *"never bother coming back to the doctor once they've figured out that the doctor can't help them*" (MP-003). Another medical professional discussed patients presenting with CFS/ME to medical services and explained how "*I just don't think necessarily the patients come through the door*" (MP-002).

In terms of CFS/ME as a medical condition, one medical professional described CFS/ME as: "*a conflicted type of condition isn't it, you know it's hard to diagnose, it's hard to know what the cause is, it's hard to know if its mixed up in some way with the family dynamic, you know yes it's quite a mystery isn't it*" (MP-003)

Most clinic parents discussed how in their experiences, there is a lack of understanding and awareness of CFS/ME amongst medical professionals they had consulted with. They discussed a need for the "*GP could be a bit more aware*" (CP-003) and the following interview excerpt details the experiences one clinic parent had when medical professionals suspected CFS/ME in their child:
"*they didn't understand, they didn't understand, so he told me what he thought it might be and sent us away but didn't really explain anything and we kind of thought she'd get better in a few weeks cos he said she'd being alright in a couple of months at the most*" (CP-002).

However, one clinic family discussed how they were "*lucky*" that their doctor was a "*believer*" (CP-005) in CFS/ME and this led to a referral to the CFS/ME clinic and a diagnosis:
"*we're really lucky round here, we have a fantastic doctor, doctor* [name] *and um she understands ME, she's a believer in it, which some aren't unfortunately*" (CP-005)

Medical professionals discussed challenges with dual diagnoses, for example a medical professional spoke about a child "*who had persistent fatigue, also had a collection of other problems, so they didn't quite fit into the chronic fatigue service*" (MP-002).

One clinic parent spoke about how a medical professional was reluctant to 'label' the condition due to the potential that a 'label' could be long lasting: "*he said we don't wanna do that at the moment cos if you label, you label her for a long time*" (CP-002). But medical professionals discussed how some parents are reluctant to have their child diagnosed due to "*parental perceptions or misconceptions about the condition and really ultimately they want their child not to have the disabling fatigue*" (MP-002). This may be because of a perception that management is not effective for CFS/ME:

"*someone's maybe told them we can't cure this but here are the things we can do to maybe make it easier to live with, and they try those things and maybe it is a bit easier to live with but they don't see necessarily the point in going back to the doctor to be told again the same thing*" (MP-003).

There are also barriers in terms of physical journeys to gain a diagnosis, such as travelling to be seen at a specialist CFS/ME service. One parent provided the following description of the journey to get a diagnosis: "*You've got a child with chronic fatigue who then has to travel all the way to* [location] *to get a diagnosis come home and be really ill*" (CP-001).

6.3.4.3.2 Family and Medical Professionals Perceptions of Referrals to the CFS/ME Service

In terms of referral to the CFS/ME clinic, one family did not know that they had been referred and other family participants discussed being referred to different services, before the CFS/ME service, such as CAMHS (Child and Adolescent Mental Health Services), paediatricians and rheumatology. Participants ultimately thought that if the GP could diagnose, that would speed the process along: "*actually if they'd done the diagnostic tool at the GP then it's very likely* [young person] *would have been referred a lot quicker*" (CP-001).

But medical professionals recognised barriers with referral, such as knowledge of available services and also when to refer. The following interview excerpt details how decisions to refer to a CFS/ME service could be made by a medical professional:

"*it needs to be around for so many months and you know GPs may not know how many months that is or you know there's also kind of low level fatigue that isn't very severe and does that warrant it?*" (MP-003).

The following interview excerpt, from a medical professional, describes the potential barriers to making a referral. The medical professional discussed how the time taken to make a referral could be a barrier amongst medical professionals, especially with CFS/ME:
"*I mean a barrier of a sort is that a referral takes time and GPs don't like rush to give themselves 10 minutes work or whatever it takes and I think the chronic fatigue service, yes they do require like quite a lot of blood tests to be done before referral which is you know, I mean you're asking me, I'm not saying this is right that this is a barrier, but I'm saying it could be a barrier*" (MP-003).

Ease of referral is important to medical professionals, and increasing knowledge of referral pathways: "*making GPs more aware of what referral pathways are and then making it as easy as possible to make the referral*" (MP-003).

Clinic participants also described the process of getting access to the specialist CFS/ME services through a referral. Some clinic participant parents discussed the difficulties: "*it was a really difficult process to actually get the final referral, it wasn't forthcoming at all*" (CP-002). This involved having "*to really really push for appointments*" (CP-002) and "*pursue it*" (CP-002) and participants recognised this as a key barrier in accessing the CFS/ME service. A family categorised the NHS as "*you've got to make them work for you in the end*" (CP-001).

This reluctance from medical professionals to refer was recognised as a key barrier, as this parent interview excerpt illustrates:
"*That would be quite a barrier, if someone's reluctant to refer you then you've got to actually fight it and that's what we had to do. If somebody had said 'oh we'll just refer you' then that's not a problem but if they're refusing to do that most people I know wouldn't be willing to go up against somebody in that medical profession cos if somebody tells you 'this is what you're going to do' then that's what you do*" (CP-002).

One parent described in detail their "fight" to be referred. The parent described their experiences of being "*ruthless*" (CP-002), printing the CFS/ME NICE guidelines and taking them to the medical appointment:
"*I had to be really ruthless, had to be very assertive and say to him really 'these are the guidelines, this is what we see, why won't you do anything about it*'" (CP-002).

The parent experienced resistance from the doctor: "*he was very offended that I wanted this and I had got these guidelines, he didn't really like that and he did put me in my place*" (CP-002). And summarised their experience as: "*it really wasn't easy, at least I think many people would just take consultants word for it*" (CP-002).

But two families did not describe a 'push' or 'fight' for referral. One clinic family mentioned that they put their '"*trust*" (CP-003) in the medical professionals. For this family, despite not discussing a 'push' for a referral, they did discuss getting "*worried*" (CP-003) and rang the hospital when their child's symptoms worsened. The following two interview excerpts summarise this family's experiences:
"*It's just that you trust the doctors and I mean you expect doctors to tell you, if it comes from them then you sort of believe them*" (CP-003)

"*We were quite dumb in a sense […] I just put my full trust on whatever they felt was right for her, I didn't question too much, but we sort of looked into it, what it was and why it was being done, we just glad we were getting somewhere*" (CP-003)

Another family discussed how they felt "*lucky*" (CP-005) to receive a referral and attributed it to understanding from medical teams in their local area:
"*the rheumatologist said I think you need to go to the ME clinic at* [location] *and she said leave it for a little while and see if things get better, it didn't and we were very lucky actually we got referred. We were very lucky in* [location] *with our medical um teams um doctors, nurses, um and we got referred straight away and um yeah they confirmed she had um ME*" (CP-005).

Some family participants and medical professionals discussed how even after a referral to the CFS/ME service had been made, "*then the journey into that service was ridiculously long*" (CP-001) as "*waiting times sometimes are, what is it? 6 to 8 months I think?*" (MP-001), with even families who did not discuss difficulties receiving a referral, recognising it took "*quite a long time*" (CP-004) to receive a diagnosis.

6.4 Qualitative Findings (2) – Improving Access

6.4.1 Section Overview

This section presents the qualitative findings on Improving Access. Detailed within this are the following four themes (Table 52) derived from the data: (1) 'facilitators; (2) 'ideas to improve access' to specialist CFS/ME services; (3) the 'role of schools' in improving awareness; and (4) 'improving recruitment to healthcare research. The qualitative findings on 'barriers' to accessing healthcare services for CFS/ME were presented in the previous section.

This section broadly covers improving access for both ethnic minority children with CFS/ME accessing specialist CFS/ME services and for recruitment to healthcare research. In section 6.4.2 participants' views on the 'facilitators' (factors that 'helped' access specialist CFS/ME services) are presented. Very few facilitators were discussed, but these were viewed as helpful and therefore should be considered for other children and young people with CFS/ME. Section 6.4.3 details the ideas to improve access to CFS/ME services for ethnic minority patients, with a focus on healthcare system improvements that could assist with accessing healthcare generally, and CFS/ME specific in terms of reducing stigma and building awareness, along with increased support for those who have CFS/ME. In section 6.4.4 the role of schools is considered, and how schools could be placed to support individuals with CFS/ME, link with healthcare and improve knowledge of the condition. Finally, in section 6.4.5 the role of terminology in recruitment to healthcare research is presented, with a focus on how the term 'community leader' was unacceptable to participants.

Table 52: Improving Access Themes and Subthemes:

Theme	Sub-Themes
Facilitators to Access	Knowledge of Condition Support
Ideas to Improve Access	Healthcare System Improvements Reducing Stigma and Improving Awareness Support with the Illness
The Role of Schools	School Support Referrals and Communication Knowledge Building in Schools
Improving Recruitment to Healthcare Research	The term 'Community Leader'

The themes and subthemes are presented and described using illustrative participant quotes, selected on the basis of providing detailed examples and to ensure the participants' own voices are heard throughout the findings.

6.4.2 Facilitators

Participants' discussion of facilitators were limited. The facilitators discussed by clinic participants and their families can be contained within two sub-themes: (1) Knowledge of the condition; and (2) Support with the illness.

6.4.2.1 Knowledge of the condition

Having knowledge of CFS/ME was discussed as a facilitator by clinic families, and knowledge improved the ability to access specialist CFS/ME services. This is also discussed generally as an idea for improvement in Section 6.4.3: Ideas to Improve Access. One parent discussed how once CFS/ME was mentioned as a potential diagnosis by the GP, they conducted personal research in order to equip themselves with knowledge. This additional knowledge was then used in subsequent medical appointments:

"*It's the usual thing, you know something's wrong with any of your kids or anything, first thing you do is, well first thing I did was, Google and learn as much as I can about it"* (CP-002).

A community influencer discussed the potential for a generational gap, with "*the generation now is a lot more educated"* (CI-014) and how education is key in acquiring knowledge. The following interview excerpt illustrates the community influencer's view on education and knowledge of healthcare conditions. The community influencer discussed how bringing knowledge to the medical consultation could help the doctor to diagnose a condition:
"they're able to you know use Google doctor in order to at least get to the point where they can self-diagnose to a point where they can go to the doctors say I think I'm suffering from X, Y and Z, which maybe that does help and trigger off the doctor to try and find it, diagnose them better, than someone who maybe who does have a culture or a language barrier" (CI-014).

This view of education being a facilitator was supported by a medical professional who discussed potential generational differences in terms of knowledge about medical conditions:
"*there's a privilege there because of them having the language and knowing, sort of you know being born in the country and growing up they know a lot more about you know what conditions are out there and so on. And obviously those families are in a brilliant place to support their child and know what symptoms are linked with what kind of conditions and so I always, you know, I always see how they're quick to spot it and they're quick to kind of get them the kind of support they need quickly" (MP-001).*

6.4.2.2 Support with the Illness

The second facilitator, discussed by two separate parents, was support with the illness, in terms of social and information support. This support was gained from friends, charities and hospital education services, and was viewed as helpful to gain appropriate access to, and support from, specialist CFS/ME services.
"*I think we were very lucky that we had friends and stuff who supported us, and we got a bit of support from them, Action for ME as well who advised us*" (CP-002)

"*You get somewhere like the hospital education service and they get it and they know it and they know about graded activity and that's because they've worked really really closely with the chronic fatigue team and miraculously that helps everyone*" (CP-001)

Increased support was also more widely discussed as helpful and is presented further in section 6.4.3.3: Support for those who are ill.

6.4.3 Ideas to Improve Access

In contrast to the limited discussions on 'facilitators', most participants (from the following participant groups: young people with CFS/ME and their family members, community influencers, and medical professionals) discussed ideas that could improve access to specialist CFS/ME services for children, described in the following sub-themes: (1) Healthcare system improvements; (2) Reducing stigma and improving awareness; and (3) Support for those who are ill.

6.4.3.1 Healthcare System Improvements

Most participants provided suggestions to improve the existing UK healthcare system. Participants described how accessing GP services and getting an appointment can be "*very hard*" (CI-003), so suggested that more GP consultations would be helpful, along with reducing waiting times for "*quicker*" (CI-003) access to services. More time in GP consultations was also considered helpful, as short appointments may not be appropriate for discussing some medical issues. This could be a common issue among all patients, but a community influencer related this to cultural factors as "*the majority of Somalis actually they will talk about the common problems before they actually talk about their specific problems that led them to seek help at that particular time, so that 10 minutes actually, you know they might feel rushed and not actually their needs accommodated*" (CI-006).

Continuity of care was also considered important and was discussed by young people with CFS/ME and their parents from the clinic as a healthcare system improvement. Parents described the need for a holistic and integrated view of healthcare services, as opposed to feeling "*like you're dealing with separate services*" (CP-001) as services are "*not linked up in the way they could be*" (CP-001). Young people with CFS/ME also echoed this view of better links between services, and thought that communication was vital: "*better communication between all departments of like your GP, the service you're going off to and then the other services, like you know everyone needs to communicate*" (CYP-001). Medical professionals also recognised the importance of the link between services, and especially to

the link between healthcare services and schools: "*another problem is the link between schools and primary health care service*" (MP-002).

Medical professionals cautioned improving access to services needs to help those who do not access healthcare, or those who have difficulties accessing healthcare, rather than those who access services "*too much*" (MP-003). A medical professional discussed how virtual consultations, aiming to improve access is "*actually having a knock on effect and reducing access, so we've increased access for the intellectually, socially mobile individuals and decreased access for the most vulnerable."* (MP-003). This could be due to availability of technology to attend virtual consultations, with barriers such as language still present in virtual healthcare appointments. In addition, "*more community outreach services*" (MP-003) were viewed as being useful, but acknowledged the challenges with this in terms of resources to provide the care: "*how do you generate enough community clinics for all the different conditions? I don't know because it's ultimately a funding issue and manpower*" (MP-003).

Community participants, where language was described in Section 6.3.4.2.3 as a prevalent barrier to accessing services, voiced a need to embed staff of different ethnicities, and with different language abilities, in healthcare settings. By employing staff who can speak different languages, it would enable communication barriers in consultations to be reduced: "*if all employee health visitor was Somali, who can speak both language, she goes to English person she can speak English, she goes to Somali house she can speak, so either train people or employ people who already have a language that the patient will understand*" (CI-003). The impact of having a more diverse workforce could reduce barriers to accessing medical care by making people more likely to consult primary healthcare:
"*I think making the clinic itself a place that people think comfortable and having a Black and minority ethnic staff member, receptionist, all these things help people to feel this is something that is for them as well*" (MP-003)

In terms of CFS/ME specific improvements, the GP having the ability to diagnose CFS/ME was an idea from a clinic parent that could reduce waiting times for referral and access to specialist CFS/ME services. The clinic parent thought this could reduce the barrier of seeing multiple GPs and attending multiple appointments, as these illustrative excerpts show:
"*I just think if GPs could use that basic diagnostic tool and go through and have you got all of these things going on then perhaps people might get there*" (CP-001)

"*you can waste a year going to the doctor over and over again seeing a different person and not progressing in any direction towards recovery*" (CP-001)

Various ideas for healthcare system improvements were discussed by participants, but can be summarised as: more appointments; quicker access to services; continuity of care, communication between different services; more outreach services; more diversity in healthcare workforce; and GPs diagnosing CFS/ME.

6.4.3.2 Reducing Stigma and Improving Awareness

Reducing the societal stigma of CFS/ME through awareness building events was discussed by most participants. As well as reporting a lack of knowledge and awareness of CFS/ME (see section 6.3.2), participants also mentioned a persistent stigma around the condition. One medical professional suggested that improving knowledge could reduce stigma: "*Chronic fatigue because it is a physical condition I think if parents knew what it was it wouldn't be such a stigma*" (MP-001). Building awareness of CFS/ME as a medical condition could empower parents to seek medical care for children who are displaying symptoms of the condition, an increase in knowledge could lead to more presentation to healthcare services: *"knowledge is really very important, understand, so that they know yes I have these symptoms now well I know it's chronic fatigue syndrome and they will go to the GP"* (CI-001).

It was also suggested that building awareness in adults could improve medical care for children. Children do not generally make their own GP consultations, so a focus on awareness building of CFS/ME as a physical condition could improve care and presentation to healthcare services: "*awareness in general anyway, to adults as well, because some people wouldn't really understand what Chronic Fatigue is because it's not a physical illness, it's something that's inside*" (CYP-003).

6.4.3.2.1 Building Awareness in Specific Communities

Participants suggested numerous ideas for how to improve knowledge and awareness. Firstly, building awareness in specific communities could be useful for reducing the stigma and increasing knowledge and understanding of CFS/ME. Building knowledge and

awareness in specific communities, could involve culturally tailored and individualised knowledge building strategies, based on recommendations from specific communities.

One way in which building awareness could occur, is in the form of "*making a name*" (MP-001) for CFS/ME within specific communities: "*I think it might be worth making a name for chronic fatigue that you know, that's the first thing*" (MP-001). In the Bristol Somali community, a medical professional discussed how making a name for the condition of Autism Spectrum Disorder (ASD) and tailored awareness building campaigns led to increased awareness:

"*I guess it's up to the community to have a name for it and then um make that awareness. Because I know this happened in one condition, ASD, because there was, because of the stigma and because there was no name, you know, it really had to go big far and wide in the community to make sort of awareness*" (MP-001).

'Jargon busting' was also suggested as helpful: "*jargon busting, perhaps outreach within targeted communities*" (CP-001). This could take the form of increased awareness of the symptoms of CFS/ME and how it differs from tiredness that is experienced by those without the condition:

"*it would really be very good if the community can understand: one, symptoms very clearly so that they can differentiate am I tired because I have done something or maybe I did some activities or I walk or I work hard in the house or am I tired because of that, or my tiredness is attributed to chronic fatigue syndrome so to differentiate that is*" (CI-001).

6.4.3.2.2 Accessible Information

Secondly, accessible information in a variety of formats was viewed as a necessity by most participants to improve general understanding and awareness of CFS/ME, and community influencers discussed how education is vital:

"*I believe, you know, by educating people, by giving workshops, then you are reaching those people and you are changing their lives*" (CI-007).

