# How do males of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress?

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# Abstract

People with physical-mental comorbidity have a poorer quality of life, worse clinical outcomes and increased mortality than those with physical conditions alone.
Those from some ethnic groups may be less likely to recognise and seek help for symptoms which may represent mental health problems, and are an under-served group within healthcare services. People of South Asian (SA) origin, are the largest minority group in the UK, and more likely to have long-term conditions (LTCs) such as diabetes and heart disease. There is little research specifically around SA men and emotional distress in the context of long-term conditions.

I am a SA General Practitioner (GP) researcher. I undertook a systematic review, synthesising studies that explored perceptions of emotional distress in SAs with long-term conditions. I undertook a qualitative study, interviewing 17 men of SA origin with LTCs on the experiences and help-seeking for emotional distress and 18 GPs. A patient advisory group of SA men was involved throughout the research.

Participants used various terms to describe ‘distress’. There was a complex relationship between physical health and emotional distress. Experiences of mistrust of GPs and trust in faith and family were described. Findings were then used to inform a conceptual model (The 3Cs) to understand emotional distress in men of SA origin with LTCs, Contextualising distress including the social determinants of distress, intersectionality, living with a LTC, Conceptualising distress including de-medicalising distress, negotiating multiple identities, alternative paradigms of health based on faith and culture, and Co-navigating care, including cultural health capital, cultural safety and professional development.

The research findings have impacted my clinical practice and have the potential to impact others, including patients and clinicians, policy-makers and commissioners, by enhancing our understanding of the challenges and opportunities in providing and commissioning care that respects the diverse health beliefs of the SA population.

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## List of abbreviations

BAME Black, Asian and minority ethnic

BJGP British Journal of General Practice

DSM Diagnostic and Statistical Manual of Mental Disorders

GP General Practitioner

IAPT Improving Access to Psychological Therapies  (now called NHS Talking Therapies)

LTC Long-term conditions

NHS National health service

NIHR National Institute for Health and Care Research

PCREF Patient and Carer Race Equality Framework

QOF Quality Outcomes Framework

RCGP Royal College of General Practitioners

RUG Research User Group

SA South Asian

SAPC Society for Academic Primary Care

SPCR National Institute for Health and Care Research School for Primary Care Research

UK United Kingdom

WHO World Health Organisation

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# Chapter 1: Introduction

## 1.1 Introduction

This thesis explores how males of South Asian (SA) origin with long-term physical conditions (LTCs) understand, experience and seek help for emotional distress. Chapter 1 provides the rationale for the research, introducing the structure of the National Health Service (NHS), key concepts of multimorbidity, SAs and emotional distress. This is followed by an introduction to myself, patient and public involvement and engagement within the thesis, the context of the covid-19 pandemic, the thesis structure and finally the chapter summary.

## 1.2 The structure of the NHS

This research is conducted in the United Kingdom (UK), where healthcare is primarily delivered by the National Health Service (NHS), although private healthcare is increasingly common. The NHS was established on July 5th 1948, shortly after the second world war, in a time of great financial pressure, food rationing more significant in England than during the war, a severe winter the year before, fuel scarcity, and disjointed healthcare and other pressures (Rivett, 2022). The NHS was based on principles set out by Health Minister Aneurin Bevan around the universality of healthcare for all and a free service (Ibid). Over 70 years later, much of the spirit remains, however some elements of universality of healthcare have been watered down or lost. The NHS was established to provide healthcare free at the point of use. There are however increasing costs incurred by patients such as prescription fees and hospital parking. The NHS is accessible to most people in the UK, however some populations are excluded such as such as failed asylum seekers (Nellums et al., 2018). The NHS is funded from taxation. Its responsibility for healthcare in the UK includes physical and mental health services. This is related to social care, which provides means-tested support for daily living, needed for example due to age, illness or disability. The Department of Health and Social Care advise ministers with regards to the budget. Broadly, most people are cared for within primary care which acts as the first point of contact for healthcare, and when indicated they are referred to secondary and tertiary care. Primary care clinicians can refer to ‘Social Prescribing’ services, a term to denote non-clinical services to support health and wellbeing (Buck, Ewbank, 2020). Whilst people can often access social prescribing directly, primary care in a main facilitator in signposting to available services. Social prescribing is often delivered by the voluntary or third sector, a broad range of non-government non-profit organisations which are values-driven, many of which are healthcare-based (National Audit Office, Not Known). The private healthcare sector is increasingly used, for example NHS spending on the private sector has been contested from the Department of Health and Social Care's 7% to around 26% of expenditure in 2019 (London School of Economics and Political Science, 2019). A broad understanding of the structure of delivery of healthcare is important to understand services for healthcare in the UK and how they should be provided based on need and being free at the point of care. With regards to this research, the management of emotional distress in SAs with LTCs should be provided by the NHS. There may also be voluntary and third sector organisations available to support SAs with LTCs within the realm of social prescribing.

## 1.3 Key concepts

Key concepts regarding the thesis will be defined below, specifically SA, emotional distress and the context of multimorbidity.

### 1.3.1 Defining 'South Asian'

South Asians include people of origin from India, Pakistan, Bangladesh, Afghanistan, Sri Lanka, Maldives, Nepal, Bhutan, Indian Ocean Islands. This is a diverse population, sharing different languages, religions, nuances in country and culture. Whilst it is impossible to consider South Asians a completely homogenous groups, it should be noted that the partitioning of some parts of South Asia into different countries was drawn up arbitrarily during British Imperialist rule (Khan, 2017). An example of this is how the arbitrary lines split the region of Kashmir into an Indian and Pakistani sides (Khan, 2017). Hence the majority of South Asia was considered as one region for hundreds of years with its diversity being part of the land. Furthermore, the present-day countries themselves are incredibly diverse. India, as an example as it is the largest SA country, in its 2011 Census described 19,569 mother tongues as languages (Office of the registrar general, 2018), and whilst the majority of the population (79.8%) were Hindu, there were an estimated over 172 million Muslims and over

27.8 million Christians (Indian Population Census, 2011) exemplifying its diverse culture. I have personally visited Pakistan and India, and an example of the diversity of SA culture I recollect is from 2019 when in Delhi I would see in multiple rickshaws a picture of the Islamic testification of faith (known as the *Shahaada*) and next to it a picture of Hindu Gods and Goddesses. Hence whilst there is heterogeneity within SA countries, this can be considered as part of the richness of SA culture, as opposed to different unrelated cultures.

SAs are the largest minority group in the UK, with Asians making up 9.3% of the population according to the Census 2021 report (Office for National Statistics, 2023); increased from 7.5% in 2011 and 4.8% in 2001 (Office for National Statistics, 2013). In comparison with the rest of the UK, there is a higher prevalence of SAs in Stoke-on-Trent (the city within the closest proximity of Keele university) in particular with 4.2% of the population of Pakistani ethnicity in comparison to 2% nationally (Office for National Statistics, 2013). The population of "Asian, Asian British or Asian Welsh" in Stoke-on-Trent has increased from 7.4% of the population in 2011 to 9.69% in 2021 (Office for National Statistics, 2023), the largest increase of high-level ethnic groups in the area, leading to increasing health needs. First-generation SAs can be considered as those who migrated to the UK, and second-generation SAs as those whose parents migrated from South Asia and they were born in the UK, and third generation as those whose grandparents migrated from South Asia and their parents and they were born in the UK.