Participants discussed various ways of presenting information in an accessible format and the most common ideas from participants were:

- Word of mouth

- Conferences / workshops
- Leaflets, especially in different languages
- Posters, for example in GP settings
- Educating children, for example at after school clubs, or Koranic school, with leaflets or information sessions
- Involving religious leaders in awareness building activities

The following table (Table 53) provides interview excerpts for the accessible information ideas proposed by participants, to provide context in the participants' own words for the ideas they perceive as helpful in reducing stigma and improving awareness:

Table 53: Ideas for Accessible Information

"*I think a combination of things, word of mouth, telling the parents about the issue, but also maybe organise a conference telling them about kind of statistics of chronic fatigue syndrome, the symptoms how it might affect, if it's not diagnosed, um so people might get awareness, but also leafleting so people can get a leaflet and can read those leaflets, sometimes in their own language might help yep raise the awareness yes*" (CI-004)
"*train people and do more workshops, work with the communities*" (CI-003)
"*We are very interested in this chronic fatigue syndrome, like we can write, maybe we can write a small leaflet or in Somali language, very few, so that here* [location] *we can put poster somewhere and people will understand about the what chronic fatigue syndrome is so that they see the word, they see the sentence in their own language or whatever, or very simple language, and then they think 'oh yes I have this' or 'this leads to that', so I need to go to the GP and so it, that would help"* (CI-001)
"*awareness you know if that means posters in GP settings and things like that*" (MP-001)
"*I think like how NHS has those kind of posters, like about diabetes, like if there was something on CF I think it could really open up and could really help other teenagers with the same thing"* (CYP-003)

"*having information available to people and easily accessed whether leaflets or given something as you know that would be really helpful and especially obviously if it would be available in different languages that would break down any language barriers as well"* (CP-002)

"Education, information, accessing information about health, providing some activities, yeah basically solved by education and information, when people get that information they will do it by themselves" (CI-005)

"*raising awareness, some children they attend specific programs, homework club, or after school club, or Koranic School so they can be targeted um or with leaflets or information sessions."* (CI-004)

"*there is inequality with us, you know, and um but to reach that quality first we need education*" (CI-007)

"*the Somali community does generally attend the Mosque, so and the Imam is a source of information and opinion so going and speaking to an Imam which we have done around things like vaccination and mental health, and healthy eating*" (MP-003)

As seen from the interview excerpts, participants requested various types of knowledge building events. One community influencer spoke about the different learning styles and literacy levels and stated that a combination of both written and verbal information would be the most appropriate way to increase knowledge:
"*people have a different learning style, yeah, so both could be ok, writing and verbal, so people can, because they are not good with reading and lesson and then they could interact*" (CI-005)

Participants did not just suggest knowledge building for the general public, education for healthcare professionals on CFS/ME was discussed as important: "*I think GP could be a bit*

more aware" (CP-001). As diagnosing CFS/ME is a diagnosis of exclusion, this can lead to a lack of awareness of the condition, as seen in this interview excerpt:
"*health professionals kind of being aware that this is um a real condition because I think sometimes people get really into that phrase you know it's, because you have to rule out everything else it's not really a condition, so yeah awareness"* (MP-001)

Finally, community influencers viewed workshops and education for healthcare professionals on working generally with ethnic minority families as helpful. The workshops are important "*to have knowledge and understand the background of this people"* (CI-007) and could reduce barriers in healthcare appointments, with improved knowledge of cultural factors in seeking healthcare.

6.4.3.3 Support for Those who are Ill

The final idea for improvements came from families of ethnic minority young people in the clinic. These participants spoke about more specialist support for those who are ill with CFS/ME. Parents described needing support during the diagnostic process and the following interview excerpt illustrates one parents experience:
"*it was frustrating because you need support at that time in your life when you've got a child with a diagnosis and actually you just come up against barriers one after the other and that's quite difficult and there should be ideally more support in place would be nice*." (CP-002)

In terms of ideas for support that could be provided, a clinic parent spoke about government support, such as disability Personal Independence Payment (PIP) and how "*it's very hard to get PIP for this group of people"* (CP-001). The parent discussed how "*a short investment in their wellbeing could help them get back out there"*(CP-001). In addition, the parent discussed how:
"*carers are just meant to give up jobs and be there for people, there's no infrastructure to support young people being ill and obviously quite a punitive system, or a very punitive system, so it means that this group falls off, falls off as being considered ill and are stigmatised all over the place"* (CP-001)

An additional support that was viewed as potentially beneficial, is that of supporting and enabling parents to access information. One clinic parent recognised the importance of their

own personal research in accessing specialist CFS/ME services for their child and described how "*I got the information I got though research"* (CP-002). The parent described how *"having people that you can ring who can speak to as many people as possible and give you some kind of direction"* (CP-002) would be beneficial to enable as many parents as possible to enhance their knowledge of CFS/ME. The parent elaborated with: "*I think something needs to be in place to be able to help people who are unable to access that information themselves and understand it*" (CP-002).

6.4.3.4 Ideas to Improve Access – Key Findings

The following table (Table 54) summarises the key findings on "Improving Access" from study participants.

Table 54: Improving Access to Specialist CFS/ME Services for Ethnic Minority Children

Sub-Theme	**Examples**
Healthcare System Improvements	More GP consultations More time in GP consultations Continuity of care / Links between different services Improving access for all, limited by resources Staff of different ethnicities GP diagnosing CFS/ME
Reducing Stigma and Improving Awareness	Awareness in specific communities 'Making a name' for CFS/ME Conference / Workshop Leaflets in different languages Posters in GP settings Awareness in children's programs or Koranic School Working with a Mosque or religious leaders Educating healthcare professionals
Support for those who are ill	Support for ill young people, e.g. easier access to PIP payments Supporting and enabling parents to access information

6.4.4 The Role of Schools

A theme derived from the findings was 'the role of schools'. This is a cross-cutting theme, as schools were found to play a key role in the diagnosis of CFS/ME in young people and accessing healthcare, but schools were also suggested as a key location to improve the knowledge and recognition of CFS/ME in young people.

6.4.4.1 Lack of School Support

Often the first symptom of CFS/ME in young people was missing school due to illness. One clinic family "*noticed that she was missing school because I just couldn't wake her up in the morning*" (CP-003) as the first symptom of CFS/ME. With another family recognising the child's ability to attend school decreasing: "*she could only manage I think it was 2 hours or an hour, through that, and then we just noticed it just got worse*" (CP-004).

Most clinic participants and their parents, discussed how their school was not supportive when the young person experienced illness, missed school and displayed CFS/ME symptoms. The most common issues were fines and threats of legal action from school for low attendance, which added to the stress levels experienced by parents and a lack of education services for the young person. One family experienced being fined by the school due to poor attendance: *"the amount of fines we've had to pay because of my attendance when it's like I really actually cannot attend*" (CYP-001) and another parent experienced being "*threatened by the local authorities on top of dealing with a child who was poorly*" (CP-002). This stress was described as: "*firefighting admin and contact from the school a lot of the time when you need to be getting on with a diagnosis really*" (CP-001).

Some families attributed the school response as being due to "*schools become so focused on attendance and you inherit a whole tier of admin to your life"* (CP-001) as attendance became *"all they were interested in, and that's shameful really*" (CP-005). This focus on attendance meant one family experienced from the school: "*constant pressure for her and just pushing, pushing all the time*" (CP-005) and switched to medical tuition due to not receiving appropriate support from the school, with the flexibility of tuition being beneficial: "*she's not suffering and then it's at times that suits her body best*" (CP-005).

Families discussed the invisible nature of CFS/ME and difficulties with diagnosis and how this impacts schooling. One family described how "*the blood tests were coming back normal*" (CP-002) so the child was thought to have "*nothing physically wrong*" (CP-002) and "*fit for school*" (CP-002). This could be due to a lack of understanding and knowledge of CFS/ME symptoms by the school:

"*they didn't understand because she looked ok sometimes, but she wasn't, they'd see her when she looked ok and couldn't see repercussions a lot later*" (CP-002)

"*unless they actually see the pupil at their worst, they don't believe it, they really don't*" (CP-005)

Once the young person received a diagnosis, and had appropriate medical evidence, one family experienced that their school was supportive, due to experiences with CFS/ME and felt "*quite fortunate because my school had students who had what I had"* (CYP-003). This support was experienced "*once they got the letter from hospital they said we understand this situation and then they were very good*" (CP-003). The parent described how they were "*very very happy with the school how they were and um and from day 1 the minute they got the letter you know they were, 'we're aware of this and will do whatever we can to help"* (CP-003). This particular school, along with knowledge of the condition from other students who had been diagnosed with CFS/ME, also had facilities where the young person with CFS/ME could manage their symptoms and rest when needed. The facilities included "*nurture rooms, where you can just if you feel too tired like not enough to go home you just need a time out you can just go to a room and then you can just close your eyes and chill, it's quite nice"* (CYP-003).

This view of school support and access to alternative education services as limited until medical evidence was provided, was discussed by a medical professional, who recognised the difficulties facing families and how: "*some families can't access home education until a diagnosis, a formal diagnosis from the chronic fatigue team um and of course in that time school are thinking that they are missing that education, they can't come to school because of the tiredness, because they are so weak, but yet they can't apply for hospital education without a, so that is in the long run quite difficult for families*" (MP-001). This was echoed by a family who recognised that their access to home medical education was due to a diagnosis and support from the CFS/ME clinic:
"*without that diagnosis from* [CFS/ME service] *we wouldn't be where we are now, absolutely no way, no*" (CP-005)

6.4.4.2 Referrals and Communication

Participants spoke in depth about communication issues between schools and healthcare. One clinic participant received a referral from school to a separate agency: "[young person]

was actually passed onto a community outreach team in Year 6 because her attendance was so bad at school and they wanted to get to the, to the underlying issue" (CP-001).

The link between schools and healthcare was important for both medical professionals and parents. The link between schools and healthcare was described as "*disparate"* (MP-002) due to a lack of school nurses. The impact of this is a lack of "*screening to general health problems and parental education*" (MP-002) within schools, and therefore referrals to primary healthcare can occur "*because of poor attendance and that's it really*" (MP-002) with no additional information provided on the symptoms the child is experiencing. Clinic families also discussed how: "*if they could work together better in terms of health, school and um looking at root causes rather than just the effect which is being absent and if they did it in a different way I think that could be helpful*" (CP-001).

Also suggested was improved communication between teachers and parents, as teachers may not "*differentiate those children that are struggling to concentrate or struggling to, you know, I guess stay aware or feeling a bit more weak*" (MP-001) and could therefore classify fatigue symptoms as "*behavioural*" (MP-001). Improved communication between parents and teachers, along with improved knowledge of CFS/ME could lead to "*schools to um spot the signs and inform those parents that might not be aware*" (MP-001).

A potential solution proposed for the lack of communication between schools and healthcare was school nurses could have the ability to refer to specialist healthcare services, instead of the GP: "*could they even make referrals, school nurses? Rather than putting the barrier of the nurse saying you have to go to the GP?"* (MP-003).

6.4.4.3 Knowledge Building in Schools

Clinic participants voiced a need for "*awareness in schools*" (CP-003) and spoke about Personal, Social Health and Economic Education (PSHE) sessions as a setting for the discussion of CFS/ME symptoms, to educate both young people and teachers as "*teachers don't understand it necessarily"* (CP-001).

"*I think awareness is the main thing, especially perhaps, but it doesn't have to be GPs, perhaps on school levels, because that's where it happens, in particular age group um I think if they have a lot more awareness for them like in PSHE*" (CP-003)

"*young people can be educated more as well in school um I know um that there's a lot going on for, in PSHE, about mental health um and I know obviously chronic fatigue is not the same but actually if they, it could go in there actually because it really affects your mood and it will teach young people to look after their health and actually go and kind of go and get checked out or you know let their parents know*" (MP-001)

As discussed in Section 6.4.4.2: Referrals and Communication, educating teachers to spot the signs of CFS/ME was also viewed as important. Participants discussed a need for CFS/ME to "*become on the radar*" (CP-001) for teachers, along with more general awareness of CFS/ME as *"if the awareness with CF was a lot better it would also make the person who has it an easier experience to deal with in school* […] *I think if there was more people who knew about it then it would make the person's experience a lot easier*" (CYP-003).

Therefore participants suggested in regards to schools: to improve awareness in schools by educating teachers; include CFS/ME awareness and how to access healthcare on the PSHE curriculum; improve the links between schools, healthcare services and parents; and enable school nurses to directly refer to appropriate medical care.

6.4.5 Ideas to Improve Recruitment to Healthcare Studies

This final theme in improving access covers improving recruitment to healthcare studies. This is an important finding that emerged early and could have influenced recruitment to this study. Therefore this finding is important for researchers to be aware of.

6.4.5.1 Views on the phrase 'Community Leader'

One finding that emerged early during recruitment is that individuals who might be identified as a 'Community Leader' by others, do not like to be called as such, and do not want to claim that they are a 'Community Leader'. Community Influencer participants described how they

"*cannot claim that we are the leaders*" (CI-002), as "*It's a big word! Claiming leadership!"* (CI-001) and they "*don't want to be a leader in the first place*" (CI-012).

There were also "*negative connotations*" (CI-009) with the word 'leader' and an association with "*responsibilities*" (CI-012) and the need to be 'bossy':
"*It just reminds people of the leader back home, and the leader back home has got like is going to be bossy and I don't like to be bossy, you see what I mean, the leader can tell people do this and do that*" (CI-009).

The only participants who self-described as community leaders, or recognised that others may refer to them as such, were working in a religious capacity. One Imam did view themself as a community leader: "*Yes, an "Imam" means actually leader*" (CI-010). In addition, another participant, working in a religious capacity, agreed that some people might view them as a community leader "*to some degree because I'm a* [job title] *I'm not a well-known community leader I'm just uh a figure that people can come*" (CI-008), but this participant stated that personally they "*would feel uncomfortable being called a leader*" (CI-008) as to be a 'leader' "*you have followers and I don't think I have any followers*" (CI-008).

When asked how they would describe themselves, instead of as a 'Community Leader', most participants tended to describe their identity as primarily just a "*member*" (CI-002) of a specific community, someone "*involved with the community*" (CI-007), or someone "*trying to help*" (CI-007).

Participants also provided descriptions of the definition of a 'Community Leader'. Most spoke about community leaders being involved in both advocating for the community and helping the community (community focussed). One participant characterised the role of a community leader as: "*somebody who is involved with the community who is active, who is trying to support the community and who is aware of lots of different cultures and people who are within the community*" (CI-014). In addition, the role was described as also "*advocating on behalf of people"* (CI-007), "*being more committed to the community"* (CI-012), "*can take action and he has influence*" (CI-012) and *"more active and proactive in the community"* (CI-014). In terms of day-to-day responsibilities, participants thought the role involved: *"raising awareness"* (CI-007)*, "attending workshops, meetings"* (CI-007) *"going and talking to families friends about what's going on*" (CI-007), and "*try to set up initiatives*

that will support the community and benefit them rather than for someone to come to you and ask for help and guidance" (CI-014).

The two community leaders involved in working with the community in a religious capacity spoke about the role being religion focussed, with a community leader being an individual whose job involves "*supporting the community religiously"* (CI-008) with a community leaders role involving religion as "*my only focus*" (CI-008), and to "*look after the people of the community to guide them according to the Qur'an and Hadith on everyday life, how they should be maintaining their family life*" (CI-010). Participants discussed how the role of a community leader needs to be decided by others, as this interview excerpt illustrates:
"*You would need something a little more I'm not sure you know maybe a group of people or a body a religious body to say 'Yes, this is the community leader we employed them and this is their sole job*" (CI-008)
A participant, working in a religious capacity, spoke about how community leaders are typically seen as being male with: "*I guess a lot of people ah um view community leaders as men that are imams of some sort of establishment"* (CI-008).

Participants viewed the term "Community Influencer" as more acceptable than the term community leader and approaching potential participants with a term that they could not relate to could have affected recruitment. Researchers need to be aware of this and ensure they do not label potential participants with a term that they do not identify with.

6.5 Chapter Summary

This qualitative project aimed to understand the barriers and facilitators to accessing specialist CFS/ME services for ethnic minority children. The key findings from this qualitative chapter are presented in this section and a further discussion of the findings, including strengths and limitations of the work and implications of the findings are contained in the following chapter, where all the results from this thesis are contextualised in the wider evidence base.

6.5.1 Key Findings – Barriers to Accessing CFS/ME Services

Table 47 (The Key Qualitative Findings: Barriers to Accessing CFS/ME Services) in Section 6.3 presented the key findings (in terms of 'barriers') from the qualitative work, but the themes are not mutually exclusive and interlink to limit access to CFS/ME for ethnic minority children. Additionally, not all the barriers may be present and individual level context is needed.

This diagram (Figure 8) illustrates the interlinking barriers that limit access to specialist CFS/ME services for ethnic minority children. As can be seen from the illustrative diagram, the barriers are interlinked and can occur at different levels of help seeking.

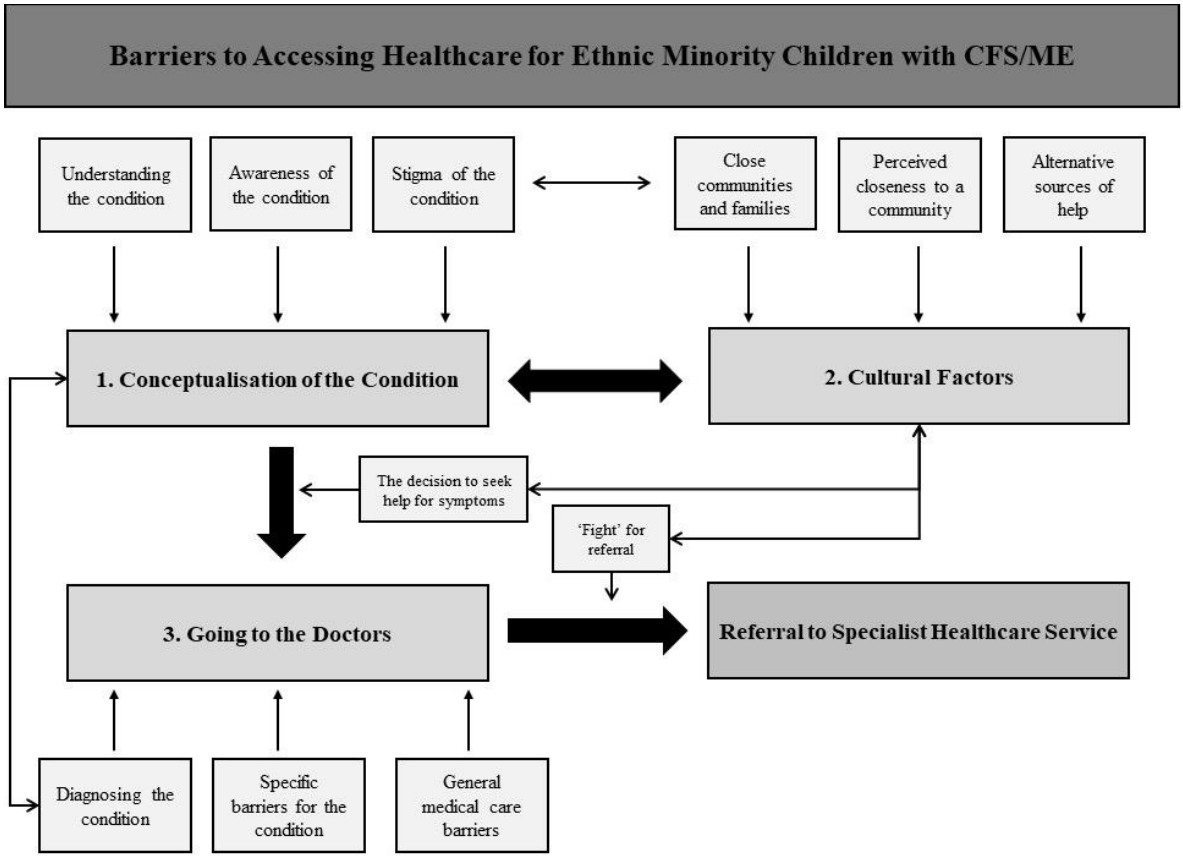

Figure 8: Barriers to Accessing Healthcare for Ethnic Minority Children with CFS/ME

There are barriers to conceptualisation of the condition: understanding, awareness and stigma. Conceptualisation interlinks with cultural factors. The decision to seek help for the symptoms can lead to 'going to the doctor's', where numerous other barriers are experienced, including diagnosing the condition and general barriers in medical care for ethnic minority

patients. After the care pathway has been navigated, and the doctor has been visited, there can be a '*fight*' for referral to specialist services, which is related to cultural factors and how culturally appropriate it is to disagree with healthcare professionals.

Specifically relating to ethnic minority children accessing specialist CFS/ME services, the findings from the qualitative work suggest that:

1) CFS/ME (and fatigue) may not be recognised as a medical condition
2) Close communities can help with accessing medical care, or some conditions can be stigmatised and close communities can make families less likely to access help for non-specific symptoms such as tiredness
3) There can be barriers in the medical appointment, such as language and cultural barriers; as children do not typically make their own medical appointments, this can be an access barrier if there is the perception that the GP will not help

The following diagram (Figure 9) highlights how the findings from the qualitative work relate specifically to children from ethnic minorities in terms of their experiences of accessing CFS/ME services. The figure shows the pathway from first experiencing symptoms, to receiving a diagnosis, and subsequent referral to specialist services. Young people and their families discussed numerous barriers in their experiences of accessing CFS/ME services, at every stage of the patient pathway, especially related to a lack of knowledge and understanding from others, including the GP.

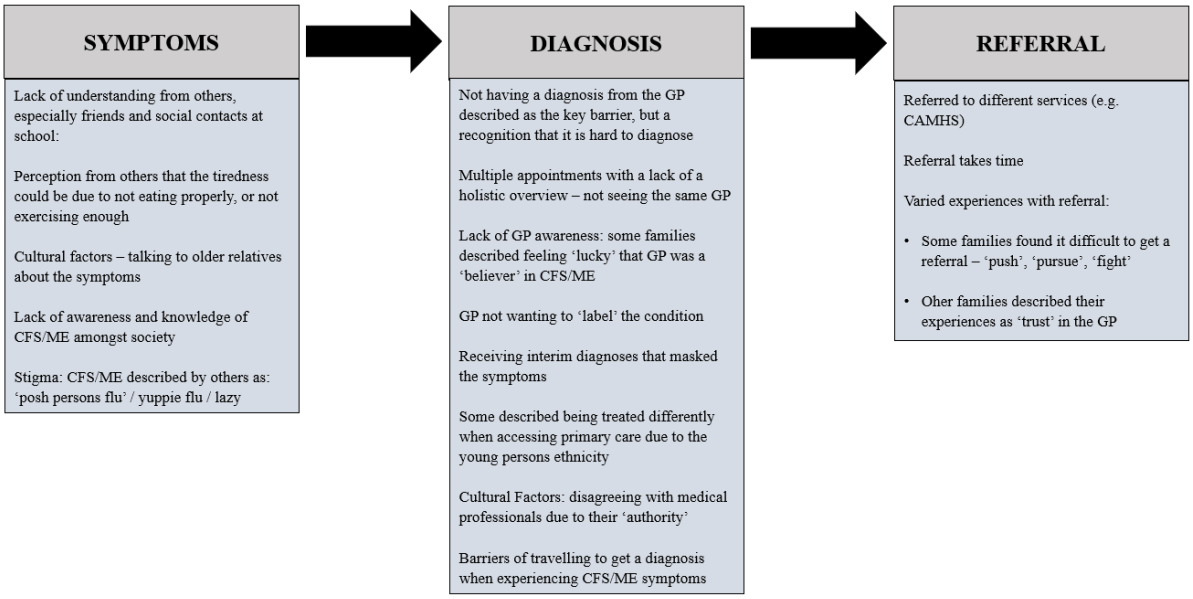

Figure 9: How the Findings Specifically Relate to Ethnic Minority Children Accessing Specialist CFS/ME Services

6.5.2. Key Findings – Improving Access

The following diagram (Figure 10) illustrates the interlinking barriers that were found in the qualitative work that limit access to CFS/ME specialist services for ethnic minority children. The Improving Access findings in terms of ideas for interventions, have been added to the diagram to show which barrier the 'ideas to improve access' targets. As can be seen from the illustrative diagram, the barriers are interlinked and can occur at every level of help seeking therefore ideas to improve access also need to be interlinked and occur at multiple levels to raise awareness, improve knowledge and understanding, and reduce barriers present in the GP consultation.

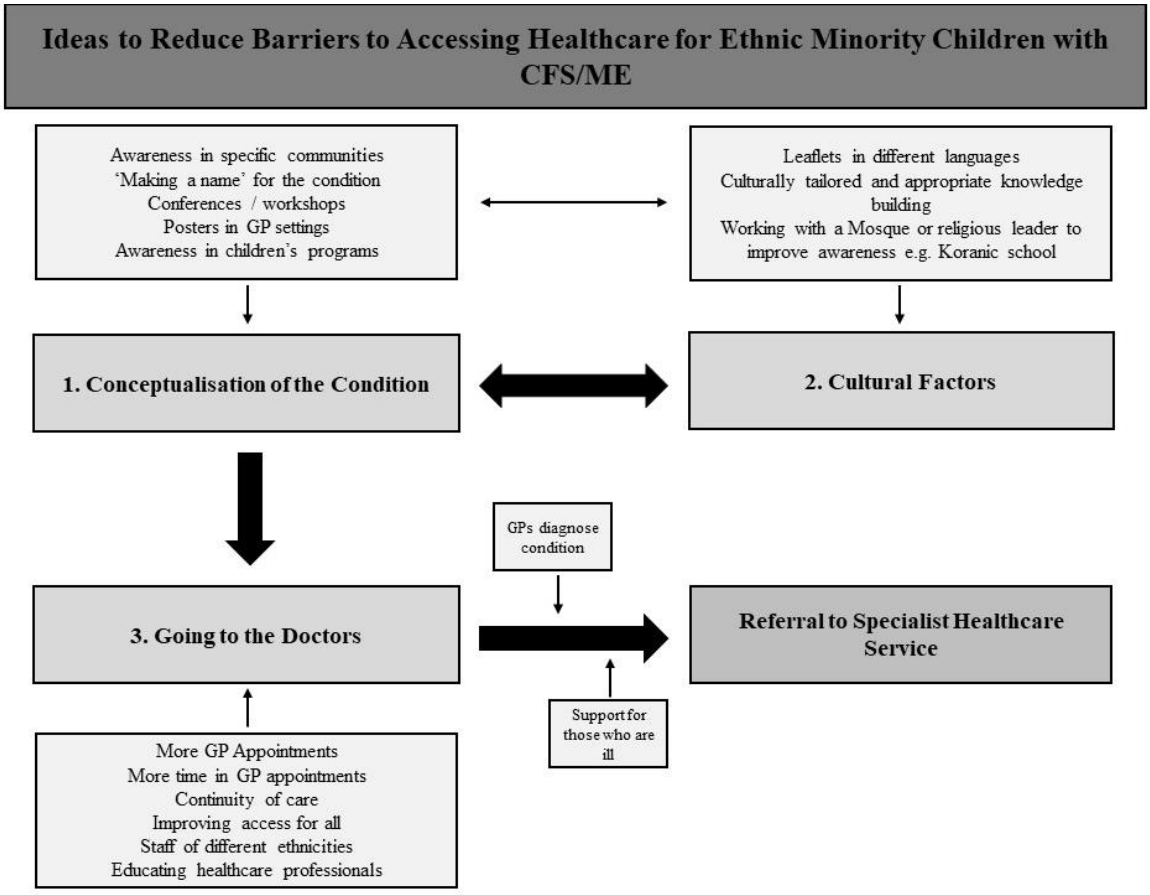

Figure 10: Ideas to Reduce Barriers to Healthcare for Ethnic Minority Children with Chronic Health Conditions

The next chapter (Chapter 7: Discussion) contextualises the findings within the wider, existing evidence base. The findings are discussed in relation to previous literature, and the new, novel findings presented in this chapter are highlighted along with the strengths and limitations and implications of the findings, including on policy and practice.

Chapter 7: Thesis Discussion

7.1 Chapter Overview

This chapter presents the overall thesis discussion on barriers and facilitators to accessing specialist CFS/ME services for ethnic minority children. Key findings from the studies (systematic review, quantitative analysis and qualitative work) are presented and contextualised in wider literature, followed by a discussion of the strengths and limitations of the studies and the overall thesis. The implications of the findings for policy and practice, ideas for future research and my reflections on the PhD are also included. This chapter ends with a closing remarks section which concludes the thesis

The overarching aim of this thesis was to understand the barriers (and facilitators) experienced by ethnic minority children accessing specialist CFS/ME services, to improve access. This was explored through a systematic review; quantitative data analysis; qualitative interviews with 1) children and young people with CFS/ME and their families, 2) community 'influencers' and 3) medical professionals; and 4) focus groups with Somali community members.

Paediatric CFS/ME is relatively common (52–55) and is a chronic, disabling condition characterised by fatigue (30). CFS/ME is difficult to diagnose, as there are no diagnostic tests (30,32) and 80% of individuals with CFS/ME report difficulties with getting a diagnosis (135). CFS/ME is a stigmatised condition (22,40,49,109) and children and young people with CFS/ME perceive a lack of understanding and knowledge of CFS/ME generally amongst society, and amongst clinicians (40,109). Little is known about the experiences of ethnic minority children and young people with CFS/ME and the barriers they face in accessing specialist CFS/ME medical services.

There may be an influx of patients to CFS/ME clinics due to 'post COVID-19 syndrome' (informally 'long-COVID') (359) with symptoms resembling CFS/ME, such as persistent fatigue and unrefreshing sleep (360). Estimates suggest that 10% of those who test positive for COVID-19 in the USA will experience 'long-COVID' and meet the criteria for a CFS/ME diagnosis; using these estimates, this would lead to an additional 10 million new diagnosis of CFS/ME globally (359). UK research supports this, with the Office for National

Statistics (ONS) estimating 1 in 10 individuals have 'long-COVID' symptoms 12 weeks after COVID-19 infection (361). Therefore any barriers to accessing healthcare services for ethnic minority children needs to be identified.

The systematic review identified 'knowledge' of chronic healthcare conditions amongst both individuals who are experiencing the symptoms and also wider society as the most prevalent barrier that limits access to specialist services for ethnic minority children. This involves knowledge of the symptoms (and what the symptoms are attributed to), and also knowledge of where to access help. The role of cultural factors and stigma were also found to be important. Therefore future interventions should focus on improving knowledge of a condition and reducing stigma in a culturally relevant and appropriate way. There are limited interventions that have been devised or piloted to reduce access barriers for chronic health conditions, and future interventions need to be multifaceted to be acceptable and improve access.

The qualitative interviews and focus groups conducted aimed to improve understanding of the issues faced by ethnic minority children and access to specialist CFS/ME services, by including perspectives and views from a wide variety of participants: ethnic minority children and young people with CFS/ME, their families, lay community views, community 'influencers' and medical professionals. Twenty-five participants took part in interviews (3 young people with CFS/ME; 5 family members, 14 community leaders and 3 medical professionals) and twenty-three community participants took part in focus groups. Interviews were transcribed verbatim and analysed using Thematic Analysis (286). Three key barriers themes were identified, with corresponding subthemes (Conceptualisation of CFS/ME, Cultural Factors and 'What's going on with the NHS?': Experiences of 'Going to the Doctor's'). These barriers are interlinked and contribute to making access to specialist CFS/ME services challenging. This work is consistent with previously identified barriers, but also found additional barriers that may be unique to some ethnic minority children with CFS/ME.

The following sections present the novel findings from this thesis and contextualise the findings in the wider existing paediatric CFS/ME evidence base. I will reflect on the methodologies used in this thesis, including the strengths and limitations of the individual projects and the thesis overall, including methodological considerations for future

researchers. Participant recommendations to improve access to specialist CFS/ME services for ethnic minority children are included and I will suggest directions for future research.

7.1.1 Key Findings

The work conducted for this thesis has resulted in four key novel findings, which will be discussed in this chapter, in combination with how other results provide further support for the existing literature and strengthen the evidence base. The key novel findings are as follows (Table 55):

Table 55: Key Novel Findings

1. Systematic Review Results
All 'barriers' literature was on mental health conditions: Knowledge was the most common barrier, but Cultural Factors and Stigma also important Interventions: screening not always appropriate or acceptable; interventions should be multi-component
2. Data Capture Methods
Ethnicity not accurately recorded Very few ethnic minority participants in clinical trials recruiting from specialist CFS/ME services
3. Recruitment Methods
The use of community-based participatory research (CBPR) to improve recruitment Terminology: • For example: Community "Leaders" → Community "Influencers"
4. Qualitative Results
Multiple barriers at every level Three Key Barriers: 1. Conceptualisation of CFS/ME 2. Cultural Barriers 3. 'What's going on with the NHS?': Experiences of 'Going to the Doctor's' Facilitators Ideas for Interventions a) Healthcare System Improvements b) Reducing Stigma and Improving Awareness of CFS/ME Crosscutting theme: The Role of Schools

7.2 Summary of Key Findings

This thesis used diverse methodologies with different participants in order to triangulate the evidence from multiple viewpoints.

7.2.1 Systematic Review

The systematic review found that the most prevalent barrier to accessing specialist healthcare services for any chronic health condition is 'knowledge' of the condition and how to access help, but also found that cultural factors and stigma of chronic hidden health conditions are integral to understanding any access barriers. All the studies identified for 'barriers' were on mental health conditions, suggesting a lack of research for ethnic minority children and chronic health conditions. This finding of 'knowledge' is consistent with a previous systematic review, looking at parental views on barriers and facilitators (not specifically with ethnic minority children) which highlights that knowledge and understanding of mental ill-health, and how to seek help, along with views and attitudes towards treatment, are the key barriers to seeking treatment for mental health problems (260).

One example of an approach to the complex issue of improving healthcare access, is universal screening, without knowledge building initiatives. Knowledge building also needs to occur, as universal screening may not lead to an uptake in access to service use if other barriers are not considered, for example parental perceptions and knowledge (259). Future work should aim to develop interventions that focus on improving knowledge of a condition and available healthcare services, whilst also reducing any stigma around the condition, in a culturally relevant way. Results from the systematic review suggest that future interventions should consist of multiple components and incorporate ideas to break down multiple barriers, or include multiple different facilitators. Different interventions are needed for different target groups (e.g. young people or parents) due to different perceptions of the barriers. Schools are seen as very influential in providing information and could potentially be used to, for example, improve knowledge of mental health and available mental health services directly to young people, whilst reducing stigma (277).

Overall the systematic mapping review provides an overview and an insight into the barriers ethnic minority children globally face when accessing healthcare services for chronic/mental health conditions. The review also provides a descriptive synthesis of interventions aimed at

improving access, and interventions that have been devised or piloted, along with barriers to implement the interventions.

To conclude, knowledge of conditions and how to access healthcare, needs to be addressed and interventions need to be multifaceted as interventions that solely target structural barriers without addressing cognitive barriers (such as knowledge, stigma, communication and trust) are unlikely to be effective in eliciting change and improve access. This review highlights the urgent need for research looking at barriers to accessing healthcare services for ethnic minority children suffering from chronic health conditions.

7.2.2 Quantitative Data Analysis

Quantitative data were used to investigate the characteristics of those who were assessed in paediatric CFS/ME services and were recruited into a research project. The data capture methods used to record ethnicity of the participants may not be specific, for example, one category used for data capture was that of "British". For further discussion see section 7.3: Understanding the Quantitative Results in the Context of the Literature.

7.2.3 Qualitative Interviews and Focus Groups

This study aimed to investigate the perspectives of those who had accessed CFS/ME specialist paediatric services, along with community leaders, medical professionals and lay community views on fatigue. I was unable to recruit community participants with disabling fatigue (see section 6.2.1.5.2)

The contribution of separate groups of participants provided different perspectives, with varied experiences and knowledge of CFS/ME. One early finding was that community leaders do not like being referred to as a 'leader' and community influencer was a more acceptable term.

The findings from the qualitative interviews and focus groups suggest there are potential barriers on multiple levels, which can interact to limit access to specialist CFS/ME services. Data were analysed thematically and the three key barriers (and corresponding sub-themes) were presented in Table 47 (The Key Qualitative Findings: Barriers to Accessing CFS/ME Services) in Section 6.3.

While evidence of barriers to access have been identified in the CFS/ME paediatric literature, the qualitative project found that cultural factors can play an important role in accessing CFS/ME services. In addition, although similar barriers were identified in Theme 1: Conceptualisation of CFS/ME and Theme 3: Going to the Doctors as previous paediatric CFS/ME literature, there are subtle differences and more pronounced barriers that expand the evidence base. These subtle differences may interact in different ways and further limit access to specialist CFS/ME services for ethnic minority children.

Although interviews explored both the barriers and facilitators, alongside participants' ideas for interventions, most of the data revealed barriers, and the participants identified very few facilitators. Most of the facilitators identified were actions by parents to overcome the barriers they experienced, for example if parents did not feel that the GP had knowledge of CFS/ME, then they researched CFS/ME themselves in order to equip themselves with knowledge, educate the GP on what resources are available and 'fight' for a referral to specialist CFS/ME services if the doctor was hesitant to refer. The participants discussed the role of schools, and made suggestions for interventions focusing on improving societal knowledge and awareness to reduce stigma. The results from the qualitative work provide additional barriers that could be used to update the barriers to help seeking model, as discussed in Chapter 2: Literature Overview and Chapter 3: Systematic Review.

7.3 Understanding the Quantitative Results in the Context of the Literature

Quantitative analysis was undertaken to understand if the presentation of CFS/ME is different in ethnic minority children. To achieve this, trial and study data were statistically analysed. The quantitative analysis was important to understand if there were particular characteristics of children from ethnic minorities that are seen in trials recruiting from CFS/ME services and to understand what triggered a referral.

The quantitative results found a low number of patients who identify as ethnic minority in the trials recruiting from the CFS/ME specialist service; this is consistent with previous work finding a low number of ethnic minority children in specialist CFS/ME services (37,127,140,175,176). As I used trial data sets, and not routine clinical data, I cannot be

certain that there are a low number of ethnic minority children in specialist CFS/ME services as data were only available for those recruited into a trial. In section 5.2.4 I described the numerous reasons participants may decline to participate in a trial. Overall, 96.07% of patients identified as non-ethnic minority (White) and 3.93% as ethnic minority with most ethnic minority individuals (76%) identifying as mixed-ethnicity. There could be different reasons for this: either there are a low number of ethnic minority children in CFS/ME specialist services altogether, a low number of ethnic minority children who took part in the trials recruiting from specialist CFS/ME services, or ethnicity was not recorded accurately in the sample.

Ethnic minority children with CFS/ME may have been missed from the analysis as ethnicity was not accurately recorded and data categorisation in order to perform the quantitative analysis was challenging. In this study, the ethnicity categories were vague and participants may have self-identified as numerous categories as participants who feel a close affiliation with their ethnic heritage might choose differently to those who do not feel a close affiliation, or participants may have selected their nationality. Patients were given different ethnicity options to choose from in each trial (see Chapter 5: Quantitative Project). The category "British" in the options could apply to White British or ethnic minority British children, depending on how they perceive themselves and their nationality. The decision was made to categorise British as not identifying as an ethnic minority. This was a potential study limitation as I could not ascertain with certainty the ethnicity of the participants, but ethnicity is a self-defined construct (3) therefore it is not unreasonable to use this method.

Accurate data collection on ethnicity is a known problem in UK healthcare settings (362), limiting investigations into ethnic minority health inequalities (362,363). This is made worse by poorly collected and incomplete data (364), including among hospital outpatients (362). This issue of data collection has been drawn to the forefront due to the COVID-19 pandemic. There is a disproportionate effect of COVID-19 on those from ethnic minority backgrounds (35,365), with racism, discrimination and social inequality being cited as factors that could have contributed to the higher risk to those from ethnic minority backgrounds (365,366). A Public Health England (PHE) report recommends that patient ethnicity should be made mandatory in NHS routine data collection (365,366). Future work, and routine NHS data collection, and clinical trials, should consider the use of using the Census categories when

asking an individual's ethnicity, to avoid vague categories, and self-reported ethnicity is recognised as the preferred option, rather than observer assessment (363).