Previous research has explored the mental health of SA women from both quantitative and qualitative perspectives (Kapadia, Nazroo & Tranmer, 2018, Smith et al., 2019), including exploring British Pakistani women's experiences of depression (Tabassum et al., 2011), recovery from depression (Kaiser, Weaver, 2019), social stress and depression in pregnant and postnatal women of Pakistani origin (Husain et al., 2012), experiences of psychological therapies (Yasmin-Qureshi, Ledwith, 2020), and SA women's narratives of recovery from mental illness (Kalathil et al., 2011). Expressions of mental health needs for men have been shown to be different to women in the UK, for example in terminology used, for example men when suffering from distress using terms such as 'pissed off' and 'angry' as opposed to 'sad' or 'feelings' (Stein, 2018). These differences are important as they can affect help-seeking behaviour and access to healthcare; over a third of men waited two years before disclosing a mental health problem, and Muslim men preferred to seek help from the mosque (Stein, 2018). Understandings of health and disease have been shown to differ amongst male and female SAs in Chicago, with men having more negative health behaviours such as smoking and alcohol as the cause of disease and women including within their concept of health the performance of home duties and positive affect (Tirodkar et al., 2011). South Asian men when undergoing mental health assessments described cultural and religious issues as important to them and relevant to their coping strategies, yet not discussed within the consultation (Bhui, Chandran & Sathyamoorthy, 2002). People from some ethnic minorities have higher rates of mental health problems, with SA adults, and in particular Pakistani men 35-54, having increased rates of mental health problems in comparison to White British  (Public Health England, 2018, Rees et al., 2016). Men from ethnic minorities are less likely to seek help for mental health problems than any other group (Memon et al., 2016). This has been related to wider concepts of masculinity, pride and self-reliance in managing illness (Bignall et al., 2020). The key report *Racial disparities in mental health: Literature and evidence review* also described inequality in access and treatment (Ibid). These are examples of health inequalities, highlighting a greater need to research and address these inequalities than other areas. There is limited research regarding mental health of males of SA origin. Hence whilst the experiences of men of SA origin is different to women, SA men's experiences are not known and it is not possible to know what support works for them despite the health need, hence the need for this research.

The perspectives of General Practitioners (GPs) have been reported to some extent on managing mental illness in people from ethnic communities  (Furler et al., 2010, Jensen et al., 2013); a study in Australia reported interviews with eight primary care clinicians managing depression in refugee communities and found that clinicians said they resorted to medication due to an inability to change structural issues which may have a significant impact on mental health such as isolation in new communities, and felt that addressing social models of disability working at an individual and community level are central to care (Furler et al., 2010). The study was of refugee communities in Australia, which may be less relevant to second or third generation SAs in the UK. There is little research understanding of the experiences of GPs managing males of SA origin with physical-mental multimorbidity and barriers and facilitators to care.

### 1.3.2 Defining emotional distress

There is no one single definition of emotional distress that is widely accepted; for the purpose of this research emotional distress will be defined as ‘upset’ or negative emotions which do not fit a diagnostic criteria for mental illness (Mendive, 2009). Emotional distress may be an appropriate response to life events rather than pathological, such as grief and distress around bereavement. When the emotional distress causes ‘harmful dysfunction’ that impacts on a person’s ability to live, it is regarded as a psychiatric disorder (Geraghty et al., 2015, Wakefield, 2007). Emotional distress was chosen for this research above mental health diagnoses such as anxiety and depression as the primary experience of interest for this research as under-diagnosis of mental health conditions as well as a and lack of awareness of mental health conditions may lead to their reduced labelling and diagnosis (Derr, 2015, Miyasato, 2016). Hence by using the broader term emotional distress, it may encompass distress suffered which is not diagnosed for a variety of reasons including diagnostic threshold and diagnostic fit, but still causes significant suffering (Geraghty et al., 2017). Mental disorders are stigmatised within the SA community and have been shown to act as a barrier to seeking professional help due to the social stigma of diagnosis, and they may present with primarily physical as opposed to mood symptoms, making diagnosis more challenging (Karasz et al., 2019). Furthermore, the purpose is to explore individuals’ understandings of what clinically may be considered mental illness but which males within the SA community may or may not regard as a diagnosable mental health condition (Geraghty et al., 2015). Within general practice there is ongoing debate as to whether classifying mental disorders is of benefit to managing people with distress (Byng, Groos & Dowrick, 2019). Byng and colleagues (2019) argue that current diagnostic criteria for mental illness are stigmatising, diagnoses are not representative of reality, do not support personalised management plans and are inconsistent across cultures. Dowrick (2013) asks if depression itself is a culture-bound syndrome (Dowrick, 2013). Others argue that current diagnoses for mental health conditions force clinicians inappropriately down biomedical models of treatment (Smith et al., 2019, Thangadurai, 2014) which may be a purposeful move to increase profits from the pharmaceutical industry (Moscrop, 2012). Some within general practice have gone as far as suggesting an ‘end to depression in primary care’ (Moscrop, 2012, Dowrick, 2016). People with diagnosed common mental health problems have significant cross-over in terms of symptoms and combined depression and anxiety can be argued to be more common than depression or anxiety, yet classifications of mental disorders force patients and clinicians to arbitrarily treat them as different conditions (Goldberg, 2019), which may not be of benefit for patients.

A criticism of using the term ‘emotional distress’ in primary care is that a diagnosed mental health condition may facilitate a shared management plan (American Psychiatric Association, 2013), and by moving away from diagnosed mental conditions there may be less psychological and medical intervention offered to patients. The reduced utilisation of mental health diagnoses may potentially exacerbate the stigmatisation of mental health, as it could lead to a scarcity of such diagnoses. These criticisms of using the term emotional distress may however be considered as less relevant to primary and community care where the majority of mental health presentations are on a less severe spectrum of illness, and the focus of this research is in the less severe spectrum of mental health problems.

Psychological distress is an alternative term that could have been used (Arvidsdotter et al., 2016). Psychological distress was considered less appropriate than emotional distress given it may indicate the cause of distress being a psychological problem such as maladaptive coping strategies, which may be a part of the cause of distress but not the full reason. Emotional distress as a term describes the emotional dysregulation and does not specify the cause of distress within the term itself, allowing for broader causes to be considered, such social and psychological (as well as potentially biological) causes of distress. Emotional distress is far more established within primary care literature (Geraghty et al., 2015, Mendive, 2009, Geraghty et al., 2019, Geraghty et al., 2017, Gray et al., 2018). In a qualitative study of 21 participants GPs found it unclear to differentiate between depression and emotional distress (Geraghty et al., 2019). A qualitative study of 20 patients identified by GPs to have emotional distress but not a diagnosis of depression found that these experiences had a significant impact on their lives and that they had different conceptualisations of emotional distress and depression (Geraghty et al., 2017). A qualitative study looking at barriers to managing depression in people with LTCs in primary care found uncertainty in labelling depression in patients with LTCs that would facilitate shared understanding and future management (Coventry et al., 2011). The authors state that clinicians' conceptualisation and explanation of depression is crucial to the diagnosis and management of patients. Figurative and metaphorical language was suggested, by healthcare professionals, to be important in people from ethnic minorities who may be more resistant to biomedical models of depression. The study did not explore perspectives of people from ethnic minorities, which is clearly needed to understand their own understandings and conceptualisation of depression. Hence emotional distress was chosen for this research given its relevance to both primary care as well as people from ethnic minorities.

### 1.3.3 Multimorbidity

This thesis focuses on a patient population of SAs with LTCs experiencing emotional distress. Experiences of people with multimorbidity are recognised as increasingly important within research. Multimorbidity is defined by the National Institute for Health and Care Excellence (NICE) as the presence of two or more long-term conditions, which can be physical or mental health conditions  (National Institute for Health and Care Excellence, 2016b). This contrasts with comorbidity which refers to a distinct additional entity to an index disease (Harrison et al., 2021). Multimorbidity is more relevant to primary care, where the focus is not on treating a specific index disease that a patient suffers from as well as additional conditions, but the holistic treatment of that person who suffers from multiple diseases (Harrison et al., 2021). The term is not without criticism, as patients felt it suggests a single disease and reinforces a biomedical approach to treatment, and preferred terms such as multiple health conditions (Chew-Graham et al., 2019), however the research arena and literature has not yet changed to reflect this. Multimorbidity is an increasing challenge facing 21st century healthcare (Pearson-Stuttard, Ezzati & Gregg, 2019). In higher income countries, multimorbidity is more common than people with single morbidities (Fortin et al., 2005, Barnett et al., 2012). Multimorbidity increases with age  (Salisbury et al., 2011, Garin et al., 2015) whilst, in lower socioeconomic groups, occurs more commonly and begins at a younger age  (Barnett et al., 2012, Violan et al., 2014). People with multimorbidity use two to three times more primary care services than those without, in particular people from

Black and Asian ethnicity. (Soley-Bori et al., 2022). People from more deprived areas develop multimorbidity 10-15 years earlier than people from affluent areas, in particular multimorbidity involving mental health problems (Barnett et al., 2012). This has been considered an example of the inverse care law, where the burden of multimorbidity is in more deprived communities, yet primary care is relatively understaffed and underfunded in these deprived areas (Barnett et al., 2012).