Due to the low number of ethnic minority patients in the data set, and unequal sample sizes, I did not have enough power for comparison between groups, and instead provided descriptive statistics in the forms of means and standard deviations. Due to this, conclusions cannot be drawn on differences between groups, but the key results found are: 1) there are a low number of ethnic minority children in clinical trials recruiting from the CFS/ME service; 2) ethnicity may not accurately be recorded; 3) 33.33% of ethnic minority children in the trials were not attending school at baseline; and 4) 76% of ethnic minority children in the trials identified as mixed ethnicity.

The previous evidence on the presentation of CFS/ME in ethnic minority individuals is mixed. In the literature, ethnic minority adults with CFS/ME had more severe symptoms in terms of: higher lack of energy, greater fatigue levels with physical exertion, and poorer cognitive function (178) and more severe fatigue (168). Contradictory evidence found no significant difference between White and ethnic minority patients in a specialist CFS/ME service, apart from less social support and lower rates of depression (176). These studies focussed on adults with CFS/ME and could illustrate that ethnic minority individuals who are in specialist CFS/ME services appear to have no significant difference in symptoms from White identifying individuals (176), whereas those who do not access specialist services have more severe symptoms (178). Future work is needed to look at differences between ethnic minority and White children in paediatric CFS/ME services. However due to barriers in service access, and the lack of ethnic minority children in CFS/ME services, sample size considerations in future work should be carefully considered.

7.4 Understanding the Qualitative Findings (Barriers to Help Seeking) in the Context of the Literature

As presented in Table 47 (The Key Qualitative Findings: Barriers to Accessing CFS/ME Services) in Section 6.3 qualitative findings suggest potential barriers on multiple levels, which can interact to limit access. The three key barriers found were: 1) Conceptualisation of

CFS/ME; 2) Cultural Factors; and 3) 'Respect for authority': Disagreeing with medical professionals.

7.4.1 Conceptualisation of CFS/ME

Findings support previous research in terms of limited understanding and conceptualisation of CFS/ME as a chronic health condition, but found additional results in terms of alternative explanations that fatigue could be attributed to. Young people with CFS/ME, their parents, and medical professionals had direct knowledge and experiences of CFS/ME. Community influencers and community views provided a different, but important, perspective, with views captured such as: different explanations for fatigue, and what understanding and views would be towards a child displaying fatigue.

The qualitative interviews and focus groups conducted for this thesis found 'Conceptualisation of CFS/ME' as a medical condition, as a key barrier to accessing specialist CFS/ME services for ethnic minority children. This barrier contained three sub-themes: understanding, awareness and stigma.

7.4.1.1 Understanding

Participants discussed how the phrasing of the medical term "chronic fatigue syndrome" could lead to a lack of understanding of what the condition is, as community influencers noted that the individual words were understandable, but not the complete phrase. In many languages, there is no word, or phrase, for CFS/ME and participants with English as a second language discussed this understanding of the individual words, but not the concept of 'chronic fatigue syndrome/ME'. Similar results were found in a study looking at autism in the Bristol Somali community, where even fluent English speakers reported that medical terminology can be incomprehensible and limit understanding of medical conditions (351).

An interesting finding in this thesis is the variation in understanding of alternative causes of fatigue symptoms and the home remedies that may be trialled before medical care is accessed for symptoms. Fatigue was viewed as either having a strong biomedical cause, or due to lifestyle factors, which could be a barrier to help seeking. Participants discussed how the symptoms of disabling fatigue could be due to the following causes: high blood pressure, hay fever, juvenile arthritis, diabetes, attitude, a curse, lifestyle choices (such as a lack of

exercise, too much exercise, diet), or vitamin deficiencies (in particular Vitamin D deficiency). The following home remedies were discussed and would be tried, depending on what the fatigue is attributed to: multivitamins, more exercise, and lifestyle changes, which may delay access to healthcare if home remedies are tried first to alleviate fatigue.

The different causes may reflect different understandings of illness, as individuals understand health risks through beliefs about the nature of an illness (367,368). Illness beliefs are gained from 'lay' sources "*through the observation and discussion of cases of illness and death in personal networks and the public arena, as well as from other sources such as television and magazines*" (369)(p.428). In the theory of lay epidemiology, individuals consult, and are influenced by, a wide range of sources to identify any potential causes of illness and ill-health (370). In terms of the interplay between public health and lay epidemiology, culture is important, and "*public health professionals need to be aware of the different cultural contexts in which a message operates*" (367)(p.463). Therefore individuals receive information on illnesses from different sources, and any public health messaging regarding illnesses needs to be aware of the cultural context.

Awareness of other health conditions may prevent individuals seeking healthcare for fatigue. Most participants discussed the role of vitamin deficiency in fatigue symptoms, in particular Vitamin D: ethnic minority individuals are more at risk of Vitamin D deficiency and associated complications (371–373) and this was a widely known fact amongst community participants. A recent study investigating Somali women's knowledge in London found most participants understood they were more at risk of Vitamin D deficiency due to their skin pigmentation and knew that exposing skin to sunlight can increase levels of Vitamin D (374).

Health seeking behaviours can be changed through general awareness and knowledge building initiatives. Public health campaigns have aimed to build awareness of the risks of Vitamin D deficiency, for example in Birmingham, UK an awareness campaign for Vitamin D deficiency amongst ethnic minority individuals used knowledge building through posters and leaflets in health centres and pharmacies, and involving local supermarkets, along with community media sources (375). This resulted in Vitamin D deficiency reducing by 59%, despite limited uptake of supplements, and individuals had high levels of awareness of Vitamin D deficiency (375). This is mirrored in the results from this thesis finding that participants were very aware of the risk and symptoms of Vitamin D deficiency in relation to

tiredness, illustrating that tailored public health campaigns can increase public knowledge and awareness of the causes and symptoms of healthcare disorders in this community. Participants in a further Vitamin D study with Somali women in London discussed that appropriate knowledge building needs to be through tailored health messages delivered verbally to mothers during community sessions, and schools and nurses to assist in increasing awareness of child health (374). This is important as in this study similar views on awareness building for healthcare conditions were identified which will be further explored in "ideas for interventions".

Participants were aware that mental health conditions, such as anxiety and depression, could cause the symptoms of disabling fatigue, especially Somali community influencers and community focus group participants. This is an important finding as mental illnesses are highly stigmatised within the Somali community (1) and consistent with previous literature, GPs discussed how CFS/ME could be misdiagnosed as depression (137,146). Therefore parents may try and hide the fatigue symptoms to avoid the child being labelled with a mental health condition.

Most participants (from the following participant groups: young people with CFS/ME and their family members, community influencers, and medical professionals) discussed a lack of general understanding of the condition and the symptoms of CFS/ME. This is consistent with previous findings which describe a limited understanding of CFS/ME in children generally, not specifically to ethnic minority communities (117) and the condition is poorly understood by others (153). This could be due to the invisible nature of CFS/ME, with the lack of visible symptoms being difficult to explain, or lead to the young person not being believed (153,154). This project did not find support for children and young people with CFS/ME being bullied by classmates from uncertainty surrounding the illness (154) but participants did discuss how some families may be ostracised, related to Theme 2: Cultural Factors.

7.4.1.2 Awareness

A finding in this thesis is the public perception regarding the continued connotations of CFS/ME, one clinic parent referred to the condition as a "*posh person's disease*" and another referenced "*yuppie flu*" when discussing the condition. Historically, CFS/ME was informally referred to as 'yuppie flu' starting in the 1980s (37), but the condition was termed CFS in

1988 and given a case definition (37). Despite this, connotations such as 'yuppie flu' continue (40) and evidence has found that ethnic minority adults seen in a CFS/ME clinic in London were viewed as 'middle class' (140). Therefore, connotations of CFS/ME continue, related to the connotation of 'yuppie flu' and the public awareness of who suffers from CFS/ME.

In the qualitative interview studies, there was limited awareness of the condition generally which might explain the low referral rate to CFS/ME services. Community influencers discussed how if they had awareness of CFS/ME, it was gained from media exposure, not in their social networks, and they have never heard of an ethnic minority individual having CFS/ME. This supports previous research, with a view that the condition is a "*White middle class illness*" (180)(p.6). As illustrated in Chapter 2: Literature Overview, despite difficulties in assessing prevalence in individuals across ethnic groups (41), studies indicate that CFS/ME is at least as common in ethnic minority patients, compared to White patients globally (56,67,166–173), but the proportion of ethnic minority patients in specialist CFS/ME services is relatively low (37,41,127,140,175–177). Other factors may impact on awareness, including: stigma and cultural factors.

7.4.1.3 Stigma

Participants discussed the stigma of the condition of CFS/ME and tiredness. Health condition stigma is defined as: "*stigma related to living with a specific disease or health condition*" (376)(p.1). Health condition stigma is a barrier to accessing healthcare globally (377) and the qualitative work explored the role of stigma of CFS/ME and tiredness.

This project found strong support for the notion (and previous evidence) that CFS/ME can be referred to as "lazy" by others (153,154). This could be due to the condition not being viewed as an illness by others, also found in this study (153) and stigma from being poorly understood (49). It was discussed how a stigma surrounding CFS/ME could even be present within the family, and therefore a child may be hesitant to report their symptoms. This stigma of 'laziness' could delay help seeking, as home remedies could be trialled first, such as increased exercise, to improve 'laziness'. A novel finding in this analysis is gender roles, with a view that girls are inherently 'lazier' than boys. CFS/ME is typically more commonly diagnosed in females than males (41,60,62,87,88), but there is a more equal gender balance in

children diagnosed with the condition aged 13 and under (55,85) and after puberty CFS/ME prevalence increases in female adolescents, but not male adolescents (86). In addition severe fatigue affects up to 20.5% of teenage girls and 6.5% of teenage boys (136) and girls attend more GP consultations with disabling fatigue than boys (137). Given that fatigue is more common in girls, and given the interpretation that this is due to laziness, this may prevent girls accessing care, but this was not supported in the quantitative data analysis, which found a higher proportion of ethnic minority girls in clinical trials recruiting from the specialist CFS/ME service than non-ethnic minority girls, therefore this interpretation may only be present in certain cultural groups.

7.4.2 Cultural Factors

Participants discussed Cultural Factors as a recurrent theme in the qualitative interviews, encompassing: closeness to a community, close communities and families, alternative sources of help and disagreeing with medical professionals. 'Culture' can be considered to be commonalities between a group amongst ethnic minority individuals, as opposed to the majority population which is not typically categorised as having a culture (2). Community influencers and community participants in this study spoke in depth about their cultural background, such as aspects of the "*Somali culture*". The role of cultural factors in healthcare access led to the development of the Cultural Determinants of Help Seeking (CDHS) Model (185) as discussed in Chapter 2: Literature Overview. The basis of the CDHS model describes the concept that individuals from all cultural groups base help seeking behaviour on assigned cultural meaning (185), with this meaning based on social significance (185).

An important aspect is how much an individual feels a closeness to a particular community. It was noticeable that young people from the clinic did not discuss cultural factors as being a barrier, while this was discussed as an important barrier for those from the community. This could be because cultural factors may not have been a perceived factor in their experiences with accessing medical care and they may not feel aligned with a particular ethnic minority community. Or, alternatively, they might not have felt comfortable discussing cultural factors with myself. Instead some clinic families mentioned cultural differences in terms of generational differences with talking to older relatives from an ethnic minority background about their understanding of hidden chronic health conditions.

In individuals who did discuss a closeness to a community (especially community members and community influencers), they described how closeness amongst a community can lead to gossip about others and a community consensus on conditions. Somali culture has been categorised as collectivist (243), defined as a culture that values "*interdependence and are oriented towards cohesion, commitment and obligation*" (378)(p.1454) as opposed to an individualist culture "*in which the members value independence, and the cultural norm is for nuclear living arrangements*" (378)(p.1454). This aspect of the Somali collectivist culture was described by a medical professional who spoke about a group consensus within the Somali community on medical conditions and also how the Somali community is closer than a lot of other communities.

Gossip is common surrounding mental health conditions (1), and community influencers from varied cultural backgrounds discussed how the reactions of others, and being sources of gossip due to close communities, could lead to families hiding their child due to a worry that people will label them or social stigma. Medical professionals also highlighted this as a potential concern when using translators, that the consultations will not be private and information disclosed could be discussed in the community. Previous research with ethnic minority adults with CFS/ME supports this, in that patients are wary of stigma from the community (22) and findings in this thesis suggest parents may be concerned that they would be blamed for the child's CFS/ME illness; this could be especially true if the fatigue is attributed to diet or vitamin deficiencies, or the child and family would not want to feel like a burden within the community. Others spoke about how after diagnosis there could be sympathy for the family.

Community influencers and community members discussed how alternative sources of help and coping strategies that are culturally appropriate may be trialled by patients with fatigue. In particular faith healers and natural healing were highlighted as an alternative source of help that could be consulted. Community influencers in this study discussed how turning to religion and religious practices is a potential source of help, such as reading the Qur'an, or consulting a religious leader for spiritual advice and support. Related to the participant attributed causes of CFS/ME, one of which could be a curse, previous research has found that symptoms of CFS/ME could be attributed to cultural explanations and individuals may

consult spiritual healers for help rather than medical professionals (23). Religion has also been found in the literature as a coping strategy for CFS/ME (168).

Finally participants in the study discussed how due to 'respect for authority' figures, disagreeing with medical professionals might not be culturally acceptable. A clinic parent spoke about how in certain cultures, due to the perceived authority of the GP, individuals may not voice a disagreement with the GP. A community influencer spoke about how being assertive can lead to referrals to secondary care, and a medical professional discussed how members of the Somali community discuss what the medical professional said in community settings to decide if they trust the opinion of the doctor. Therefore these divergent views illustrate how cultural factors may interact with healthcare encounters and it may not be culturally acceptable to disagree with a GP, which could be a barrier to care, along with not trusting what the GP says, as individuals may be less likely to follow management options. This could especially be the case in communities where CFS/ME is not viewed as an illness, or the symptoms are attributed to something else, as individuals may not wish to be referred to specialist CFS/ME services due to potential stigma.

7.4.3 'What's going on with the NHS?': Experiences of 'Going to the Doctor's'

7.4.3.1 General Healthcare Barriers

There was much discussion by community influencers and community participants around barriers when attempting to consult a GP. Divergent views were found about when a doctor would be consulted, with participants commenting that they may hide the child due to stigma, with others commenting that they would always take a child, or it would depend on fatigue severity.

In terms of general medical care barriers, focus group and interview participants (community influencers) discussed numerous barriers that can impact the consultation. These barriers have been described before in the literature and it is important that future work addresses these barriers to enable patients from ethnic minority backgrounds to access appropriate healthcare. Participants described being treated differently due to their ethnicity, consistent with previous work that found ethnic minority adults with CFS/ME, along with their carers and community leaders, believe GPs may have stereotypical views which can hinder or delay diagnosis (22), or individuals stated that due to their ethnicity their symptoms were not taken

seriously and explained as mental illness (180). Health professionals in previous work also recognise the influence of stereotypes in diagnosing CFS/ME (22). Participants in the qualitative work discussed language barriers, which are known to hinder the ability to communicate symptoms to a GP, or to understand the GP (22,145). Interpreters can be used, and community participants in this study discussed positive experiences with interpreters, but GPs spoke about potential privacy concerns and the variation in ability of the interpreters as causes of further barriers (22).

Other barriers found may be true for all individuals, such as not being able to book a GP consultation, as participants recognised this is a UK wide issue not limited to ethnic minority patients. Understanding the UK healthcare system and a relationship with a specific GP were also important, as some participants discussed not feeling that the GP helps, with others discussing a good relationship with medical professionals.

7.4.3.2 Going to the Doctors: CFS/ME Specific

Young people with CFS/ME, and their families, described difficulties accessing help, consistent with previous studies, which could affect the numbers of ethnic minority children seen in specialist CFS/ME services. Participants discussed frustrating experiences accessing healthcare (109,116), negative medical encounters (49), multiple appointments to diagnose the condition (22,109,116), and multiple diagnostic tests to rule out other conditions (116). Waiting times for healthcare appointments were described by participants as being stressful (116) with an uncertainty (117) and potential misdiagnosis (148). Medical professionals discussed difficulties with diagnosing CFS/ME, especially if co-morbid conditions were present (116).

Clinic families discussed different levels of understanding of CFS/ME among healthcare professionals, consistent with previous work finding a lack of understanding is a key barrier to accessing specialist CFS/ME services (40,109,116,117,379). Parents discussed the unhelpful information they received from medical professionals (109), including that their child will feel better quickly, with a view that medical professionals displayed uncertainty, and a lack of confidence, in diagnosing CFS/ME (23,116,139,145). Families highlighted how some medical professionals did not want to label the young person and warned of a potential stigma of a CFS/ME diagnosis (23,109). In addition, patients also described not

feeling believed by medical professionals (117,148), not listened to (109) and unsupported (49).

Some clinic families described a 'push' or fight which may be related to a lack of GP understanding (109). Mothers had to be 'pushy', such as printing the NICE guidelines (30) to take to the appointment to educate the GP. This has been found in previous paediatric CFS/ME literature, with mothers describing acquiring knowledge in an attempt to bypass gatekeepers (116) and parents having to inform and educate the GP about CFS/ME and specialist CFS/ME services (109). Participants in this study described how they were able to conduct personal research and recognised that some families may not be able to (22), potentially due to language, cultural or educational barriers. Children and young people with CFS/ME and their families, did discuss how they were generally happy with the care they received once they had gained access to the CFS/ME service, but there were waiting times to access the service, along with an impact on attending appointments on the child's fatigue levels.

The findings highlight the general difficulties with accessing CFS/ME specialist paediatric services and an urgent need to assist young people with CFS/ME to access healthcare. None of the clinic participants spoke of language or cultural barriers in accessing GP consultations and therefore different, or additional CFS/ME specific barriers may be found in future work in ethnic minority young people that do report general medical care barriers.

The following table (Table 56) presents the novel barriers that were found in this project on accessing specialist CFS/ME services for ethnic minority children. Table 4 and Table 5 in the Literature Overview Chapter (2.1.5.3: Summary of the Barriers to Accessing Paediatric CFS/ME services), presented the previous barriers found in the paediatric CFS/ME literature, on predominantly White British children.

Table 56: Novel Barriers for Accessing CFS/ME Services Identified in this Thesis

Theme	Sub-Theme
Conceptualisation of CFS/ME	Terminology Alternative explanations for fatigue Condition affects White British Gender Roles
Cultural Factors	Perceived Closeness to a Specific Community Close Communities and Families – Stigma, Gossip, Community Views on Conditions Alternative Sources of Help Disagreeing with medical professionals
'What's going on with the NHS?': Experiences of 'Going to the Doctor's'	Perception of treated differently due to ethnicity Language / Cultural Barriers Structural barriers – SES, Single Parent etc. Communication with different services

7.4.4 The Use of and Expansion of Existing Barriers Models

Three Healthcare Access models were presented in the Literature Overview of this thesis to give the reader an overview of previous work in this area and models that have aimed to capture barriers to accessing healthcare. These models were useful to guide my understanding of the research area, by highlighting what barriers have previously been found, and were used when designing the topic guides to ensure that barriers could be captured, as it was helpful to understand what domains previous models have captured barriers in, for example structural and cognitive.