Interventions for multimorbidity within primary care have been shown to improve quality of life from communities in areas of high socioeconomic deprivation, such as the whole-system intervention involving structured longer consultations, relationship continuity, practitioner support and self-management (Mercer et al., 2016). It is not known if this research is translatable to SA communities. Relationship-based care, defined by the RCGP is '*care in which the processes and outcomes of care are enhanced by a high-quality relationship between doctor and patient'* (Royal College of General Practitioners, 2021, p4). This is different to continuity of care which pays more attention to the continuous and coordinated delivery of healthcare over time, with relationship-based continuity focusing on the quality of the relationships. A 2021 report focused around multimorbidity described how '*small but powerful adjustments*' can have a '*huge'* impact, such as simple and clear explanations of diagnoses and what people need to do to manage their condition, professionals checking patient understandings, and asking opinions on what patients want regarding shared management (The Richmond Group of Charities, 2021, p3); all of these have a potential role within primary care. The first two priorities suggested by the report of a need to improve understandings of communities experiencing inequity and disadvantage and addressing distance and distrust between communities and healthcare (Ibid) may both apply to the population of SA males with LTCs. Shared decision-making is a challenge that both patients and GPs are aware of given the medicolegal vulnerability of managing multimorbidity in a context of disease-specific guidelines and uncertainty (Brown et al., 2022). This highlights the need for research to support GPs more when managing multimorbidity.

People from some ethnic minority groups are more likely to have cardiovascular multimorbidity, i.e. two or more of hypertension, ischaemic heart disease, heart failure, stroke, and diabetes (Mathur et al., 2011). SAs have a higher prevalence of LTCs such as diabetes with a prevalence of 14% compared with 6.9% in the general population (Holman et al., 2011) and coronary heart disease prevalence 11% compared with 5% of Europeans (Anand, 1997). Diabetes and coronary heart disease can be considered as exemplars of LTCs for the research given their higher prevalence in SAs. Other common LTCs such as asthma and COPD were considered, however the prevalence of diabetes and cardiovascular disease is much higher in SAs in comparison to the general population as described above. Diabetes and cardiovascular disease share multiple similarities in terms of risk factors, symptoms, disease progress, self-management and lifestyle changes, and have been described to have a *‘common soil’* (Fernandes Silva, Vangipurapu & Laakso, 2021). They have been described to share similar pathophysiological, psychological and social factors such as increased visceral adiposity, lower beta-cell function, sedentary lifestyles, poor medical concordance and high-carbohydrate meals (Shariff et al., 2020). This makes the experiences of SAs with diabetes and heart disease more relevant to being explored together than other LTCs.

Previous published research in SAs with comorbid depression and LTCs is primarily quantitative. A cross-sectional study of 124 people with type 2 diabetes in south India found 41.9% of patients to have diabetes-related distress  (Kumar et al., 2017). Kumar et al. (2017) defined diabetes-related distress as ‘*patient concerns about disease management, support, emotional burden, and access to care*’ (Ibid, page 217). This was a small population for a quantitative study, so conclusions need to be tentative. A study in Canada of SAs with type 2 diabetes found 15% had depression and 52.5% had diabetes-related distress  (Sidhu, Tang, 2017). Again, the population in the study was very small with 41 people recruited. A study in a Karachi hospital in Pakistan found psychological stress to be an independent risk factor for coronary heart disease, at a similar level to other risk factors (Kurd et al., 2014). The study was again small, with a sample of 60 people, thus findings cannot be generalised. Whilst there is some quantitative research around SAs with comorbid depression including above and other papers, there is a lack of research and gap with regards to understanding the views and perspectives of SA males with LTCs about emotional distress.

## 1.4 Research Question

The overall research question of the study was to explore: How do males of South Asian origin with long-term conditions understand, experience and seek help for emotional distress? The aims and objectives of the study will be described in chapter 2.

## 1.5 Introduction to the Author

I am a GP of South Asian origin with a passion for primary care mental health research. I decided to become a GP due to my interest in people's lives and stories, and how they can be holistically treated whilst experiencing illness. I live within and between cultures, being born and brought up in the England and I consider myself as Mancunian. At the same time, I am a second generation SA. My mother came to the UK from Pakistan as a child with her parents, and my father came to the UK from Kenya as a child with his parents, although my paternal great grandfather was initially from what is now called Pakistan but was still all known as India when he migrated to Kenya. I have basic language skills in Arabic and Urdu and have a deep love of languages. I have undertaken this research as part of a Wellcome fellowship (part-time). The initial idea stemmed from seeing many SAs with LTCs experiencing emotional distress in my clinical work and having seen the need for more support for this group and GPs supporting them. This is related to my interest in addressing healthcare inequality and improving mental health and emotional wellbeing within community settings. I have experience as a faith leader including teaching Arabic and Islamic Studies. I consider myself an active community member in Manchester, and as a charity trustee I am in contact with officials such as my local MP and Police. I deliver regular community speeches in venues primarily around Manchester. An advantage of this may be that interviewees view myself as part of the same group and may be more trusting and willing to explore sensitive issues, giving richer data (Chew-Graham, May & Perry, 2002, Aira et al., 2003). A disadvantage could be with myself being embedded in the community there is a potential risk of coercion to participate and people may not wish to disclose their understandings to someone viewed as being from within the community (Chew-Graham, May & Perry, 2002). A study of an academic GP interviewing GP participants found that when GPs were interviewed in research interviews by GPs, they felt that the interview is a test of their professional knowledge and also an educational process in which the interviewer has authoritative knowledge of the area of interest (Coar, Sim, 2006). ‘Concept blindness’ can occur when the interviewer’s opinions govern the dialogue and interpretations (Andersson, Troein & Lindberg, 2001). Reflexivity, the ongoing self-critique and self-appraisal of the research based upon the researcher observations and background (Koch, Harrington, 1998), is essential in minimising bias and acknowledging one’s own assumptions. I wrote a reflexivity diary throughout the research, to record observations and emotions and appreciate my role and positionality in relation to the research, reflect upon and challenge my own assumptions and multiple roles, avoid ‘concept blindness’ and be aware of any bias and take account of this.

## 1.6 Patient and public involvement and engagement

Patient and public involvement and engagement (PPIE) is an integral part of this research. In any study, the voice of those to whom the research is trying to benefit is critical to ensure that the research is relevant and effective (Chief Scientist Office, Health and Care Research Wales, Public Health Agency and National Institute for Health Research, 2018). To ensure the ethnicity of the patient advisory group is most appropriate for the study, the *Student-Link* initiative has been utilised; this was a Keele University initiative led by Professor Athula Sumathipala to support ethnic diversity within PPIE within the School of Medicine, Keele University. I attended a workshop in which students and staff at Keele University explored ways of increasing diversity within the Research User Group (RUG) by acting as *community champions* encouraging diverse community members to join. I attended further meetings about developing the *Student-Link* project, and developed a patient advisory group consisting of males of South Asian origin.

The patient advisory group was utilised throughout the research according to the National Standards for Public Involvement (Chief Scientist Office, Health and Care Research Wales, Public Health Agency and National Institute for Health Research, 2018). The six standards used are ‘inclusive opportunities’, ‘working together’, ‘support and learning’, ‘communications’, ‘impact’ and ‘governance’. Keele University was a test-bed for these standards. Throughout each chapter of the thesis, there is a section detailing the role of the patient advisory group with regards to that chapter, followed by a summary of PPIE involvement in the discussion chapter.

## 1.7 Context: Covid-19 Pandemic

The research was conducted in the context of the covid-19 pandemic [declared as such by Dr Tedros Adhanom Ghebreyesus, Director-General of the World Health Organisation (WHO) on March 11th 2020 (World Health Organisation, 2020)]. People with LTCs such as diabetes and coronary heart disease, were disproportionately affected by acute covid-19 infection (Yang et al., 2020). SAs are more at risk of developing covid-19 as well as increased morbidity and mortality from acute covid-19 infection, with increased prevalence of such LTCs, as well as more common cultural practices such as multi-generational households (Tang et al., 2019). Larger households increase the risk of transmission of covid-19 (Sjödin et al., 2020). Hence, SAs were disproportionately affected by the pandemic with regards to health outcomes.