Of the models presented, I chose the HCAB model (182) to be directly used in this thesis (in the systematic review) due to the model being specifically designed to capture barriers for ethnic minority patients. The model focuses on three broad barriers (financial, cognitive and structural) which lead to health outcomes, disparities through late presentation to medical/healthcare services, decreased prevention behaviours and decreased levels of care (182). I recognise the limitations of all the models, that they were all designed in the USA and for adults, but the HCAB model was the most closely related to my topic area so was chosen as the basis for data extraction for the systematic review. As discussed in the Systematic Review chapter, the HCAB model was useful for making sense of the data, but

was unable to capture all the barriers identified in the literature and so the categories of culture, stigma and trust were inductively coded from the data.

Due to the multi-method approach of this thesis and the systematic review being conducted first, I decided to inductively code the qualitative findings, instead of using the HCAB model for data extraction as I had in the systematic review, as the HCAB model was unable to capture all the barriers from the identified literature. Therefore, this thesis was not testing the models, but instead inductively coding to identify the themes that emerged from the qualitative findings.

I have considered after completing the qualitative work how well my findings map onto the HCAB model and similarly to the systematic review, cultural factors were important to all groups of participants. The results from this thesis did not find financial barriers present in accessing healthcare. Some clinic participants spoke about more support for those who are ill, and socio-economic status, in relation to help seeking, but most participants did not discuss this. This combination of projects identified that in ethnic minority children in the UK, 'Cultural Factors' are more important to some patients than financial barriers as a key theme in accessing help. I am aware that this is person specific – some participants in the study did not mention cultural factors explicitly but instead spoke about how this impacts understanding and talking to older relatives. There were differences between participants who mentioned cultural factors (community leaders, community members, and some medical professionals) and those who did not mention cultural factors (young people recruited from the CFS/ME clinic), and those who only mentioned it in passing (some clinic parents). This may suggest that in those whom cultural factors are important are less likely to have access to specialist CFS/ME services for the reasons described and this is also important for any implementation of ideas to improve access to specialist CFS/ME services.

7.4.4.1 Alternative Models

Alternative models could have been considered, for example Dixon-Woods' model of access which includes candidacy as a key factor (380). Dixon-Woods's theoretical framework of candidacy is defined as "*the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services*" (380)(p.7). The process of candidacy is dynamic and there can be a misalignment between their priorities of

the patient and those of the healthcare service, causing vulnerabilities in access (380). Therefore the concept of candidacy can be used as a framework to explain why patients engage with healthcare services and consists of seven dimensions. The first dimension is 'identification of candidacy' and involves how individuals recognise that the symptoms they are experiencing require medical assistance, and therefore how they assert their candidacy for care (380). The framework then covers: navigation, the permeability of services, appearances at health services, adjudications, offers and resistance and operating conditions and the local production of candidacy (380).

Candidacy could have been useful to investigate the patient-healthcare interactions in this thesis, as numerous barriers were identified at the GP consultation; some patients experienced difficulties with having their symptoms recognised and with referral to the CFS/ME service, whereas other families did not. But I was also interested in step one (or pre-step one) of the candidacy framework (identification of candidacy) (380), such as knowledge and awareness of the condition, cultural factors, attitudes and beliefs, and contextual factors, which are covered in detail in the broad models presented in the Literature Overview of this thesis (181–185). For example, what happens when symptoms are first experienced, what factors influence how the symptoms are conceptualised, and are there cultural factors that may interact with how symptoms are experienced, or is there potential stigma. Previous work has highlighted that CFS/ME is more common in those from ethnic minority backgrounds and this exploratory work aimed to broadly capture these barriers from the patients perspective.

Therefore, I was interested in understanding the barriers from multiple perspectives, not just deciding and then accessing healthcare and the GP consultation. I did not ask in the qualitative interviews about a specific healthcare encounter individuals had experienced, including the decision making around that encounter, which if I had been using candidacy would have been useful to understand patient choices. Instead, the interviews focused on perceptions of the barriers, and what was important for them to discuss, rather than focusing on the GP consultation and negotiations in accessing care. Therefore, as I wanted to understand the stages before healthcare use, and also wider contextual barriers, in addition to the relationship between patients and healthcare services, candidacy was not utilised in this work. As this exploratory work has found that numerous barriers to accessing CFS/ME services are present in the GP consultation, future work in this topic area could utilise candidacy by incorporating the work in all aspects of the study design to understand further

the importance of this negotiation for access. It has also been suggested that future work could expand the candidacy framework by addressing and investigating the stages before utilising healthcare, and how individuals may self-manage their symptoms (381).

7.5 Understanding the Qualitative Findings (Facilitators) in the Context of the Literature

Clinic participants, and their parents, discussed very few facilitators, despite being asked if any factors had helped them gain access, illustrating difficulties accessing specialist CFS/ME healthcare. Due to a perceived lack of GP knowledge, mothers in this study discussed how undertaking personal research to enhance knowledge of CFS/ME can help (143) and this includes taking information gained from Internet searches to the GP consultation (379). These methods can be a successful method to bypass gatekeepers (116). In addition, mothers of clinic patients discussed how support from social contacts, charities and education services acted as facilitators, as this support equipped mothers with further knowledge and helped with accessing, and continuing with, appropriate healthcare services.

7.6 Understanding the Qualitative Findings (Ideas to Improve Access) in the Context of the Literature

Improving access ideas were discussed in detail by study participants and this work found that healthcare system improvements along with reducing stigma and improving awareness and knowledge of CFS/ME, were key ideas to improve access to specialist CFS/ME services for ethnic minority children.

7.6.1 Healthcare System Improvements

Providing more GP consultations, with more time in appointments, was discussed as helpful. These suggestions have been previously recognised, and UK GPs have reported that they are dissatisfied with the time available in appointments (382) with the British Medical Association (BMA) recommending that GP consultations in England could be increased to 15 minutes, from 10 minutes, due to patients presenting with increasingly complex conditions

that may need more time (383). In addition, waiting times to see GPs are increasing, with 20% waiting over two weeks for an appointment in October 2018 (384).

Clinic participants discussed continuity of care and the barrier of seeing different GPs each time. Continuity of care is important in other health conditions, such as Multiple Sclerosis (MS), for creating positive experiences of accessing healthcare (385) and patients with chronic health conditions value seeing the same GP, with communication between care settings important (386).

In addition, community participants in the study suggested having staff of different ethnicities and cultural backgrounds, would be useful for reducing barriers in accessing healthcare. The NHS workforce is diverse with an increasing number of ethnic minority doctors: in January 2020, 57% of Senior Doctors identify as White, with 31% Asian and 3.5% Black, compared with 53% of Junior Doctors identifying as White, 28.7% Asian and 6.2% Black (25) and a previous study looking at autism in the Bristol Somali community found that Somali healthcare workers or Link Workers would be considered useful for Somali families (351). Link Workers can be wellbeing advisors or CBT therapists working in primary care, and can increase referrals for ethnic minority patients (387).

The community participants suggested English language ability was a barrier to accessing care, and additional resources to overcome this barrier were suggested. Language barriers can contribute to health inequalities, as communication is essential in healthcare appointments (388). In appointments, family and friends often interpret (389) but interpreters specifically trained for interpreting during medical consultations can help minimise any language barriers (390). The use of interpreters in medical appointments should be carefully considered as medical professionals views captured during this project, reported issues with interpreters, including variations in ability to interpret. Further limitations in using professional interpreters also include privacy concerns and the logistics of arranging to have an interpreter present during the consultation (388).

The final healthcare system improvement suggested was that GPs could diagnose paediatric CFS/ME. Current NICE guidelines state that children displaying CFS/ME symptoms should be referred to a paediatrician within six weeks, but GPs are able to diagnose adult CFS/ME cases (30,32). Participants in this study questioned whether this should be extended to

children, or a further suggestion was that school nurses could have the direct ability to refer to CFS/ME clinics, as they would be familiar with the child's abilities and energy levels in school, and this could bypass GPs as gatekeepers to other services.

7.6.2 Reducing Stigma and Improving Awareness of CFS/ME

The second suggestion for improving access to specialist CFS/ME services was increasing awareness through knowledge building campaigns that could reduce the stigma of the condition. Due to the finding of a lack of knowledge of CFS/ME generally amongst society, these campaigns could increase wider understanding that CFS/ME is a medical condition and therefore increase the presentation of these children to medical services.

Participants had varied ideas for the format of awareness building campaigns including: conferences or workshops; leaflets in different languages; posters in GP settings; education through children's programs or Koranic schools and working with a Mosque or religious leader to disseminate information in a culturally appropriate way. Participants spoke of how individuals may prefer to receive information in different formats, therefore a combination of verbal and written information was suggested as the most beneficial. These findings are consistent with a systematic review looking at behavioural interventions for ethnic minority communities, which identified interventions should: "*(i) use community resources to publicize the intervention and increase accessibility; (ii) identify and address barriers to access and participation; (iii) develop communication strategies which are sensitive to language use and information requirements; (iv) work with cultural or religious values that either promote or hinder behavioural change; and (v) accommodate varying degrees of cultural identification*" (391)(p.248).

Previous work on UK children with CFS/ME highlighted the difficulty in having CFS/ME recognised and appropriate support provided by educational authorities (44), with a lack of knowledge among teachers of CFS/ME, but a formal diagnosis can increase the level of support in schools (392). The interaction between healthcare providers and schools is "*fundamental to acknowledge the condition and manage the impact*" (44)(p.1144-1145). Schools would provide an integrated way for young people to access healthcare and traditional barriers to accessing services, such as language, knowledge and cultural barriers could be overcome through the use of school based interventions (240). Despite this, as seen

in the systematic review, when one study conducted universal screening of a school year group, there was very limited take up from parents of the recommended healthcare referral (259). Therefore a combination of interventions could be appropriate, to ensure knowledge building and structural access barriers are addressed.

In addition, community participants spoke about 'making a name' for CFS/ME. Work looking at autism in children in the Bristol Somali community found autism was a new word (351) that did not directly translate into the Somali language. Health stigma was found in the Somali community in Bristol in terms of autism, where stigma was related to a lack of understanding of the condition and "*a lack of vocabulary related to autism*" (313)(p.781) in the Somali language (313). Multiple Somali participants in the qualitative project spoke of their improved awareness of autism through knowledge building initiatives, and thought that 'making a name' for CFS/ME, similar to the autism work, could raise awareness.

Finally participants spoke of educating healthcare professionals on CFS/ME. Previous work has identified that there is a training need in primary care on CFS/ME (379) and families in this study described how more awareness among healthcare professionals could assist families in accessing specialist care.

The following table (Table 57) provides a summary of recommendations from participants on 'Ideas to Improve Access' to specialist CFS/ME services for ethnic minority children.

Table 57: Recommendations from Participants on 'Ideas to Improve Access'

Barriers to accessing specialist CFS/ME services	Recommendations from participants to reduce the barriers
Conceptualisation of CFS/ME (Understanding, Awareness, Stigma)	• Awareness in specific communities • 'Making a name' for CFS/ME • Conference / Workshops • Leaflets in different languages • Posters in GP settings • Awareness in children's programs or Koranic school
Cultural Factors	• Awareness: working with a Mosque or religious leader • Staff of different ethnicities
'What's going on with the NHS?': Experiences of 'Going to the Doctor's' (CFS/ME specific and general barriers in accessing medical care)	• Educating healthcare professionals on CFS/ME • More GP consultations • More time in GP consultations • Improving continuity of care and links between different services • GP diagnose CFS/ME

7.7 Qualitative Findings – Recruitment

There are low participation rates in those from ethnic minorities taking part in healthcare research, despite a higher burden of disease, and there is a need to improve recruitment methods to ensure results from healthcare studies are relevant to different ethnic communities (162). Therefore, methods using community participation are needed to improve recruitment in healthcare research studies with ethnic minority individuals. I used a combination of recruitment strategies during this project with an aim to improve participation in the study (393).

During recruitment to the study (as discussed in section 6.2.1.4) recruitment was limited using my initial approach. To recruit 'community leaders', I contacted relevant community groups, with the aim of explaining more about the study and recruiting them to take part in interviews, and to gain their support with the study (394). Similarly to other studies, this method resulted in very limited interest (395) and low participation rates in the project, potentially due to lack of awareness of CFS/ME and a perception that CFS/ME was not an issue in their social contacts (395), or due to trust with a researcher from outside the

community. The majority of individuals approached did not respond to emails or telephone calls.

I therefore changed my approach, becoming a trusted and engaged outsider and a visible presence within the Bristol Somali community, by volunteering weekly at a mother and child club. Developing trust was important to recruiting to the research study (393,395) as:

"*Collaborating with community members is an essential first step that is eased when the researcher knows and is known by community members and leaders*" (396)(p.44).

I was able to build trust by being transparent about the research process and what participating would involve, ensuring confidentiality, and attempting to ensure that the study would be beneficial to both participants and the wider community (395). This increased recruitment as people were interested in the project and were willing to help and snowball sampling occurred (393), but still resulted in limited participation, as only those who it was thought would provide useful information and who were confident in the English language were approached. This could have influenced the participation pool and increased the risk of bias in recruitment into the study.

I also directly supervised a summer placement medical student to assist with the community influencer interviews. The medical student provides the following self-description of their ethnic and cultural background: "*Though I was born and raised in Bristol, my family are originally from Libya (ethnically Arab)*". The student has a wide network of social contacts from different cultural backgrounds, and utilised these networks to gain different perspectives for the community influencer interviews, through an established rapport with the participants and shared cultural similarities (393):

"*An age, gender, and culturally matched research assistant may have an increased ability to establish rapport with minority or immigrant participants and thus encourage participation*" (394)(p.240)

However, cultural similarities between researcher and participants can also have the effect of limiting recruitment to studies, due to a fear that anything the participant does say during the study may be spoken about to others (393), therefore some participants may prefer to talk to those outside their community (393).

Finally, I co-produced research with community partners (1). The community partners and myself devised a study, to provide evidence for Somali views on mental health and barriers to

accessing healthcare services. We used a community-based participatory research (CBPR) approach, a methodology used to conduct studies in partnerships with community organisations (351). CBPR utilises respect and co-learning between researchers and community members, along with community engagement, in a research process where community partners contribute their unique strengths to enhance understanding (307–309). The CBPR methodology chosen for this study combined expertise in qualitative research methods from University researchers along with community members' experiences and knowledge (312,313). Using the CBPR methodology we were able to run focus groups with 23 participants and included discussion points on fatigue in this study for a lay community view. CBPR research was the most successful recruitment strategy and resulted in 23 individuals being recruited within a month to take part in focus groups researching a highly stigmatised topic area. Those recruited might not typically take part in healthcare research due to limited English language ability and trust, but the community partners' 'endorsement' and advertisement of the study, along with providing translators and logistical assistance, led to improved recruitment over a short time frame.

Therefore, research that uses a CBPR approach, emphasising co-learning and respect, in combination with community partners (307–309) has the potential to improve recruitment into healthcare research, methodology and the dissemination of results. CBPR research is a valuable method in engaging those who would typically not take part in healthcare research studies, including conducting work with ethnic minority participants (306,311). Having community partner input creates ownership from the community in the research process, and improves trust from potential study participants (29,311); this engagement from community partners is vital in producing evidence that is relevant to those it aims to help. Relationship building with community organisations and groups can lead to involvement in deciding preferences and strategies on how to communicate the findings in a culturally sensitive way (306).

7.7.1 "Community Influencer"

An unexpected recruitment finding that emerged at the beginning of data collection was that "community leaders" in this study, did not like to be referred to as such. I recognised after the first few interviews that individuals did not like to be labelled as a community leader as they felt they could not speak in that capacity for their community. This is common term in

research and has been used in many studies, including a study looking at ethnic minority adults and barriers to accessing specialist CFS/ME services, through interviewing of 'community leaders' (22). This finding has implications for recruitment into healthcare studies generally, as assigning labels to participants can hinder recruitment to studies.

To my knowledge, there has been no research on the acceptability of the phrase community leader to study participants. The role of a UK community leader has been suggested to involve: "*local council candidates, organisers of events, managers of community centers/religious organisations, or people in a position of power within the community*" (326)(p.807). However, a UK study found individuals from Indian, Pakistani and African-Caribbean communities are critical of those who claim to be community leaders (326) as they were viewed as 'self-proclaimed' leaders who work for their own personal interests and have their own agendas, with little contact with the community they claim to be working for (326).

In the qualitative work for this thesis, most participants declined the label of a community leader, with exceptions for those who were working in a religious capacity. Therefore researchers should be hesitant of using their own labels on study participants and identifying potential community leaders themselves, instead a more community participatory approach is necessary. Those who can traditionally be defined as community leaders can in fact be referred to in communities as those who are 'well-known' or by asking 'who runs the charities? Who does a lot of work within the community?'

Future work and best practices should always include detailed public and patient involvement and engagement (PPIE) to gather opinions on the appropriateness of the recruitment methods. At the beginning of an interview, or on a recruitment/consent form, space and a short discussion about what the participant is comfortable being referred to as should be included. I found 'Community Influencers' was more acceptable, but this may vary with different individuals in different locations, who may prefer other terminology. Researchers can positively engage with potential study participants, and aid inclusive recruitment to healthcare studies by not assigning labels to study participants.

7.8 Project Integration

The systematic review did not aim to solely investigate mental health conditions. I searched for all papers related to any chronic condition (physical or mental health) and I was surprised that all of the papers that described 'barriers' focused on mental health. This finding suggests that more research is required to investigate the barriers facing children with chronic physical health conditions. The focus on mental health conditions may limit the conclusions that I can draw from these papers as CFS/ME is not a mental health condition (see Section 2.1.3.1,; in the World Health Organisation (WHO) International Classification of Diseases 11th Revision, CFS/ME is classified under Classified under 'diseases of the nervous system' (397). Despite CFS/ME not being a mental health condition, stigma around the condition remains and CFS/ME can be misdiagnosed as depression (146).

In Section 6.2.3.3, I discussed how I analysed and triangulated the qualitative data from the interviews and focus groups. Similarly to the interviews, focus group participants provided divergent views on what fatigue could be attributed to, such as vitamin deficiencies, stress, and depression. The focus groups also enriched my understanding around access to care and cultural factors that could influence help seeking. For example, a detailed discussion took place around community social support and turning to religion for support. The participants in community influencer roles chose to express their thoughts in English, whereas nearly all participants in the focus groups spoke in the Somali language therefore as an interpreter was present in the focus groups providing an English-Somali translation, these views in the Somali language were able to be captured.

I fully recognise the limitations of the inclusion of data from the focus group discussions exploring mental health in this thesis, as CFS/ME is not a mental health condition. Participants may have discussed different barriers to accessing healthcare for mental health conditions rather than physical health and discussing fatigue within a focus group on mental health could have directly influenced the answers participants provided (see Limitations, Section 7.10.2.4.2). However, the detailed discussion in the focus group around barriers to accessing healthcare merits the inclusion of these data in this thesis to understand from a lay perspective experiences of accessing healthcare. During analysis of relevant focus group data, shared themes around access to healthcare were evident across the data from focus

group and community influencer participants. This consistency across different data sources suggests there is some validity in the findings.

The focus groups were a convenient source of data to gain a community perspective and enhance understanding of the factors that influence help seeking and access to care. Although it may have been informative for the focus groups to solely investigate fatigue and fatigue in children, I did not choose this method as the initial interview findings revealed that CFS/ME is a relatively unknown condition. Therefore inviting community members to a focus group about CFS/ME or fatigue in children could have resulted in very little interest and as found with interviews, recruitment could have been challenging.