The psychological impacts of the pandemic have been reviewed by a number of researchers. A rapid review on the psychological effects of quarantine found negative consequences to include post-traumatic stress symptoms, confusion, and anger, with potentially long-lasting effects (Brooks et al., 2020). Hence the pandemic is very relevant to research around emotional distress as multiple factors around the pandemic led to and influenced distress. My qualitative study, exploring perspectives of males of SA origin with LTCs and General Practitioners, was adapted to take place during the pandemic, as well as further explored during the pandemic, and is further detailed in chapter 6. The impact of the pandemic was explored in interviews with participants as well as within my reflexive diary.

The pandemic significantly affected my research, in particular the qualitative interviews. This is discussed in further details in chapter 6.

## 1.8 Thesis Structure

Chapter 2 provides a background of relevant literature, including multimorbidity, the wider NHS context, ethnic minority groups and mental health, SA culture and health, and covid-19 and ethnic minorities. Chapter 3 focuses on the published systematic review of emotional distress, anxiety, and depression in South Asians with long-term conditions (Awan et al., 2022). Chapter 4 discusses the methodology for the qualitative study, including the research paradigm and research quality. Chapter 5 discusses the methods of the qualitative study in further details. Chapters 6 and 7 present the findings of the qualitative study - interviews with men of SA origin with LTCs and GPs. Chapter 8 is a discussion of the research findings with reference to existing research, its implications and areas of future research. The references follow as well as appendices such as front-facing documents for participants.

## 1.9 Chapter Summary

Chapter 1 provides the rationale for the research, introducing the structure of the National Health Service (NHS), key concepts of SA, emotional distress, and multimorbidity. This is followed by an introduction to myself and my reasons for undertaking the research. Patient and public involvement and engagement within the research is introduced, followed the context of the covid-19 pandemic, the thesis structure and finally the chapter summary. Chapter 2 provides a more detailed review of the literature.

# Chapter 2: Literature review

## 2.1 Introduction

This chapter begins by introducing health inequalities and the social determinants of health, including their relation to ethnic minority groups and mental health inequalities. Race and mental health is explored as well as approaches to addressing mental health inequalities in people from ethnic minority groups, followed by ethnic minority groups and inequalities in health research. Public involvement with ethnic minority groups is explored, followed by SA culture and health. I then describe the wider NHS context and key policy documents. Long-term conditions (LTCs) and multimorbidity are explored, in particular mental-physical multimorbidity and health of ethnic minorities in a context of mental-physical multimorbidity. The lived experience of mental-physical multimorbidity is described, as well as managing people with mental-physical multimorbidity including emotional distress in a context of LTCs. The covid-19 pandemic and its impact on people from ethnic minorities is reviewed, including inequalities with regards to acute infection, the impact of changes of access to healthcare widening existing health inequalities, physical health inequalities, and mental health inequalities. The chapter concludes with the research aims and objectives and the chapter summary. Due to the scope of the research exploring emotional distress in SAs with LTCs, some areas are not included such as extensive detail regarding general physical health inequalities related to SAs and other ethnic minority groups.

## 2.2 Health inequalities

The following section describes health inequalities, initially how they are related to the social determinants of health, followed by ethnic minority groups and health inequalities. Approaches to addressing mental health inequalities in people from ethnic minority groups are then discussed, as well as ethnic minority groups and inequalities in health research and SA culture and health.

### 2.2.1 Health inequalities and the social determinants of health

I addressed this research from a lens of addressing an aspect of health inequalities within primary care. Definitions of health inequalities are relatively consistent, with The King's fund defining health inequalities as '*avoidable, unfair and systematic differences in health between different groups of people* (Williams, Buck & Babalola, 2020).' Professor Sir Michael Marmot argued in his report *Fair Society Healthy Lives* (Marmot et al., 2011) that reducing health inequalities are a matter of fairness and social justice. He promoted the concept of 'proportionate universalism' whereby health inequalities should be reduced by working to improve the health for all within society, yet a proportionately greater level of work is needed in those groups suffering from health inequalities (Ibid). A report published in 2020, *Health Equity in England: The Marmot Review 10 Years On* suggested that health inequalities have increased since the original report, which can be measured for example by increased inequality in life expectancy and the reduced life expectancy of the most deprived communities outside of London for women and in some areas for men (Marmot, 2020).

The social determinants of health are increasingly recognised as the non-medical factors that influence health outcomes, such as where people are born, grow, work, live, and age, and are shaped by economic policies and systems, development, social norms and policies and political systems (World Health Organisation, No date.b). The social determinants have been shown to be more important than healthcare or lifestyle choices, accounting for 30-55% of health outcomes (Ibid). The social determinants of mental health further stated that mental health and common mental health problems are significantly shaped by the social, economic and physical environments in which people live, and risk of mental health problems is increased with social inequalities (World Health Organisation, 2014). A main message from the WHO paper was the need for universal and inclusive, yet proportionate action, to address health inequalities. A report by the Centre for Mental Health describes how mental health inequalities mirror wider inequalities such as social and economic inequalities, and are deep-rooted within society, and offers community-based solutions to addressing these (Commission for Equality in Mental Health, 2020).

Primary care is considered key actor in reducing health inequalities; over 90% of patient contacts occur in primary care and avenues of reducing health inequalities can be from clinical care, patient advocacy, community engagement and wider political influence (Hutt, Gilmore, 2010). 40% of GP consultations were related to mental health in a survey of 1000 GPs (Mind, 2018). The 2015 RCGP policy paper on Health Inequalities further described the role of general practice as ‘pivotal’ in addressing the causes of health inequalities and dealing with their effects, given the position of general practice as the expert medical generalist at the heart of the community and usually the first point of contact for patients (Baker, Mawby & Ware, 2015). One of its six recommendations was to fund outreach programs to help often excluded groups such as those with mental health conditions (Ibid). The following section describes how people from ethnic minority communities experiencing mental health problems may be considered as one of these under-served groups.

### 2.2.2 Ethnic minority groups and mental health inequalities

Ethnic minority groups and mental health will be discussed, followed by race and mental health.

#### *2.2.2.1 Ethnic minority groups and mental health*

People from ethnic minorities are less likely to recognise mental illness, perceive a need for medical intervention or utilise services  (Villatoro, 2014, Miyasato, 2016) and are under-supported by services (Bhui, Halvorsrud & Nazroo, 2018). Reasons for this have been reported to include cultural beliefs about illness, its nature and attitudes, emotional display, shame, stigma and mistrust of service providers (Meyer, Takeuchi, 2014). People from ethnic minorities may be less likely to trust healthcare services and feel treated without dignity (Harries et al., 2019). They may experience acculturative stress, the stress related to incorporating the culture of a new country into a person’s previous culture (Karasz et al., 2019). A systematic review exploring stigma for common mental health disorders in racial minorities and majorities found that stigma is much greater in ethnic minorities, which may be linked to poverty as well as discrimination from policies and institutions, in line with social identity theory and being considered as outsiders (Eylem et al., 2020). The authors suggested that culturally specific anti-stigma strategies should be promoted to improve mental health outcomes (Ibid). Help-seeking behaviour and willingness to take medication for mental health problems has been shown to be influenced by cultural and religious beliefs and stigma (Park, Jang & Chiriboga, 2018, National Institute for Health and Care Excellence, 2009). For example in SAs, stigma has been shown to be a barrier for individuals seeking help for their own mental health problems as well as that of family (Karasz et al., 2019). It is recognised that cultural and religious factors must be considered by service providers when developing and delivering health services (Park, Jang & Chiriboga, 2018, National Institute for Health and Care Excellence, 2009). People from ethnic minority groups may present with physical symptoms, rather than identifying an underlying psychological problem (Bhui, Halvorsrud & Nazroo, 2018). This provides a challenge within primary care for identification of mental health problems, diagnosis and management; if a patient does not recognise they have a mental health problem they may be less willing to accept treatments for the problem they don't know they have. A meta-analysis in minority communities in America found the highest level of racial discrimination in relation to health outcomes within mental health (Carter et al., 2017). People from ethnic minorities are under-served within healthcare (Derr, 2015, Meyer, Takeuchi, 2014); poor access may be related to caregivers deterring or diverting help-seeking in ways inappropriate for their mental health needs and is influenced by social and cultural factors (Gask et al., 2012). Recovery rates for psychological therapies have been shown to vary according to ethnicity and faith, with Pakistani men having the lowest rates of recovery, 33.5% in comparison with Irish women who had the highest rates of 50.5% recovery (NHS Digital, 2016). Muslims have some of the lowest recovery rates, with Jain, Christian and Jewish people having the highest rates of recovery (Ibid). This may be related to services being culturally inappropriate to the patients. People from ethnic minority communities in the UK described barriers to accessing mental health services including recognising and accepting mental health problems, reluctance to discuss or seek help from men, cultural identity, language barriers and cultural naivety, insensitivity and discrimination from clinicians as some reasons.