7.9 Summary of Findings

The diagram presented in Section 6.5.1 (Figure 8: Barriers to Accessing Healthcare for Ethnic Minority Children with CFS/ME) illustrates the barriers found in this project, that can limit access to specialist services for chronic health conditions for ethnic minority children. As illustrated in the figure, the barriers are interlinked and can occur at different levels of help seeking.

There are barriers to conceptualisation of the condition: understanding, awareness and stigma. Conceptualisation interlinks with cultural factors. The decision to seek help for the symptoms can lead to 'going to the doctors', where numerous other barriers are experienced, including diagnosing the condition, specific barriers for the condition, and general barriers in medical care for ethnic minority patients. After the care pathways has been navigated, and the doctor has been visited, there can be a 'push' for referral to specialist services, which is related to cultural factors and how culturally appropriate it is to disagree with healthcare professionals.

Participants provided numerous ideas, focused on awareness and knowledge building, to reduce the barriers and improve access to specialist CFS/ME services for ethnic minority children. In addition, reducing barriers in medical care appointments was also important to participants. Figure 10 (Ideas to Reduce Barriers to Healthcare for Ethnic Minority Children

with Chronic Health Conditions) presented in Section 6.5.2 illustrates the participant ideas to reduce the barriers and the barrier it aims to address.

7.10 Strengths and Limitations

7.10.1 Strengths

7.10.1.1 Strengths of a Multi-Method Thesis

A multi-methods approach appreciates that each individual method has unique strengths and limitations and by using a multi-method approach, a researcher can "*attack a research problem with an arsenal of methods that have nonoverlapping weaknesses in addition to their complementary strengths*" (398)(p.4). This is evident in this study, as the strengths and limitations of each individual method chosen are discussed in detail in this section, but overall the projects can combine to form a holistic understanding of the patient pathway to the CFS/ME clinic and potential barriers and facilitators. A further strength of using multi-methods in this thesis, is the flexibility and by using this approach I was able to select the most appropriate method for the separate research questions in each component (289,291).

7.10.1.2 Systematic Review

The systematic review was carefully considered and planned in order to fill the lack of literature reviews in the topic area of access to specialist services for ethnic minority children for any chronic or mental health condition. Close collaboration with a systematic review specialist ensured the review was appropriate, answered the research questions and fit in with the wider body of work being conducted for this PhD.

The search terms were devised in collaboration with the systematic review specialist, and the search strategy was piloted and refined multiple times, to ensure the final search strategy was appropriate and identified all relevant literature. A "second screener" team was used to ensure that no potentially relevant papers were discarded during the screening process. The systematic review found a substantial breadth of literature, which added to the evidence base of this thesis.

7.10.1.3 Quantitative Data Analysis

For the quantitative work, secondary data analysis of trial data was used. This is the largest study of paediatric CFS/ME that has explored the number of ethnic minority children. A large participant pool was available for the data analysis and the information recorded in the trial data sets may have been richer and more accurate than routinely collected NHS data. However, there was a lack of ethnic minority children and not enough statistical power for group comparisons (please see Section 7.10.2.3 for this key limitation). Despite the lack of power, this analyses highlights how ethnicity data capture methods could be improved and standardised in NHS care and clinical trials and illustrates how few ethnic minority children access specialist CFS/ME services and are recruited into trials.

7.10.1.4 Qualitative Interviews and Focus Groups

A particular strength of the qualitative interviews is the trust I built with participants, especially in regards to the community influencers work. Most interviews were obtained through volunteering with the children's and community group. It was important to build those relationships, be someone that the participants could trust, and to gain an insight into the community. This snowballing strategy through being a visible presence and volunteering with the group meant people who might not have previously considered taking part in research studies were willing to talk to me about the issue. Due to trust with the participants, for the community influencers work I was able to interview both male and female participants and a wide range of occupations were included to gain a varied sample of participants.

When interviewing community influencers a private space was booked at a community centre to provide a neutral location and participants could be assured they would not be overheard. Some participants spoke to other community members about the process of taking part in the study and one informally characterised it as "*easy and interesting*" and another mentioned to a social contact "*it might help the kids*". This informal endorsement and encouragement for others to take part in the study was very much appreciated and might have enabled the study to reach individuals who might not have typically taken part in qualitative interview research.

I became visible and well known in an area in Bristol where a lot of Somali families live. By embedding in the community and becoming categorised by a participant as "*one of us now*" I

found that by walking to the community centre I would often be stopped on the street by individuals who recognised me and wanted to discuss the study. People also suggested other individuals who fit the recruitment criteria and might be willing to talk to me. Similarly to above, this community 'endorsement' of the study, and by being a visible presence, allowed confidence to be built and people were interested in taking part in this study.

A medical student completed a summer placement with the department and interviewed eight individuals for the community influencer work. The medical student has a wide network of social contacts from different cultural backgrounds, and utilised these networks to gain different perspectives for the community influencer interviews, through an established rapport with the participants.

7.10.2 Limitations

7.10.2.1 Limitations of a Multi-Method Thesis

A key limitation of the overall multi-method approach taken in this thesis is the lack of integration between the separate studies as each component aimed to look at the phenomena from a different perspective and had different research questions, but were attached to the overall study aim. In multi-method research, integration is not required throughout due to the lack of dependency on other components (287) and the nature of the studies (290–292,399). An alternative could have been a mixed-methods design in which qualitative data could have been collected after quantitative; for example a survey (in schools to investigate disabling fatigue, or in the CFS/ME clinic) with follow up interviews and focus groups for survey participants to explore their answers in depth; however due to time constraints, this may not have been feasible within the three year limit of this PhD research. Instead, different data sources were used and it is unknown if any young people interviewed from the clinic had also consented to take part in the trial, and therefore participants may, or may not have taken part in multiple elements.

7.10.2.2 Systematic Review

The papers included in the systematic review may have been subject to self-selection by the participants and how participants were recruited to take part in the studies included in the systematic review are unknown and therefore it is unclear how this might have impacted the

results and the generalisability of the findings. In addition, due to time and budget constraints, only papers published in the English language were included, potentially leading to relevant papers not being considered.

7.10.2.3 Quantitative Data Analysis

This study aimed to investigate the baseline characteristics of children and young people with CFS/ME to see if there were any differences in those from ethnic minority groups compared to those from non-ethnic minority groups. However, due to the small sample sizes of children from ethnic minority backgrounds, I did not have statistical power to look for differences between the two groups, therefore descriptive analyses were used. This small sample size of ethnic minority children in the data sets was despite one trial being the only CFS/ME management available for children due to the lack of CFS/ME specialist services in some areas of the country (293–295). Ultimately the data sets could not answer the research question as there was insufficient power and the data were from young people who were diagnosed with CFS/ME, received a referral to specialist services and were recruited into a clinical trial. Those recruited into a trial are likely to be different to those treated in a clinical service. Therefore these underpowered data sets were only able to provide descriptive data on children and young people from ethnic minority backgrounds who were recruited into a treatment trial.

Despite the large sample size and high recruitment rate of one of the trials, the data analyses on these data sets demonstrated that very few children from ethnic minority backgrounds were recruited into these trials. I do not know if this reflects the low numbers of ethnic minority children attending the service, as we do not know if the number of ethnic minority children seen in the trials is less than the number seen in the clinic, or if this data is biased. Additionally, due to the small sample sizes of ethnic minority participants, I did not have statistical power to look for differences between the two groups.

There are several reasons the trials data could be biased including: ethnic minority children may be less likely to be approached or recruited into a trial, or they may be less likely to get a diagnosis of CFS/ME and referred to specialist services (reducing opportunities to take part in research). Additionally for the SMILE trial, participants were excluded if they, or their parents, did not have sufficient English language skills to understand the patient information

sheet and consent form (331), which could have been a further barrier to participation for ethnic minority children.

Furthermore, trial participants may not be representative of their non-participating peers. Those included in the data sets chose to take part in the research, and individuals who identify as being from an ethnic minority background are often underrepresented in health research, especially RCTs (161,162,400).

There are further limitations with the quantitative work, which should inform future routine data capture in clinical settings. Ethnicity was not accurately recorded due to the limited or overlapping categories patients could select. Patients may have selected "British" as that is their nationality and their personal affiliation and citizenship, rather than selecting the category that best matches their ethnicity. In addition, there is heterogeneity and differences between individuals who classify themselves as belonging to the same ethnic group as "*such broad categories may not fit with self-identity of ethnic group*" (3)(p.442). Therefore, broadly grouping all ethnic minority individuals together in the analysis may ignore important ethnic variations both within and between ethnic groups.

For the statistical work, it would have been informative to investigate routine NHS clinical data collected from secondary services, but due to the lack of paediatric CFS/ME services this may not have been representative of the true prevalence as with only 12 available services, most children in the UK do not have local access (112). Analysing GP records could also have been useful to understand ethnic differences in the presentation of fatigue, but due to resource and time limitations, this was beyond the scope of this PhD project. It would also have been informative to understand ethnic differences in declining to participate in the clinical trials, to understand if potential participants from different ethnic backgrounds are more or less likely to consent to take part in the trial.

7.10.2.4 Qualitative Interviews and Focus Groups

For the qualitative work, recruitment relied on self-selection into the research studies; only those willing to be involved in research might have chosen to take part, although by becoming well known I attempted to mitigate this. In addition, I identify as White British, which could have influenced the willingness of participants to talk openly about sensitive

topics with those viewed as being outside of their community (314,325). Conversely participants also spoke about high levels of stigma from within their community, so by not have identifying as part of the community could have been a strength to enable discussion. In addition, the medical student who conducted community influencer interviews shared a cultural background with some of the participants, potentially increasing the levels of trust in the interviews.

7.10.2.4.1 Data Saturation

Data saturation is an important methodological principle in qualitative research, defined as "*the point in data collection and analysis when new information produces little or no change to the codebook*" (342)(p.65). Reaching data saturation is a rationale for discontinuing recruitment of participants and further analysis (401), is a marker of "*qualitative rigor*" (402)(p.587) and is seen in quality criteria guidelines of academic journals (403). The small number of participants recruited, due to disruptions from the COVID-19 pandemic and wider difficulties with recruitment, meant that data saturation was unlikely to have been reached in the young person, family and medical professional interviews. The explanatory power of the themes identified might therefore be limited. However, as similar themes were developed in the data from participants, the descriptions of the themes identified through my study are likely to be valid, but the lack of additional data is likely to have reduced the explanatory power of the themes as well as their granularity and richness.

Despite a larger sample size for the community influencer interviews, data saturation was also unlikely to have been reached, as data saturation is not just the amount and richness of the data, but also who participated in the research, in terms of adequate and appropriate sampling (402). Although no new codes or themes were identified from the data during the last interviews, there was a dominance of data from the Bristol Somali community and additional data could have yielded more nuanced findings and potentially identified differences between ethnic groups.

Further interviews with young people, family, community influencers and medical professionals could have identified other themes and insights if recruitment had been continued. In relation to the research questions, the amount of data I collected provided

useful initial descriptions of concerns, uncovered interesting and original insights, and provide the basis of future work in this topic area.

7.10.2.4.2 Focus Groups

Focus groups were also used to explore attitudes and perceptions of mental health and ill-health held by community members. They were chosen as individuals might have attended a focus group and discussed their views within a group setting, rather than committing to an individual interview (315). The inclusion of focus group data was a pragmatic decision taken to address the lack of data from the target group and enhanced my understanding around access to care. The focus group study was designed to elicit views, experiences and perceptions on mental health and illness, a topic that in some minority ethnic communities as in the mainstream population is heavily stigmatised. CFS/ME is often wrongly associated with mental illness and likely to be equally stigmatised. The findings from the additional discussion points must therefore be interpreted with caution and place considerable limitations on the overall findings (as also discussed in section 7.8 Project Integration) because the focus group data were different in the following ways:

(1) Participants were from a different group than originally planned and were self-selecting:

Focus group members had been invited to a focus group to discuss issues around accessing mental health support. This may have influenced those choosing to take part, for example it may have increased those with lived experience of mental health problems. However only one person in the group described experiences of a family member with mental ill-health, and the participants normally met at the community centre so it is possible they were representative of the Somali community who met at the centre. There was a volunteer bias, with participation in the focus groups dependent on those able and willing to take part in the group discussions but, through the use of CBPR methodology in partnership with community organisations, those who might not have typically taken part in a focus group study could have joined through 'endorsement' of the study from the community partners. During the running of the focus groups, most participants chose to speak in the Somali language, and therefore a synchronous translation from Somali to English was relied on, which could have affected the ability to guide the focus group discussions in response to comments from the participants (404). To maximise the reliability of the translated study data, the same male

interpreter was used for the two male focus group discussions, and the same female interpreter was used for the female groups (405).

(2) Different research focus:

Another key limitation is that discussing fatigue within a focus group on mental health could have influenced the answers participants provided. For example, participants could have discussed fatigue related to mental health problems. However, the detailed discussion in the focus group around barriers to accessing healthcare merits the inclusion of these data to understand from a lay perspective, experiences of accessing healthcare and perceptions of fatigue. During the process of triangulating findings from my analysis of the focus group data with the interview data, it was evident that themes were shared amongst focus group and community influencer participants, especially around access to healthcare and the focus group data provided insights that complemented the interview data. This consistency across different data sources suggests there is some validity in the findings.

(3) Different qualitative methods:

I also recognise the limitations of bringing together qualitative data from two different data collection methods in in this thesis. A pragmatic multi-methods approach (318) was taken to maximise the number of participants and participant groups in order to seek a wider range of experiences and enhance understanding around access to care. Although combining data from interviews and focus groups can provide complementary data on a phenomenon, enhance data richness, and contribute to a more complete understanding (318), interviews and focus groups are different methods of data collection and the data generated are not interchangeable. Analysing focus group data differs from analysing interview data, as an additional consideration in focus group analysis is the data generated through interaction between participants, and the overall group dynamics (315). With focus group data, there are additional analytic opportunities, for example consideration of the influence of group dynamics and how some members of the group may have influenced individual contributions (304,315). This is particularly evident as in one focus group, a male participant self-identified as a "leader" in Somalia. Although during the focus group I aimed to include all participants, the presence of this individual might have changed the dynamics of the discussion, as other group members may have not felt comfortable challenging, or disagreeing with, the views of a "leader".

7.10.2.4.3 Qualitative Interviews

The sample size for the qualitative interviews was smaller than planned due to recruitment limitations. Due to the issue of a lack of ethnic minority children in specialist services for CFS/ME, there was a limited potential recruitment pool to begin with, along with challenges of engaging young people in research studies (406). Multiple strategies of increasing recruitment were tried, such as: using different clinicians to recruit, giving participants time to think about taking part in the study, and reminding potential participants about the study on multiple appointments. This was further compounded by the COVID-19 pandemic as families had verbally agreed to take part prior to the pandemic and UK Lockdown in March 2020 but these participants either did not reply to further contact or due to life events could not take part. The health and wellbeing of participants in the study was a priority and I was careful not to put participants under any further stress with taking part in the study during the pandemic (407).

It was difficult to arrange interviews with some families. In total nine 'consent to contact' forms were received from the CFS/ME clinic but only seven families were able to be contacted and eight participants were interviewed from the clinic (five mothers/carers and three young people, from four families). This could be due to a number of reasons including that participants might have been too busy to take part in the research study. This was mitigated through being very flexible with timings, with interview times offered during evenings or weekends. Secondly one young person could not take part because they had become more severely ill with CFS/ME and I did not want to burden them. I was very aware that asking an unwell child to take part in an interview study was burdensome and therefore I made sure the family had my contact details and to get in touch if they felt that their child had recovered enough to take part in an interview. Finally some participants might have said yes to being contacted but on further consideration decided that the study was not right for them due to a myriad of reasons. I contacted potential participants three times and if I did not hear from the potential participant, I assumed they had declined to take part in the study and ceased communication attempts.

In addition, only mothers and female carers took part in the family interviews, no fathers, so the results are missing a key insight into the journey the young people with CFS/ME took to

get to the specialist services. Fathers spoken to on the telephone, when discussing taking part in the study, commented informally that their wife "*knows more about that than me*" and "*you better speak to her*". It would have been informative to further investigate these views from the father's perspective to understand their role in seeking healthcare for their child as there has been very little literature looking at the different roles mothers and fathers play. Although this study found that both mothers (from clinic participants and community influencers) and fathers (from community influencers and focus groups) said that they would take their child to the doctor, there might be further gender roles that influence who takes control of this care.

Finally I did not recruit any children suffering from fatigue who had not been referred to the CFS/ME service. Despite becoming a visible presence and building trust and relationships, and by asking contacts, I was unable to recruit any children suffering with disabling fatigue who had not been diagnosed with CFS/ME. During the course of the project I was approached but none of these individuals were willing to be interviewed. The results of the qualitative work found that stigma and cultural factors are important barriers; therefore these families may not have been willing to talk to me due to potential community stigma of having a child with disabling fatigue.

This work was intentionally broad due to the exploratory nature of the study, and looked at ethnic minority children in general. Ethnic minority groups were broadly classified and may have ignored diversity in the 'communities' or individuals who participated in this study. It is important to note that there are differences both within and between ethnic minority groups and that the barriers identified are not solely unique to ethnic minority individuals, as illustrated in this discussion section (23). Despite this, participants in a study looking at the barriers to accessing adult CFS/ME studies reported that barriers can be more pronounced in ethnic minority groups (23), so although some of the same barriers may be present in ethnic minority and non-ethnic minority (White) children, certain barriers may be more pronounced in ethnic minority children.

In the qualitative interviews with families and young people who had been diagnosed with CFS/ME and had received a referral and accessed specialist services, participants were asked about past events and their journey, in terms of what they thought 'should' have happened or what 'could' have made the journey easier. With the families and young people who

participated there could have been degradation of memory or a bias for or against certain medical professionals, or a part of their journey, as for some families it had been many years since diagnosis. For medical professionals and community influencers, the participants were asked theoretically about what they thought 'could' help. Due to this, the participants were talking generally, not specifically, in contrast to the clinic participants who were able to describe their journey in detail and provide ideas for recommendations based on their past experiences.

Virtual interviews were conducted with some participants and this was a strength as it meant these participants could be included in the study and their views captured, however important communication cues, for example eye contact, were lost due to the technology barrier (408). Some young people might have been hesitant to speak in a virtual interview, whereas other participants might have spoken more freely due to a perceived 'distance' created by the screen. Furthermore, in all family interviews, parents/carers and young people chose to be interviewed together. In some interviews the parent would speak more than the child, whereas in others the parent would prompt the child to speak. This was mitigated through asking direct questions to the child or asking their opinion after the parent had spoken, in order to capture their views on the subject area.

Finally, this study is situated in the UK, a country with healthcare free at the point of access to all eligible to receive it (296,297) and it is not possible to generalise these findings due to the location. The themes and ideas for interventions produced during this work may not be suitable for countries where healthcare has a high cost or the medical system is organised differently. In the UK, GPs provide referrals to secondary healthcare (specialist services) and patients cannot self-refer (296); in comparison with some countries where patients can have the option of selecting the specialist they would like to see, and directly arrange an appropriate appointment (409).

7.11 Ideas for Future Research

This is the first study to date to look at ethnic minority children and access to specialist CFS/ME services and has provided an overview of the barriers and facilitators. This work was exploratory in nature and looked generally at the barriers and facilitators from different

diverse viewpoints. Despite the novel findings and promising results from this thesis, questions still remain and future research should be conducted in this topic area, with the following suggestions for study designs.

1) Different Locations

Future work is required to investigate the barriers and facilitators in areas with different availability of services, for example rural-urban differences, in different locations of the UK. This work is South West England specific and there are issues with generalising the findings. Firstly, there is the availability of specialist paediatric CFS/ME services in this location and different barriers may present in locations without access to specialist CFS/ME services. Secondly, Bristol is an increasingly ethnically diverse city, with 16% of the population of Bristol identifying as from an ethnic minority, up from 8.2% in 2001 (410), with 187 countries of birth and 91 main languages spoken by those living in Bristol (410). There are numerous charities and healthcare services providing initiatives in Bristol with an aim to ensure everyone is able to access healthcare; different locations, with different availability of services, may find different healthcare access barriers. Future work could be undertaken in other areas of the country where there is a large ethnic minority population and also CFS/ME specialist services, for example London, to see if similar access barriers and facilitators are found. Alternatively, future studies could also be located in areas with different levels of cultural and ethnic diversity, or with a lack of available services.

2) Different Ethnic Groups

A key limitation of this work is that it investigated ethnic minority individuals generally and did not focus on one particular ethnic group, which may have ignored differences between ethnic groups. To develop a full picture of the barriers facing ethnic minority children, future research could consider focussing on one particular ethnic group to understand the barriers and gain specific recommendations, tailored to particular ethnicities and communities (306).

3) Different Methodology

For this project, qualitative interviews were conducted with participants after they had gained access to specialist CFS/ME services. A future study with more focus on a longitudinal design is therefore suggested, as time had elapsed since clinic participants had experienced the journey to accessing specialist CFS/ME services. Future work could identify young

people with disabling fatigue when they first present to a GP and follow their medical pathway.

4) Implementing 'Ideas to Improve Access'

Further work is also required to establish the viability of the participant suggested interventions. Ideas such as improving knowledge of CFS/ME in various formats could be piloted and trialled in locations such as schools, or the community, along with providing information to healthcare professionals about the symptoms of CFS/ME and how it may present in children.

5) Terminology

This study found that community leaders did not like to be called leaders and instead preferred the term 'community influencers'. Future work is needed to investigate the use of the term 'community leader' further and also to research if similar results are found in different geographical locations and across different ethnic groups.

6) Different Conditions

A final suggestion for a future research study could compare the barriers and facilitators identified in the qualitative work conducted for this study against other difficult to diagnose chronic hidden health conditions. This would enable researchers to identify if the barriers, such as stigma, alternative explanations, and issues with accessing medical care are identified generally amongst ethnic minority children with chronic hidden health conditions, or if the barriers identified in this work are CFS/ME specific.

7.12 Implications of the findings from this thesis on policy and practice, and for healthcare practitioners.

The findings from this thesis have several implications for policy, practice and for healthcare professionals. In the UK, healthcare is free at the point of access to all citizens/residents who are eligible and need to receive it, through the NHS (296,297) but the findings from this thesis highlight that the UK healthcare system may not be responding to the needs of ethnic minority individuals. This is not a new finding, as previous work has found there is not

equity in coverage (157,298) and the UK Equality and Human Rights Commission Report (159) recognises that there are disparities in healthcare access and outcomes amongst ethnic minority individuals. The NHS and the UK Department of Health and Social Care (DHSC) have introduced various reports and initiatives to try and improve equal access to healthcare services for ethnic minorities (202,299).

8.12.1 Healthcare Policy Context

This thesis aimed to identify the key barriers and facilitators to access and therefore the findings will be relevant to future policy development and implementation. The relationship between academic research, government policy officials and the resultant policy, is opaque. How different government departments interact with academic literature and academia in the formulation of policy is unclear, and often not as strong as it could be owing to policy makers identification of relevant experts and literature, and a lack of academic networks that policy officials can draw upon (411). The findings of this thesis must therefore be considered within the context of the academic – policy divide.

Nonetheless, research findings provide excellent evidence that has, in the past, contributed to policy making decisions (412) as to address healthcare access, policymakers need to identify the barriers between patients and the healthcare system (413). Research can influence policy and practice at different time points, for example a short term impact could be improving policy makers' knowledge, medium term could be the impact of research on revising existing policy or developing new policy and long term impacts may be implementing policy or evaluating existing policy (414). Concrete steps could be: using the research findings of this thesis to support government interventions via submissions to Select Committees, calls for evidence and consultations, for example the upcoming 'Transforming the public health system: reforming the public health system for the challenges of our times' (415). These forums present a unique opportunity to influence policy at an early stage of development and foster academic – government relationships which will be critical in helping further academic research influencing policy outcomes.

It is important to note that healthcare "*policies aimed at improving access will work only if they address the source of inequities which means identifying the key barriers to access and these barriers are unlikely to be uniform across sectors, services and groups of people*" (416)(p.205). For example, to address inequities in GP access, NHS England has produced a

guide to promote understanding of barriers for groups in the local community and help address barriers through improvements in access to GP services (417). The guide provides examples of barriers at different points on the patient pathway and 'practical tips' (417) for GP practices to implement.

8.12.2 How this research can directly inform future policy

Despite the work for this thesis taking place in a specific location, and therefore not generalisable to the overall UK population, the findings from this thesis can contribute to policy and practice as identifying the barriers "*requires small-scale, in-depth qualitative research*" (416)(p.205) as without these insights from qualitative work, "*there is a danger of designing policies that appear to be sensible and straightforward (e.g. targeting resources at the most deprived areas), but in practice fail to achieve the predicted results*" (416)(p.205).

The findings from this thesis show multiple barriers to accessing CFS/ME services for ethnic minority children at multiple levels and policy makers need to be aware of these findings as they add to the evidence base that there is not equal access for all. Specifically relevant to policy and practice, and healthcare professionals, the findings from this thesis suggest the following should be targets for policy and practice interventions:

1. Knowledge and awareness of CFS/ME amongst practitioners and healthcare professionals

The importance of practitioners and healthcare professionals to be aware of paediatric CFS/ME and the presentation of symptoms in the consultation, the availability of specialist CFS/ME services and referral pathways and also guidance for the diagnosis and management of people with CFS/ME. Overall findings suggest there is a lack of knowledge of CFS/ME amongst both the general population and healthcare professionals and there is an urgent need to provide training to healthcare professionals on CFS/ME.

2. Knowledge and awareness of CFS/ME generally and access to healthcare services

Ethnic minority families may benefit from accessible culturally tailored information to improve knowledge, understanding and access to available healthcare services (418), specifically related to CFS/ME. However, any education should acknowledge different worldviews and should be a two-way process involving "*intercultural exchange rather than cultural imposition*" (419)(p.597).

3. Practitioners and healthcare professionals understanding of cultural contexts

Healthcare professionals also need to be aware of the different constructs in which illness may be experienced, or attributed to. As found in this work, some individuals may not view fatigue as an illness and therefore medical professionals need to be aware that the symptom of fatigue may not be mentioned in the consultation. Some patients may be hesitant of a CFS/ME diagnosis, due to cultural factors related to stigma surrounding the condition and the legitimacy of CFS/ME, whereas other patients may push for a diagnosis. There is also a need to improve the cultural competence of healthcare professionals to understand the role of culture in an individual's illness experience.

4. Policy makers understanding of local needs

In areas with large ethnic minority populations, healthcare policy makers and local authorities need to be aware of cultural contexts to ensure equal access for all. There is a need to consider specific cultural needs of local communities (418):

"*We have to consider how a patient understands their diagnosis, their beliefs about health in general, their views and knowledge of the healthcare system and how their religious beliefs might play a role in their interactions with and access to healthcare. Systems should be put in place for healthcare providers to recognise these potential barriers and provide robust policies to tackle them*." (418)(p.37)

5. Use of interpreters in healthcare appointments

In the medical consultation, to ensure equality in care, there needs to be adequate UK policy guidance and standards in place to avoid informal interpreters and to always encourage using formally trained medical interpreters (418) to reduce cultural stigma and improve trust in the medical appointment. Formally trained interpreters are important for patients and families to be assured that they can accurately communicate their symptoms and to understand a diagnosis and treatment or management options (420).

6. Improve routine data capture and monitoring of services

There is a need to improve routine data collection in clinical settings for future work to investigate access to healthcare for different demographic groups. A Public Health England (PHE) report recommends that patient ethnicity should be made mandatory in NHS routine data collection (365,366). Future work, and routine NHS data collection, should consider the

use of using the Census categories when asking an individual's ethnicity, to avoid vague categories, and self-reported ethnicity is recognised as the preferred option, rather than observer assessment (363). There is also a need to include "*mandatory monitoring*" (418)(p.37) of the experiences of those accessing healthcare, "*due to the variety of demographics across the UK, it is logical for local CCGs to track and review their interpreter use and patient outcomes*" (418)(p.37).

7. Monitor the use of virtual consultations

Finally, during the COVID-19 pandemic, the vast majority of primary care appointments changed to virtual consultations (421). This could have the unintended impact of amplifying existing healthcare access inequalities (422) due to the impact of language and cultural barriers in a digital/virtual appointment, alongside access to technology and IT literacy (418,422). Policy makers should be closely monitoring this change to virtual consultations to ensure equity of access to healthcare (418).

7.13 Reflections on the PhD

During the course of the PhD, and during this writing up of this thesis, I have been reflecting on what I have discovered and learned throughout the process, in terms of both the findings from the thesis work, and what I have learned personally, in terms of carrying out a research project and what I could have done differently. Initially I was drawn to the project due to the topic area and the potential to discover avenues for change that could improve equality. Reflections on the study design are also included in Chapter 4: Methodologies.

I believed that recruitment to the qualitative interviews would be an easier process that it was, and I had presumptions about taking part in research. To start with, I assumed the term "*community leader*" was a widely used term. Exposure to the term in the media, and through previous academic work, had highlighted the use of the term in recruiting participants to capture the views of a particular 'community'. It quickly became apparent that this term was unacceptable to participants during the qualitative interviews and I was able to capture why. On reflection I realised that I would personally not know who my "community leader" was,

and therefore the term could be problematic by assuming those from minority ethnic groups have a “community” and a “leader”.

I also had a lack of knowledge of community structures. I believed that by engaging with community leaders this could engage a “community” in the research process, but I realised that trust and relationships needed to be formed. In addition, I reflected on my role as a White British researcher and how that could have impacted the research process.

Although PPIE was used throughout the projects in this thesis, as I recognised the need for inclusive and culturally sensitive research, it would have been helpful to have taken the results of the qualitative work to an advisory group for their perspectives on the findings. A combination of the COVID-19 pandemic and a lack of resources hindered my ability to do this. A common challenge is the resources required for PPIE in terms of cost (165) and adequate funding and resources for PPIE activities is key (306,423). Funding is a particularly common challenge in doctoral studies, with many doctoral programs not having allocated PPIE funding (164). This is a challenge I experienced throughout the research process and it would have been helpful to have set up an advisory group, or the inclusion of community co-researchers, to aid recruitment, data analysis and dissemination of the research findings.

7.13.1 Acknowledgement of the Research Process: The impact of COVID-19 on this Research

The research for this thesis has taken place between 2017-2021 and has been subject to disruption from the COVID-19 (33) pandemic in the final year of research, resulting in a smaller sample size than was originally planned. Families, community leaders and medical professionals had either agreed to take part or shown interest in the study prior to the pandemic and UK Lockdown in March 2020, but these potential participants could not take part due to life circumstances, such as additional demands on parents and families due to home schooling, or they did not reply to subsequent communication. Further recruitment was factored in, but this was limited, and my sample size for the thesis is smaller than I initially hoped for. It would have been valuable to include the perspectives of additional participants. The health and wellbeing of participants in the study was a priority and I was careful not to put participants under any further stress with taking part in the study during the pandemic (407).

In addition, this thesis was written during large scale demonstrations and global protests in support of the Black Lives Matter (BLM) movement (34). This occurred at the same time as the disproportionate effect of COVID-19 on those from ethnic minority backgrounds was identified (35,365), with racism, discrimination and social inequality being cited as factors that could have contributed to the higher risk to those from ethnic minority backgrounds (365,366).

7.13.2 What elements of the thesis could have been conducted differently?

In addition to the Ideas for Future Research (section 7.11) and my reflections on the research process (section 7.13), I have been reflecting on what elements of the thesis would be done differently if I was starting again.

7.13.2.1 The term 'CFS/ME'

If I was redesigning this study, I would not have focussed on the term 'CFS/ME' when interviewing community leaders and instead would have focussed on 'tiredness' or 'fatigue'. As seen throughout the presentation of results, CFS/ME is a stigmatised, contested, hidden condition and therefore by inviting 'community leaders' to an 'interview' about 'CFS/ME' participants may have found this challenging, not known what to say, and could have assumed that they *should* know about this condition.

7.13.2.2 Recruiting Children with Disabling Fatigue

I focussed on PPIE work at the start of the project when designing study materials, to ensure that they were clear, easy to understand and culturally acceptable and sensitive. I did not focus the PPIE work on how to approach and recruit study participants and how to structure the project. If I was redesigning the study, I would have incorporated a CBPR approach (306,308,309,351) from the beginning in collaboration with community groups. I would have considered using a community co-researcher to recruit those suffering from disabling fatigue and not accessing medical care. I was unable to recruit any children suffering from disabling fatigue and a community co-researcher could have enabled this through knowledge of community structures and trust with potential participants, although this would have required careful consideration due to the stigma around the symptom of tiredness found in

this thesis. However, the use of community co-researchers can aid trust in a study and could have improved recruitment (29,424).

I used data from focus groups that I was running to enhance my understanding around factors that influence help seeking and access to care. This was essentially a convenience data sample to understand the issues from a different perspective. Alternative approaches (that were not possible because of capacity and then the pandemic) would have been to run focus groups entirely on fatigue or physical health, or continued to try and recruit families with fatigued children who had not accessed help.

Additionally, due to ethical considerations, I did not explore recruitment of those suffering from disabling fatigue through schools to ensure anonymity of study participants. However, I could have carefully planned to distribute information about the study through schools, for example a school newsletter with interested participants able to contact me. I would also have considered recruiting teachers to take part, to understand how common disabling fatigue is from their experiences and how many ethnic minority children access medical care for fatigue symptoms.

Recruiting children suffering from disabling fatigue through social media was also considered, but this has typically not been an effective recruitment method for healthcare studies (425). Recruiting through social media can only loosely target participants on their demographics and was discounted as a recruitment strategy for this work due to: the need to recruit from the Bath/Bristol area, the risk of sampling bias through excluding those who do not use social media or do not have access to technology, ethical considerations, and recognising privacy concerns of those who may be targeted via social media recruitment (426).

7.13.2.3 Quantitative Project

I have also reflected on the quantitative project conducted for this thesis. As discussed in Section 7.10.2.3 (Limitations), the data sets used were not the most appropriate sources of data for my research question and my aim of investigating the characteristics of children who access CFS/ME services. Ultimately for this PhD these data sets were the largest paediatric CFS/ME data sets available, but they were not NHS patient data and they had small numbers

of ethnic minority children. Equally, the data were from participants recruited into a clinical trial, which meant that it was not routine NHS clinic data and could not answer my research question.

A key learning point, that I have been reflecting on, is choosing appropriate data sets. For the quantitative study, I should have checked the data sets that I received were appropriate to answer my research question and address my research aim before commencing analysis. It is a recognised issue when conducting secondary analysis of a data set that if the research is studying a specific subpopulation, there may be too few cases to conduct the desired statistical investigations (427). Checking the data sets before commencing analysis would have alerted me to the fact that there were few ethnic minority children included. Whilst I could not have looked at the FITNET-NHS data when designing the analyses, (as recruitment was ongoing), I could have examined the MAGENTA and SMILE data before conducting the analyses. In the future, when conducting secondary analyses of unfamiliar data sets, I would firstly perform some initial statistics to check the data available and if the data sets are appropriate. If the data are not available to check before commencing analysis, I would read trial protocols and talk to the Principal Investigator, or those working on the trial and who collected the data, to understand exactly what the data sets include and the extent of missing data.

I have considered other approaches to answering this research question in the future. Possible approaches include: a) prospectively recruiting those from ethnic minority backgrounds (with CFS/ME) into an observational study to collect symptom data, or b) using routine symptom data from patients seen in clinic with consent. Potential issues include: a) prospectively recruiting patients may be biased as those from ethnic minorities may not be approached or consent to take part in research (161,162,400), or b) identifying potential participants in clinic to use routine symptom data depends on clinician identification of ethnicity in clinic. Neither of these methods is likely to capture all children in specialist CFS/ME services, as participants may not take part in an observational study or may not consent to their data being shared for research purposes. One final approach would be to use routine clinical data without consent but this would still require the identification of participants which would be imperfect using NHS data on ethnicity (see Section 7.3 for the reasons why).

7.13.2.4 Recruiting Children with CFS/ME and Medical Professionals

Due to difficulties with recruiting medical professional and family participants to the study, it could have been valuable to interview CFS/ME clinicians working in the service for their perspective on ethnic minority children with CFS/ME and if they perceived any differences in symptoms, although the low numbers of ethnic minority children in the service could have limited the experience the clinicians had with this population.

To recruit ethnic minority children with CFS/ME who were accessing specialist services, I could have considered carrying out a multi-site study in collaboration with CFS/ME clinics in other locations, for example London, to increase the number of potential participants and investigate differences in access in different locations.

If my project would have been eligible for NIHR support, I would have used Clinical Research Networks (CRNs) to recruit GPs, instead of snowball and convenience sampling. The research in this thesis was funded by the University and was not eligible for NIHR CRN support and if the study would have been eligible, this could have been utilised for recruiting medical professionals from GP practices in the local area who were interested in taking part in the research study. I could also have considered working with primary care networks at the University to publicise the study to medical professionals. Additional resources available for the study would have also enabled reimbursing medical professionals and community groups for their time and could have increased recruitment to the study.

Ultimately, if I was starting again with this thesis I would have: checked the data sets that I received were appropriate to answer my research question and address my research aim before commencing analysis; worked closely with teachers and community co-researchers to recruit children suffering from disabling fatigue; partnered with different CFS/ME services to recruit ethnic minority children with CFS/ME; and identified and utilised alternative networks to recruit medical professionals.

7.14 Closing Remarks

This multi-methods thesis has provided a comprehensive overview of the experiences young people with CFS/ME from ethnic minority backgrounds experience when accessing specialist services. Barriers and facilitators were covered in the qualitative work aiming to understand what did help (or could help) ethnic minority young people accessing specialist services, and what hindered them, or could have hindered, access.

This work is the first study to investigate the experiences of ethnic minority children with CFS/ME and the barriers and facilitators to accessing specialist healthcare services and ideas for interventions, to improve equality in healthcare access for all. The inclusion of substantial qualitative work in this research allowed the participants' voices and their personal journeys to be heard. The participants explored numerous, interlinked barriers that limit access at multiple levels.

Ideas for interventions were asked of the participants, and knowledge and awareness initiatives to increase understanding of CFS/ME as a medical condition were considered valuable. The recommendations from study participants to improve access provide a basis for future work.

This thesis has made a unique contribution to the literature and expands the knowledge base in the following areas:

This work is important to improve equality and this is the first study, to my knowledge, that has been carried out looking at ethnic minority children and access to CFS/ME services. As this systematic review illustrated, chronic health conditions and ethnic minority children is an under researched area of the literature. This PhD project has aimed to fill part of this knowledge gap.