People from ethnic minorities with mental health problems are more likely to become unemployed, homeless and die by suicide (Bailey et al., 2018). The Marmot 2020 report comments on health inequality based on ethnicity, with people of Pakistani and Bangladeshi ethnicity having the lowest life expectancy in the UK (Marmot, 2020). The report linked this inequality to poverty, with those who are Black and Pakistani and Bangladeshi origin having some of the highest rates of poverty of up to 50%. The report also noted how people in persistent poverty are much more likely to have poor physical or mental health. People from ethnic minorities with mental health problems can clearly be considered as those suffering health inequalities who require greater attention as part of 'proportionate universalism' to reduce this health inequality and improve the health of the society from both ethnicity as well as confounding factors such as poverty. Marmot's 2021 review of health inequality in Manchester described how ethnic disadvantage and racism are increasing health disparity (Marmot et al., 2021).

#### *2.2.2.2 Race and mental health*

There is a growing body of research around race and mental health. The Race Equality Foundation report about racial disparities in mental health highlighted several key findings, highlighted in five main areas (Bignall et al., 2019). The literature review highlights increased prevalence of mental illness in ethnic communities, in particular Pakistani men, reduced access to mental health services, inequalities and discrimination during assessment, treatment inequalities such as being more likely to be refused talking therapies and being more likely to be medicated, and discrimination during the recovery process (Ibid). They are disproportionately affected by the social determinants related to mental health. The report suggests matching cultural, religious, linguistic and/or racial identity of clinicians and patients can improve treatment outcomes. The report discussed how people from ethnic minority communities want the impact of racism and wider inequalities on their mental health to be addressed. It also states that better understanding of cultural and faith beliefs and providing culturally appropriate advice and support will improve recovery, as opposed to a Eurocentric approach, as well engagement with voluntary, community and social enterprise organisations (Ibid). It states that clinicians should have a better understanding of patients' cultural and faith beliefs, and care must address this holistically (Ibid). The report suggests that policy makers should better commission talking therapies according to local needs and engage with ethnic minorities to ensure the therapies are culturally appropriate (Ibid). Many of these suggested actions seem lacking and ethnic disparities were only highlighted in a greater manner during the covid-19 pandemic.

Causes of inequality in health of ethnic minorities run much deeper than purely biological, lifestyle and cultural factors. The widely-criticised UK government report of the Commission on Race and Ethnic Disparities describes how the health of ethnic minorities is better in many outcomes than the white British population (Commission on Race and Ethnic

Disparities, 2021). Critics described how statements of the report contradict decades of evidence and cherry-picks data, whereas structural racism is a fundamental cause and driver of ethnic disparities in health (Razai, Majeed & Esmail, 2021). The government paper made statements contradicting its own data, such as data showing lower life expectancies of Black and SA populations in comparison with the white population yet the paper stating the opposite. This highlights structural racism against ethnic minorities from the most powerful of power structures in the UK. The UN working group of experts on people of African descent described the race report as normalising white supremacy (Mohdin, 2021). This directly impacts healthcare of ethnic minorities, as healthcare budgets are centrally-driven in the UK, and also highlights discrimination which may be felt by ethnic minorities from all echelons of society. A meta-ethnography to understand mental health inequalities in the UK found models of healthcare a barrier to care due to monocultural and reductionist frameworks as well as experiences of racism within healthcare (Bansal et al., 2022).On the grassroots level at a similar time, the Royal Society for Arts, Manufactures and Commerce found that 52% of Asian origin people felt discriminated against when accessing local services for covid-19 (Burbridge et al., 2021). The study was a survey of 2,677 people including a weighted sample of 1,000 people from ethnic minorities and did not explore the reasons people felt discriminated against. The government paper and grassroots survey provide a narrative of discrimination faced by ethnic minority groups, which is important for and relavent to mental health research given that experienced discrimination is a known risk factor for mental health problems (Karasz et al., 2019).

### 2.2.3 Approaches to addressing mental health inequalities in people from ethnic minority groups

A key challenge in addressing mental health inequalities in ethnic minority groups is the challenge of access to care. Different models have been used to describe access such as a ‘pathways to care model’, describing the journey of a patient, initially seeing their GP and then accessing specialist mental health care as needed, and a ‘process of care model, describing the processes required in accessing care (Gask et al., 2012). The model was built around the work of Dixon-Woods of access to care for vulnerable groups (Woods et al., 2005). Gask and colleagues (2012) argue that a ‘pathways to care’ model of mental illness focusing on areas such as illness behaviour, recognition and referral in primary care, specialist referral and care may increase the access inequalities for hard-to-reach groups such as ethnic minorities. This however remains a prevalent approach within healthcare, although patients are able to now directly refer themselves for psychological therapy via NHS talking therapies (NHS, 2021).

The first process in the ‘process of care model’ is that of ‘candidacy,’ the negotiation between individuals and healthcare services about eligibility for healthcare. It describes identity as a core component which is very much related to culture and social understandings. Candidacy is important when considering the treatment journey of people with LTCs and can be used to understand the barriers to people particularly from low socioeconomic backgrounds accessing healthcare (Dixon-Woods et al., 2006). It is equally relevant to people from different cultural backgrounds such as SAs. Illness identity has been argued to be a core component of candidacy, how a patient understands their illness and is diagnosed directly affects their access to services and how they are treated in healthcare services according to candidacy (Macdonald et al., 2016). This may be a reason to explain the disparity in need and access to healthcare to people from ethnic minorities, based on their understanding of illness (Derr, 2015, Meyer, Takeuchi, 2014).

Arguably, support for emotional distress in the UK are limited in facilitating candidacy with ethnic minorities due to a lack of understanding of culture and beliefs. Gask and colleagues (2012) propose a conceptual model of access to care involving three elements: community engagement, addressing the quality of interactions in primary care and the development and delivery of tailored psychological interventions (Ibid). Community engagement has been defined by the National Institute for Health and Care Excellence (NICE) as ‘*a range of approaches to maximise the involvement of local communities in local initiatives to improve their health and wellbeing and reduce health inequalities. This includes needs assessment, community development, planning, design, development, delivery and evaluation*’ (National Institute for Health and Care Excellence, 2016a). Community engagement in the AMP study by Gask and colleagues (2012) was felt to be the most effective way of improving access to psychological therapies, by establishing partnerships with local voluntary organisations, increasing knowledge and health literacy about mental health interventions and increasing judgement of candidacy (Gask et al., 2012, Woods et al., 2005). Health literacy is the degree to which individuals are able to find, understand and use information and services to make health-related decisions. Recent literature separates personal health literacy and organisational health literacy, whereby organisation health literacy refers to the extent to which organisations effectively facilitate individuals in accessing, comprehending, and utilising information and services to make informed health-related decisions and take appropriate actions for themselves and others (Brach, Harris, 2021). For community engagement to be productive, it is vital to hear the voice of those within the community; for quality of primary care interactions to be developed as well as the delivery of tailored psychological interventions, both the voices of patients and clinicians must be heard (National Institute for Health and Care Excellence 2016a).

‘Cultural competence’*,* can be considered as an element of patient-centeredness, whereby clinicians put individuals specific health needs and desired outcomes first (Hernandez et al., 2009). Clinicians attempting to understand the world from the patient’s perspective is integral to clinicians developing a ‘shared narrative’ with patients in which they feel listened to (Gask et al., 2012). Mental health awareness workshops, run by community organisations sensitive to cultural constructs of mental health, have been shown to reduce stigma of mental illness in people from ethnic minorities and are potentially more effective than top-down public educational interventions (Knifton et al., 2010). However, there is limited understanding of needs of communities with regards to mental health. Clinician understanding and interpretation of different cultures, including the culture to which they belong, further affects consultations and how the patient’s history is obtained, understood and management plans are formulated (Bhui, Halvorsrud & Nazroo, 2018). To provide effective care for under-served groups, it is argued that

> ‘*GPs must understand the patient’s view of self and world and demonstrate this to the patient.’* (Lamb et al., 2012, p98)

### 2.2.4 Ethnic minority groups and inequalities in health research

The below section describes ethnic minority groups in health research and public involvement with ethnic minority groups in healthcare.

#### 2.2.4.1 Ethnic minority groups in health research

Ethnic minorities are an under-represented group in research, which may make health research less generalisable to this patient group and increase health inequalities (Masood et al., 2019, Hall, 1999, Heiat, Gross & Krumholz, 2002). White British people were found to be 64% more likely to take part in research that people from ethnic minorities (Islam et al., 2021, Smart, Harrison, 2017). Analysis of trial data found South Asians (SAs) made up a mean of just 0.6% in six research trials (Mason et al., 2003). SAs have been found to be more reluctant to be involved in research due to fear and mistrust, related to eugenic racism, as well as viewing trials as a means of experimentation (Hussain-Gambles et al., 2004). A qualitative systematic review around dementia research in ethnic minorities found barriers to involvement to include attitudes and beliefs about dementia in ethnic minority communities such as stigma and discrimination, language and cultural issues in assessment with ethnic minority communities preferring the culture of where they migrated from and hence unfamiliar with the culture of the country of migration and assessment tools being not culturally appropriate (Waheed et al., 2020). Lack of knowledge of SA culture was felt to hinder communication and issues around non-SA researchers struggling to interpret interviews due to having different world-views and understandings (Ibid). These may be transferable to research in emotional distress which may be viewed with similar hesitancy and have similar challenges. A scoping review of barriers and facilitators of SAs in health research similarly found highlighted language and cultural barriers, mistrust of research, and suggested facilitators to include engagement of SA communities and cultural competency (Quay et al., 2017). They may be partially addressed with using emotional distress and not mental health diagnoses as well as research being primarily conducted by a researcher of SA background, as per this research. The lack of research with ethnic minority communities provides a greater need to not only include ethnic minorities within research, but also to research about ethnic minorities. Tackling health inequalities related to race and ethnicity can be considered an urgent health priority (Bastos, Constante & Jamieson, 2021).

#### *2.2.4.2 Public involvement with ethnic minority groups in healthcare*

Public involvement is another challenging area with a lack of diversity from ethnic minorities within public involvement and engagement; a 2017 survey of public contributors to health research found only 3% were Asian (Health Research Authority, 2017). The NIHR describe it as essential for diverse and inclusive public involvement in research to ensure that research is relevant (NIHR, 2015). Involvement of ethnic minority groups when included is often limited (Dawson et al., 2018). This has been heightened by the covid-pandemic whereby the digital divide may further marginalise ethnic minority communities (Adeyemi et al., 2022). Working flexibly and making sensitive adaptations have been highlighted as key markers to promote ethnic minority involvement in public involvement (Ibid), these were considered in this research. Community-led approaches have been suggested to improve involvement from groups labelled ‘hard to reach’, but in fact may find it ‘hard to trust’ (Islam et al., 2021, Routen et al., 2022). A toolkit developed for increasing participation of ethnic minority communities in research highlighted six main areas of considering the communities which the research needs to involve, effective public involvement, effective recruitment of ethnic minority communities, cultural competence in research, effective feedback to participants and recognising the importance of recruiting from ethnic minority communities (Farooqi et al., 2022). These challenges were considered in the research and will be described further in chapter 5.

### 2.2.5 South Asian culture and health

Culture can be defined as ‘shared values, norms, feelings, and ways of thinking that are learned, transmitted, and shape a group’s beliefs, attitudes, and behaviours’ (Osokpo, Riegel, 2021). Culture is intertwined within health, in particular with regards to conditions which are associated with lifestyle factors, and patients’ understanding and acting upon health promotion advice (Al-Bannay et al., 2014, Airhihenbuwa, Ford & Iwelunmor, 2014). Diabetes and coronary heart disease can be considered as some conditions which are influenced by culture due to the cause and management being strongly related to this. Diabetes is a metabolic disease characterised by hyperglycaemia (high blood sugar) and coronary heart disease is a disease whereby the blood vessels supplying the heart are narrowed or blocked. As stated in the introduction chapter, they share in risk factors, pathophysiology and some treatments such as lifestyle factors and the taking of long-term medication. Cultural determinants of health, how ideological, socioeconomic and practice level processes affect health-related perceptions, categorizations, and behaviours, have been shown to affect understanding of illness and help-seeking behaviour (Saint Arnault, 2018). A study of SAs in Chicago found that concepts of health and disease fell into behavioural, physical, psycho-social and spiritual domains, with Muslims consistently evoking spiritual factors of faith and prayer, specifically the five daily prayer, as a means of disease prevention (Tirodkar et al., 2011). The study described how SAs conceptualised disease incorporating spiritual and psycho-social factors as well as physical factors. The research focused on immigrants, and it is not clear if they are applicable to SAs other than first-generation SAs. Furthermore, over half of the participants were recruited from a health clinic, and their perspectives may not be the same of SAs within the community who do not seek help from medical practitioners. The relation and potential evolution of SA concepts of health and illness is not known in SAs with LTCs.

Higher rates of diabetes and heart disease in SAs were noted in the previous chapter. Some research has been conducted with regards to the experience of people of SA origin with LTCs. A mixed-methods study involving 67 participants of SA origin with diabetes found that some emotional distress was experienced (mean =5.73, SD = 3.09), which was less in people with higher levels of support networks (Patel et al., 2015). This qualitative study reported that fatalistic attitudes and beliefs influence self-management and people of SA origin look for alternative treatments (Ibid). Semi-structured interviews elicited a belief in God as the controller of illness, particularly in first-generation migrants, and a key finding was the role of family in the management of illness. However, the research did not explore qualitatively what emotional distress meant to participants. A study in Canada which found that rates of diabetes-related distress were as 52.5% and depression 15% (Sidhu, Tang, 2017). This is similar to levels in the UK where older SAs with diabetes found depressive symptoms in 15.5% in comparison to 9.7% in White European populations. Researching diabetes-related distress and depression symptoms are related to emotional distress. However, researching diabetes-related distress is a narrower approach as it looks at distress only which is directly related to the LTC. Emotional distress researches distress directly from the LTC as well emotional distress broadly and not only from the LTC, which people with LTCs may experience differently. In this way researching emotional distress can be considered a more whole-person approach. An integrative review in cultural factors that affect care in cardiovascular disease found in people of SA origin cultural beliefs such as fatalism, collectivism and traditional gender roles adversely affected self-management and adherence to dietary advice (Osokpo, Riegel, 2021). An exploratory study of health beliefs and behaviours of British Indians with type II diabetes found that participants wanted culturally sensitive forums to manage their diabetes (Patel, Iliffe, 2017). Again, emotional distress and the link of physical illness and emotional distress was not explored. With regards to help-seeking behaviour for mental health problems, shame has been shown to be a key barrier for seeking help and adherence to some cultural norms such as emotional self-control reduce help-seeking behaviour when distressed (Pulianda, 2020, Shahid et al., 2021).

## 2.3 Wider NHS context

The composition and role of the NHS and healthcare sector have been discussed in chapter 1. Key policy documents have attempted to address the health inequality of people with both mental and physical health problems. The NHS Long Term Plan  (NHS, 2019a), building upon the NHS Five Year Forward View (NHS, 2014) outlines the 10-year plan for the NHS. Its third action plan to deliver the Plan is ‘preventing illness and tackling health inequality,’ highlighting that people from ethnic minorities have an increased risk of poor health and premature death. It also describes multimorbidity as more common in poorer areas. There is a focus on improving physical and mental health. This includes preventing 150,000 heart attacks, strokes and dementia cases, and investing at least £2.3 billion a year more on mental health care. It describes delivering community-based physical and mental care for 370,000 more people with severe mental illness (as opposed to common mental health problems) annually by 2023/2024. The Plan also prioritises bringing together different professionals to coordinate care better, such as via ‘Integrated Health Systems’ combining NHS organisations and local partners to deliver joined up services to improve healthcare. Whilst the Plan described increased funding to areas of greater health inequality, it lacks direction towards improving the health of those with multimorbidity with nothing specifically to address multimorbidity. Instead, the Plan focuses on a single-disease model to improve health, focusing on specific diseases and how they can be better prevented or managed. This makes it arguably less relevant, meaningful or effective to a population in which multimorbidity can be considered the norm and not the exception (Luijks, Lagro-Janssen & van Weel, 2016). Linked to this, the NHS Mental Health Implementation Plan 2019/20 – 2023/24 (NHS, 2019b) provides a framework for delivering the NHS Long Term Plan with regards to mental health, building upon the Five Year Forward View for Mental Health (The Independent Mental Health Taskforce, 2016). Its key message is the additional £2.3 billion funding annually for mental health by 2023/24 and has ambitions related to improving the physical health of people with mental illness such as integrated community models for people with severe and enduring mental illness and 390,000 more to receive annual health checks. Whether this is enough, or instead aiming for increasing quality of care or even quality of annual checks rather than solely increased numbers of annual checks, is an area for consideration to truly have health benefits. The document describes developing a Patient and Carer Race Equality Framework (PCREF) to improve health outcomes of people from ethnic minorities. The Implementation Plan states a commissioning requirement for Improving Access to Psychological Therapies (IAPT) to provide a service for people with LTCs, a much-needed aspect of integrated care. However, there is a significant policy gap to integrating physical-mental health services; The King’s Fund’s highlights the need for a more integrated approach and ‘joined-up services’ to the significant number of people with both mental and physical multimorbidity after years of underinvestment and neglect to mental health services funding (The King's Fund, 2019).