Quantitative analysis of data from those who had accessed specialist CFS/ME services and been recruited into a clinical trial showed ethnicity data capture might not be specific enough and therefore it is challenging to investigate differences between ethnic groups. Additionally, results confirmed a lack of ethnic minority children in CFS/ME specialist services and

recruited into a clinical trial, despite research showing a higher prevalence rate of CFS/ME in ethnic minority adults (56,67,166,168–173).

The qualitative results show that there are potential interlinked barriers at every level, from recognition of the condition, to deciding to seek medical care, to barriers in the GP consultation and receiving a subsequent referral to specialist services.

A variety of recruitment methods are proposed in order to reach participants. Different recruitment methods may be needed to engage with communities, build trust with research projects, and engage those who typically would not take part in research studies. Community consultation and careful use of terminology to ensure a varied and representative sample in all aspects of future work is important and this thesis provides guidance and examples of how terminology can hinder recruitment, and therefore the validity and representation of research study participants.

The combination of projects in this thesis provides ideas for updates to a barriers to help seeking model for CFS/ME. The updated barriers to healthcare model that is proposed, along with facilitators and ideas for interventions from the study participants should form the basis of a future intervention aimed at improving access to specialist CFS/ME services.

Early intervention in paediatric CFS/ME leads to improved outcomes for the patient, and a decreased cost for the NHS. Management for paediatric CFS/ME is moderately effective with up to 66% of treated children making a full recovery compared to 8% of controls (120). Therefore it is vital that these young people receive appropriate medical care. In addition, improved access to services and management is likely to improve the health of ethnic minority children and the wellbeing of families; this could be through reduced time off school and reduced work absence for parents. NICE guidelines (30,32) for the management of people with CFS/ME emphasises that management should be started early (31). Therefore barriers to children and young people with CFS/ME accessing specialist services, need to be addressed to improve the prognosis for the patient and improve equality in NHS access; future research is needed in chronic health conditions in paediatric settings, especially for ethnic minority children. Finally this work has the potential to benefit other paediatric

services, with a potential extension to other chronic health conditions. Future work is of paramount importance to implement solutions to improve equality with access to healthcare.

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9. Appendices

9.1 Systematic Review Search Strategy

Description	Search Terms
Ethnicity	1. exp Ethnic Groups/ 2. (Black or BME or Indigenous or African American or Native American or Maori or Aboriginal or Asian American Hispanic American or Emigration or Immigration or refugee* or race or ethnicit* or culture or asylum seeker* or undocumented migrant* or minority group* or cross-cultural comparison).ti,ab,kf. 3. ethnic minorit*.ti,ab,kf 4. 1 or 2 or 3
Child/ Adolescent	5. adolescent/ or child/ or child, preschool/ 6. (paediatric* OR pediatric* OR highschool* OR high school* OR secondary school* OR student* OR youth* OR young OR teen* OR prepubescent* OR pre-pubescent* OR pubescent OR puberty* OR preadolescent OR pre-adolescent OR adolesc* OR minors* OR juvenile* OR schoolage* OR school-age* OR kids OR child* OR young adult*) 7. (parent* or mother* or father* or grandfather* or grandmother* or sister* or brother* or famil*).ti,ab,kf. 8. 5 or 6 or 7
Mental / Chronic Condition	9. exp Mental Disorders/ 10. chronic disease/ or multiple chronic conditions/ 11. ((mental or psychiatric* or psychological* or chronic) adj3 (condition* or disease* or problem* or health*)).ti,ab,kf. 12. 9 or 10 or 11
Barrier / Intervention	13. health services accessibility/ or health equity/ or healthcare disparities/ or Mental Health Services/ or Health Planning/ or Adolescent Health Services/ or Child Care/ or Community Health Services/ or Health Services, Indigenous/ or Rural Health Services/ or Urban Health Services/ or Delivery of Health Care/ or health disparit*/ or place-based disparities/ or access to care/ or risk factor*/ or child health services/ or cultural diversity/ or health services needs and demand 14. (health* adj3 (equity or disparit* or knowledge* or availab* or access* or program* or statistic* or barrier* or culturally competent* or attitude* or povert* or deliver*)).ti,ab,kf. 15. (intervention* or treatment* or programme* or service* or referral* or provision* or awareness* or education* or inform* or trial* or study* or studies* or investigat* or evaluat*).ti,ab,kf. 16. 13 or 14 or 15
Secondary / Specialist Health Service	17. (health* adj3 (secondary* or specialist* or tertiary* or referr* or consult* or appoint* or view* or diagnos* or special* or investing* or access* or availabil* or hosp* or serv* or clinic*)).ti,ab,kf. 18. (medical* adj3 (secondary* or specialist* or tertiary* or referr* or consult* or appoint* or view* or diagnos* or special* or investig* or

	access* or availabil* or hosp* or serv* or clinic*)).ti,ab,kf. 19. 17 or 18
Date	20. (2007$ or 2008$ or 2009$ or 2010$ or 2011$ or 2012$ or 2013$ or 2014$ or 2015$ or 2016$ or 2017$ or 2018$).ed,dc
Combined Search	21. 4 AND 8 AND 12 AND 16 AND 19 AND 20

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9.4 Information Sheet Example (Parent/Family)



University of BRISTOL

NHS

Chronic Fatigue Syndrome (CFS)/ME in Black and Minority Ethnic children and adolescents

Parent/Family Views

Parent/family (of child diagnosed with CFS/ME)
Participant Information Sheet
V2 20/06/2018
IRAS Project ID: 242160

We are inviting you and your child/family member to take part in a research study.
This study will help us to understand more about chronic fatigue syndrome or myalgic encephalitis (CFS/ME) in Black and Minority Ethnic children, and how we can provide help and support.

Before you decide whether you would like to take part, it is important to understand why the research is carried out and what it will involve. Please take the time to read the following information. If anything is unclear, or you would like more information, please ask.

Thank you for reading this

What is the purpose of the study?
This research project aims to understand the experiences and needs of children and adolescents from Black and Minority Ethnic (BME) backgrounds with chronic fatigue syndrome/ME, along with parent/family views. This project builds on research previously carried out.

Why have I been chosen?
You have been chosen as you have a family member from a BME background, who is aged between 11 and 18 years old, and has been diagnosed with chronic fatigue syndrome/ME.

Do I have to take part?
It is your decision whether or not to take part. You do not have to give a reason if you decide not to take part. If you do decide to take part you will be given a copy of this information sheet to keep we will ask you to sign a consent form.

What if I wish to withdraw?
You can withdraw from the study at any time and you don't need to tell us why, up until any data you have provided has been published. If you do decide to withdraw, any data we have collected from you will be removed.

What will happen to me if I take part?
You will be asked, with your child/family member to talk about your experiences and opinions living with a family member with chronic fatigue syndrome/ME and any medical care they have accessed.

The discussion will take place at your home, a CFS/ME clinic, the University of Bristol, or over the phone or Skype. The discussion should last around 45 minutes. If you give permission, we will audio-record the discussion and will later type up your actual words spoken for analysis.

What are the possible disadvantages and risks of taking part?

We don't think that the discussion will cause you any problems. You can take breaks during the discussion and can end it at any time.

Will my details be kept confidential?

Yes. It is very important that the information you give us is private.

When the interview is transcribed, any information that could identify you (such as locations or names) will be replaced with a code number or a general summary. We may use small bits of what you say when we report the study, but this will be anonymised and will not be able to be linked with you in any reports or publications.

The interviews will be transcribed by members of the research team and an external company which is approved by the University of Bristol and has signed confidentiality agreements.

Any data collected that could identify you will be encrypted and stored on a password protected computer or kept secure in locked cabinets in locked offices. Data will be destroyed in line with University of Bristol policies after 5 years.

We are very careful about how we use your data. For more information on the principles we follow, please see https://www.hra.nhs.uk/information-about-patients/

What will happen to the results from this study?

The University of Bristol research team will analyse the discussions independently, then discuss their findings to see if common themes emerge. The findings of this research project will be written up as part of a PhD thesis and may be published in a journal. If you wish to be given a copy of any reports resulting from this project, please contact the investigators.

Who is organising and funding the research?

This project is for a doctoral degree (PhD) registered with the University of Bristol and based at the Centre for Population Health Sciences, Bristol Medical School. The research is funded by a University of Bristol Research Scholarship.

Who is organising and funding the research?

This project is for a doctoral degree (PhD) registered with the University of Bristol and based at the Centre for Population Health Sciences, Bristol Medical School. The research is funded by a University of Bristol Research Scholarship.
The study has been reviewed by the South West – Central Bristol Research Ethics Committee.

Author personal details removed.

9.5 Consent Form Example (Parent/Family)

University of BRISTOL

NHS

Chronic Fatigue Syndrome (CFS)/ME in Black and Minority Ethnic children and adolescents

Parent/family (of child diagnosed with CFS/ME) consent form
V4 19/07/2018
IRAS Project ID: 242160

Parent/Family Member Interviews

Your child/family members name:

Please initial boxes if "yes"

I confirm that I have read the information sheet dated 20/06/2018 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

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 rights being affected.

I understand that relevant sections of my child/family member's clinical records and data collected during the study may be looked at by individuals from the Royal United Hospitals or from regulatory authorities, where it is relevant to taking part in this research. I give permission for these individuals to have access to my child's records.

I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.

I agree that my discussion with research staff can be recorded and notes can be taken

I understand the topic of the discussion

If you agree to take part, please complete the box below:

Your name	Date	Signature

We will give you a copy of this consent form. The consent form will be kept in a locked filing cabinet in a locked office in the University of Bristol.

9.6 Topic Guide Example (Parent/Family)

University of BRISTOL

Family Interview Topic Guide
V1. 07/03/2018
IRAS Project ID: 242160

Chronic Fatigue Syndrome (CFS)/ME in Black and Minority Ethnic children and adolescents

Interview Topic Guide – Family interviews

This topic guide details interview topics to be covered. The interviewer might also ask additional questions to clarify information.

Prior to the start of the interview:
The aim of this study is to understand children's experiences of disabling fatigue and access to medical services. This interview will be recorded, during transcription any details will be made confidential and informed consent will be carried out.

Part A: Information about illness

- What are your family member's main symptoms?
  - Do they have any other symptoms?
- How long have they experienced disabling fatigue?
- How many days a week are they able to attend school/college?
- How has the family changed since the child/adolescent has been unwell?

Part B: Information about medical care

- Do you (and your family) have a good relationship with a GP?
  - What are your experiences accessing medical care for yourself and your family members?
- Has XXX (your family member) visited a GP about your symptoms / how many times have they visited a GP about the symptoms?
- Have they received a diagnosis?
- What was their experience like visiting a GP?
- Have you consulted anyone else about their symptoms, e.g. a herbalist, spiritual healer?

Part C: Information about community

- Do you know anyone else in your community who experiences similar symptoms?
- How is fatigue viewed in your community?

Part D: Close

- Are there any issues you would like to raise that we have not talked about?
- Thank you for your time and contribution to this study.

Prompts: The following prompts may be used by the interviewer to explore certain answers in more detail:

- Can you describe that?
- Could you give me an example?
- Why did you do that?
- Could you tell me more about that?

9.7 HRA Approval Letter

Author personal details removed.

Dear Miss Linney

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Improving access to specialist CFS/ME services for Black and Minority Ethnic (BME)children**
IRAS project ID:	**242160**
REC reference:	**18/SW/0120**
Sponsor	**University of Bristol**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations in England and Wales that are recruiting GPs within their practice should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter. You should then work with each organisation that has confirmed capacity and capability and provide clear instructions when research activities can commence.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

9.8 REC Approval Letter

Author personal details removed.

Dear Miss Linney

Study title:	**Improving access to specialist CFS/ME services for Black and Minority Ethnic (BME)children**
REC reference:	**18/SW/0120**
IRAS project ID:	**242160**

Thank you for your undated letter 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 HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

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.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

9.9 Qualitative Analysis Draft Coding Framework

Barrier 1: Conceptualisation of CFS/ME	Understanding
	- Alternative explanations
	  o Vitamin Deficiencies
	  ▪ Specifically Vitamin D
	  o Diabetes
	  o Mental Health
	  ▪ Depression
	
	Awareness
	- Knowledge of the condition
	- "posh persons disease"
	
	Stigma
	- Stigma of the symptom tiredness
	  o Is it a medical symptom?
	  o Lazy
	  ▪ Gender roles – girls lazier
	- Stigma of a diagnosis of CFS/ME
	  o Is it a medical condition?
	  o Lazy
	
	Home Remedies for tiredness
	- Multivitamins
	- Exercise
	
	When would a doctor be consulted?
	
	Lived Experiences of Fatigue

Barrier 2: Cultural Factors	Close communities and families - Gossip - Look to others in the community for advice and support - Community consensus on conditions Alternative sources of help for symptoms - Religion - Alternative medicine Perceived closeness to a specific community - First generation vs. third generation - Talking to elderly relatives o Stigma invisible conditions

	○ Mental Health
Barrier 3: "Going to the Doctors"	The decision to seek help Doctor-patient relationships Unconscious Bias in Medical Appointments - Treated differently due to ethnicity CFS/ME Specific - Diagnosis ○ Multiple appointments ○ Different GPs each time ○ Other diagnoses before CFS/ME ○ "Tipping point" - diagnosed with CFS/ME ○ Who diagnosed child with CFS/ME? Referral - "fight" for referral - Vs. let medical professionals decide what's appropriate care General Barriers in Medical Appointments - Getting an appointment - Language - Understanding the system Going back to medical care once received a diagnosis
Facilitators	- Knowledge of condition - Family/friends for support - Support from GP / Medical Professionals - Support from school
Ideas to Improve Access	Healthcare System Improvements - More GP consultations - Continuity of care - Doctor of the same ethnicity Increasing Awareness of CFS/ME - Targeted outreach with specific communities - Posters/information leaflets - Different Languages

	Reducing the Stigma
The Role of Schools	Referrals - School Nurses? Knowledge building - PSHE - Teachers School support: - Support OR Fines / legal action for non-attendance

9.10 Qualitative Analysis Tables

Theme 1: Conceptualisation of CFS/ME

Barriers to accessing specialist CFS/ME services for ethnic minority children		Clinic participants	Community 'influencers'	Community views	Medical professionals
Barrier 1: Conceptualisation of CFS/ME					
Understanding	Understanding the condition and the symptoms	✓	✓		
	Terminology		✓		✓
	Other Alternative Explanations	✓	✓	✓	✓
	Vitamin Deficiencies		✓	✓	✓
	Vitamin D		✓	✓	✓
	Diabetes		✓	✓	
	Mental Health	✓	✓	✓	✓
	Depression	✓	✓		✓
	Lack of exercise	✓	✓		✓
	Home Remedies for tiredness	✓	✓	✓	✓
Awareness	Knowledge of the condition	✓	✓		✓
	"*posh persons disease*" / condition affects White British	✓			✓
Stigma	Stigma of the symptom tiredness	✓	✓		✓
	Is it a medical symptom	✓	✓		✓
	Lazy	✓	✓		
	Gender roles - girls lazier		✓		
	Stigma of a diagnosis of CFS/ME	✓			✓

Theme 2: Cultural Factors

Barriers to accessing specialist CFS/ME services for ethnic minority children		Clinic participants	Community 'influencers'	Community views	Medical professionals
Barrier 2: Cultural Factors					
Close communities and families	Gossip		✓		✓
	Look to others in the community for advice and support		✓	✓	✓
	Community consensus on conditions		✓		✓
Alternative sources of help for symptoms	Religion		✓	✓	✓
	Alternative medicine		✓		✓
Perceived closeness to a specific community	Generation		✓		✓
	Elderly relatives	✓	✓		
	Stigma of invisible condition	✓	✓	✓	
Disagreeing with medical professionals		✓			✓

Theme 3: Going to the Doctors:

Barriers to accessing specialist CFS/ME services for ethnic minority children		Clinic participants	Community 'influencers'	Community views	Medical professionals
Barrier 3: Going to the doctors					
When would a doctor be consulted?			✓	✓	✓
General barriers in medical appointments	Treated differently due to ethnicity	✓	✓		
	Getting an appointment	✓	✓	✓	✓
	Language / cultural		✓	✓	✓
	Don't feel the GP helps OR good relationship with doctor		✓	✓	✓
CFS/ME specific, diagnosis	Multiple appointments	✓			✓
	Different GPs each time	✓			✓
	Other diagnoses before CFS/ME	✓			✓
	"Tipping point" - diagnosed with CFS/ME	✓			
	GPs / Medical professionals understanding of CFS/ME	✓			✓
	Reluctant to label with a diagnosis of CFS/ME	✓			✓
	Structural barriers, SES, single parent etc	✓			✓
	Who diagnosed CFS/ME?	✓			
CFS/ME specific, referral and treatment	"fight" for referral	✓			
	let medical professionals decide appropriate care	✓			✓
	Reluctant to refer - resources, time etc	✓			✓
	Opinions on CFS/ME service	✓			✓
Communication with different services		✓			✓
CFS/ME illness	Start of illness	✓			
	The decision to seek help	✓			

progression	Current CFS/ME symptoms	✓			
	Life before CFS/ME	✓			
Going back to medical care				✓	✓

Facilitators:

Barriers to accessing specialist CFS/ME services for ethnic minority children	Clinic participants	Community 'influencers'	Community views	Medical professionals
Facilitators				
Knowledge of the condition	✓	✓		
Support	✓			

Ideas to Improve Access:

Barriers to accessing specialist CFS/ME services for ethnic minority children		Clinic participants	Community 'influencers'	Community views	Medical professionals
Ideas to Improve Access					
Healthcare system improvements	More GP consultations		✓		✓
	Continuity of care	✓			✓
	GPs diagnose	✓			
	Doctor/ healthcare staff of the same ethnicity		✓		✓
Increasing awareness of CFS/ME	Targeted outreach with specific communities	✓	✓		✓
	General public recognition / awareness	✓	✓		✓
	Posters / information leaflets	✓	✓		✓
	GP awareness	✓	✓		✓
	Different languages	✓	✓		
	Reducing the stigma				✓
Support for those who are ill, e.g. PIP		✓			

The Role of Schools

Barriers to accessing specialist CFS/ME services for ethnic minority children		Clinic participants	Community 'influencers'	Community views	Medical professionals
The Role of Schools					
Referrals	School Nurses				✓
	Referrals to healthcare through schools	✓			✓
Knowledge Building	Assemblies				
	PSHE				✓
	Teachers	✓			✓
School Support	Supportive	✓			
	Fines or legal action for non-attendance	✓			✓

Views on the phrase Community Leader'

Other PhD Study Findings		Community 'Influencers'
Views on the phrase 'Community Leader'		
Phrase 'Community Leader'	Do not like to be called 'Community Leader'	✓
	Cannot claim to be 'leaders'	✓
	Responsibility with being called a 'leader'	✓
	Negative connotations with the word 'leader'	✓
	Implication that if you are a leader you have 'followers'	✓
	Called 'Community Leader' if work with a community in a religious capacity	✓
How participants would describe themselves	A member of a specific ethnic community	✓
	'Involved' with the community	✓
Definition of a Community Leader'	Advocating for the community	✓
	Helping/ supporting the community	✓
	Involved with the community	✓
	Setting up community initiatives	✓
	Religion focussed - guiding or supporting in a religious capacity	✓
	Typically seen as male	✓