## 2.4 Long-term conditions and multimorbidity

This section describes LTCs, followed by mental-physical multimorbidity.

### 2.4.1 Long-term conditions

Long-term conditions (LTCs) refer to chronic diseases for which there is no current cure; around 15 million people in the UK have long-term conditions (Department of Health, 2012). LTCs are primarily managed in primary care by a mixture of professionals such as GPs, practice nurses, and clinical leads from different backgrounds and they account for 50% of all GP appointments (The King's Fund, No date) and 70% of healthcare resources (NHS, 2014). The Quality and Outcomes Framework (QOF) delivers pay-for-performance to primary care for effective management of people with LTCs. QOF measures achievement based on health indicators to which practices score points according to their level of achievement. QOF is not without criticism, a systematic review of the role of QOF for the management of LTCs found a modest slowing of emergency admissions for severe mental illness and modest improvements in diabetes care, and no effect on mortality, integration or coordination of care, holistic care, self-care or patient experience. A second concern is that QOF may inadvertently worsen aspects care as general practices have to focus on QOF outcomes to secure income at the expense of other work (Hamel, Roland & Campbell, 2014).

Research has been conducted primarily in the general population regarding the experiences of living with long-term conditions. A meta-review of systematic reviews of qualitative studies exploring experiences of long-term life-limiting conditions found that help-seeking and decision making was influenced by the level of structural advantage, such as socioeconomic status and quality of health service, interactional advantage such as cognitive advantage, and the degree of structural resilience, such as managing adversity (May et al., 2016). The meta-analysis highlights the challenges of living with LTCs for both patients and carers although it focused on experiences of healthcare and did not explore experiences of emotional distress. The ‘work’ of living with multimorbidity causes a significant treatment burden, i.e. the work that a patient needs to do to care for their health and the effects of their health (May et al., 2014, Mair, May, 2014). Treatment burden is not just affected by the work of living with disease, but also its effect on patient identity (Demain et al., 2015). A scoping review providing the state of evidence on measuring the burden of treatment in chronic disease described a lack of research amongst ethnic communities and understandings of different cultures, and how it is a challenge due to different understandings of concepts such as health and illness (Sav et al., 2017). A systematic review exploring ethnic inequalities in management of LTCs in the UK found that SA and Black people had suboptimal disease management in comparison with people from other ethnicities (Hayanga, Stafford & Bécares, 2021). The authors did not find any qualitative studies which could explain reasons for this.

Mental health conditions are one of the most important LTCs, and range from common mental health problems such as depression and anxiety, to rarer conditions such as schizophrenia and bipolar affective disorder. Mental health problems are the leading cause of disability worldwide, accounting for 32.4% of years lived with a disability (Vigo, Thornicroft & Atun, 2016). Mental illness causes 11.2% of disability-adjusted life-years, second only to cardiovascular disease (Ibid). This highlights the importance and impact of mental health problems on society. Particularly at-risk groups for mental health problems include people with LTCs (MacMahon et al., 2018), older adults (Luppa et al., 2012) and ethnic minorities (Rees et al., 2016). All of these groups are relevant to this research.

People with depression and LTCs are likely to have poorer self-care than those with LTCs without depression, poor concordance with medical treatment and may disengage from lifestyle and behavioural changes that are known to be protective in people with LTCs (McKellar, Humphreys & Piette, 2004, Gonzalez et al., 2008, Penninx, 2017). This may be due to the psychological symptoms of depression such as poor motivation, physical symptoms such as lack of energy, and social symptoms such as withdrawal, added to an extra treatment burden of managing a LTC. Concordance refers to agreement after negotiation between clinicians and patients, whilst respecting patients' beliefs, about medication and whether/when/how it is taken (De las Cuevas, 2011). A cohort study in patients with diabetes started on medication for diabetes found that depression is an independent variable to medication nonadherence, although the odds ratio was only 1.24 with a 95% confidence interval of 1.13-1.37 (Lunghi et al., 2017). Whilst I prefer the term concordance, as it includes the negotiation between the patient and clinician, as opposed to adherence which is doctor-centric, the authors of the study used the term adherence. The study followed patients for one year so it is not known if this remains long-term. A systematic review and meta-analysis of depression and diabetes complications found increased micro- and macro-vascular diabetes complications by 33% and 38% respectively in patients with depression, and reported a bi-directional relationship with increased risk of depression in people with diabetes and increased risk of diabetes in people with depression, with the latter being a far greater risk (Nouwen et al., 2019). Culture and diversity were found to be important in epidemiological studies of diabetes and depression where is was felt a ‘culture-centred’ approach towards mental health was important (Lloyd et al., 2012). A comprehensive literature review assessing cross-sectional and longitudinal data from multiple studies reported that coronary heart disease is both a cause and effect of depression in a bi-directional relationship  (Khawaja et al., 2009). These studies highlight the poorer health outcomes of physical-mental health multimorbidity, as well as bi-directional relationship of both cause and effect, which makes research to improve physical-mental health multimorbidity a priority.

### 2.4.1 Mental-physical multimorbidity

Mental-physical multimorbidity is described as a priority, followed by the lived experience of mental-physical multimorbidity, managing people with mental-physical multimorbidity and managing emotional distress in a context of LTCs.

#### *2.4.1.1 Mental-physical multimorbidity as a priority*

Multimorbidity was discussed in Chapter 1. The Academy of Medical Sciences 2018 international policy report *Multimorbidity; a priority for global health research* (MacMahon et al., 2018) frames the research priorities for health on a global level. It summarises the existing research around multimorbidity and highlights research gaps and priorities. It prioritises mental health problems alongside physical health problems, with its first research priority including mental and physical health morbidity and its sixth research priority includes understanding strategies and organisational factors to better support patients with multimorbidity (MacMahon et al., 2018). Stigma around mental illness may lead to significant under-reporting in studies of multimorbidity (Mercer et al., 2012). A study found under-reporting of mental health problems to be far greater than under-reporting of physical health problems in multimorbidity (Bharadwaj, Pai & Suziedelyte, 2017). In people taking antidepressant and diabetic medication, under-reporting of a mental health problem was 45%, in comparison with under-reporting of diabetes of 14% (Ibid). This study was of over 250,000 people in Australia aged 45 and over, and the data may not be fully translatable to UK populations. Data covered 2007-2010 and perceptions around mental health may have significantly changed since over a decade. Data reporting prevalence of mental illness with multimorbidity must therefore be interpreted with caution due to under-reporting of mental health problems. Despite this, mental illness has been shown to be increased in patients with physical multimorbidity, with a *bi-directional* relationship (Mercer et al., 2012, Melis et al., 2014). People with mental health problems are more likely to develop chronic physical conditions and conversely people with chronic physical conditions are more likely to develop mental health problems (Ibid). A cross-sectional study of 181,845 people throughout 42 countries found that people with one LTC had a two-fold increase of anxiety symptoms, and increasing number of LTCs increased anxiety symptoms (Vancampfort et al., 2017). A systematic review assessing prevalence of combinations of multimorbidity found that people with a long-term physical condition (LTCs) are more likely to suffer from depression than any other physical or mental health condition (Sinnige et al., 2013). A cross-sectional analysis of 1,751,841 patients in Scotland examined the relationship of depression and 32 common chronic physical health conditions such diabetes, heart failure and asthma, found people with depression are more likely than the general population to have each of the 32 physical health conditions  (Smith et al., 2014).

People with physical-mental multimorbidity have poorer clinical outcomes, measured for example in quality of life and mortality  (Boast, 2018, Mujica-Mota et al., 2015, Gallo et al., 2016). A WHO survey of 245 404 participants from 60 countries found that depression has the largest effect on worsening health scores than any other condition (Moussavi et al., 2007). A survey of general practice patients (n=831, 537) in England found that having a comorbid mental health problem had the biggest impact on health-related quality of life in comparison to any physical health problems, with the exception of neurological conditions such as Parkinson’s disease (Mujica-Mota et al., 2015). A study in America found that people with depression and medical comorbidity were more likely to die than those without depression, with a hazard ratio of 3.02 (95 % CI, 1.32 to 8.72), and those with highest levels of medical comorbidity associated with depression were three times more likely to die than those with the same medical comorbidity and no mental health condition (Gallo et al., 2016). Notably, risk of mortality went back to baseline in the intervention arm of the trial that involved assigning a depression manager and proactive care of depression with psychotherapy and antidepressants when appropriate (Ibid). A Danish cohort study of 118,410 participants followed over four years found that in people with multimorbidity, mortality rates increased with increased perceived stress in a dose-response relationship (*P*-trend < 0.0001) independently of multimorbidity status (Prior et al., 2016). Most of the research on outcomes focuses on cross-sectional studies and there is a need for further longitudinal cohort data.

Research exploring depression with chronic disease has been conducted; A mixed methods systematic review exploring how patients understand depression associated with chronic physical disease described difficulties in labelling depression and emphasised the importance of patient beliefs with depression screening (Alderson et al., 2014). The beliefs of SA males with LTCs experiencing distress were not explored. In a q-methodology study of people with heart disease or diabetes and comorbid depression participants initially ranked statements and then explored reasons for these. The authors described differences primarily related to the cause of depression such as being overwhelmed, a medical problem, a shameful weakness or part of someone's personality, and whether medication would be helpful, but did not consider ethnicity and differences amongst these populations (Alderson, Foy & House, 2015). Similarly, a qualitative study of people with depression or coronary heart disease exploring their understandings of comorbid depression found that patients describe depression in the context of having a LTC not as a distinct physical illness but rather a change in their sense of self in the context of their life-story, and were unsure about seeking help from GPs (Alderson et al., 2014). Two of the 26 participants in this study were SA, and the study did not explore potential differences from people from different cultures and ethnicities (Ibid). A seminal paper addressing mental health research priorities for the 2020s unsurprisingly highlights its second priority as '*research to improve understanding of the links between physical and mental health, and eliminate the mortality gap* (Wykes et al., 2021, p4)*.'* This is relevant to my PhD study of SAs with LTCs experiencing emotional distress.

#### *2.4.1.2 The lived experience of mental-physical multimorbidity*

Within the general population, studies have taken place examining the lived experience of people with physical-mental multimorbidity. A systematic review and qualitative meta-synthesis found a line of argument synthesis around three main areas (Coventry et al., 2015). Encounters with complexity described how multimorbidity is more than the sum of its parts, with participants feeling that their bodies are falling apart. Marshalling medicines, emotions, and resources refers to patient experiences of balancing multiple medicines and side-effects. Emotional health (not defined in the study) was found to be managed differently to physical health, with behavioural strategies including social and spiritual components, as opposed to the physical health focusing on tactical use of medication. Emotions were martialled by changing *pace* and *place* of everyday life as well as social engagement including engagement with God. Self-preservation and prevention included patients 'doctoring themselves' and understood their inner-self to be fighting disease. Of note, 8/18 studies in the systematic review did not include ethnicity data and only two included recruited primarily from ethnic communities, meaning that the results cannot be extrapolated to ethnic communities. A meta-ethnography of qualitative studies coping with multimorbidity found four main themes; appraising multiple conditions (such as prioritising of conditions), maintaining a normal life and reducing treatment burden maintaining a positive attitude, and coping within their social context (Cheng, Inder & Chan, 2019). The meta-ethnography found that the cultural contexts and social stigma attached to LTCs was stressful and caused negative feelings (Ibid). The cultural contexts of SA have some differences to those in the general population.

Some research has been conducted in ethnic minority communities with multimorbidity from a qualitative perspective. A qualitative study in New Zealand of culturally and linguistically diverse patients' views on multimorbidity from Samoan, Cook Island Maori and Cambodian ethnicities (McKinlay, Graham & Horrill, 2015). The study reported that whilst these patients wanted to make lifestyle changes, but had difficulty in understanding how to manage their conditions, potentially due to their health beliefs (Ibid). Whilst there are some similarities in context of New Zealand and the UK, as well as the context of being ethnic minorities, there are many nuances and differences of the UK context, and it is not known how transferable these findings would be to SAs within the UK context.

#### *2.4.1.3 Managing people with mental-physical multimorbidity*

In the UK, the NICE guideline *Depression in adults with a chronic physical health problem: recognition and management* (2009) to support the management of people with depression in the context of LTCs (National Institute for Health and Clinical Excellence, 2009) emphasises an active approach of case-finding for depression in LTCs which has been supported by QOF financial payments for case-finding, and provides guidance around management including collaborative care. The perspectives of primary care clinicians on case-finding for depression for patients with diabetes and coronary heart disease has been explored. Participants described barriers with the implementation of case-finding leading to systematic under-detection of depression (Maxwell et al., 2013). There were multiple reasons for this, including a perception of care moving from being personalised to mechanistic care, a disconnect in nurses managing physical and mental health, bias towards negative answers, and nurses feeling they lacked the skills to provide support at the time (Ibid). A qualitative evidence synthesis around screening for diabetes distress and depression in people with type 2 diabetes found the only barrier of high confidence to be poor awareness about the rationale for screening (McGrath et al., 2021).

Collaborative care models can ensure integrated care in managing both mental and physical illness, emphasising mental health, shifting multimorbidity research priorities and holistically caring for people with mental-physical multimorbidity (Mercer et al., 2012, Struckmann et al., 2018). A pragmatic cluster-randomised trial of general practices in England and Scotland where practices were randomly allocated usual care or a comprehensive patient-centred 3D approach to multimorbidity based on dimensions of health, depression and drugs found that quality of life was not improved with the patient-centred approach (Salisbury et al., 2018). Notably, patient-centred outcomes such as the *Patient Assessment of Chronic Illness Care* (PACIC) and the *Consultation And Relational Empathy (*CARE) measures improved (Ibid). As it was a pragmatic trial reflective of the delivery of routine care in general practice, only 49% of intervention participants received their two planned 3D reviews, potentially limiting the potential effectiveness of the intervention (Ibid). Qualitative findings of a computer template to enhance patient-centredness in multimorbidity interviewing patients and clinicians found that patients welcomed holistic and comprehensive reviews, and that they uncovered some unmet health needs (Mann et al., 2018). Clinicians valued identifying patients' agendas, although some felt it diverted care from care of long-term conditions. A Lancet editorial reflecting the findings of the 3D paper suggested that delivering more patient-centred care in multimorbidity has been argued to be a goal in itself (Dowrick, 2018). Clinicians and patients have been shown to value collaborative ways of working, including a multi professional approach to care, structured management plans, scheduled follow-ups, and enhanced inter-professional communication, holistically manage emotional and physical health (Knowles et al., 2015).

Interviews exploring collaborative care integrating depression care with the management of LTCs found that whilst patients and professionals valued the holistic management of mental and physical health, they also preferred a therapeutic and spatial separation between mental and physical health, in particular patients with LTCs wanting a separate space to be able to describe their emotional problems (Ibid). Ethnic status was not noted for participants, and it is not known how much the findings would be applicable to people from ethnic minorities. A systematic review of 33 qualitative studies of GPs managing multimorbidity found that GPs struggle with practising without supportive evidence, working within a fragmented health care systems organised around single condition care and specialisation, as well as battling with clinical uncertainty around the complexity of multimorbidity (Damarell, Morgan & Tieman, 2020). GPs managed the challenges of multimorbidity by offering patient-centred care and relational continuity. Some GPs described their roles as that of a priest or friend. Notably the interviews from the study were with GPs so describing what GPs may like to do rather than may actually do (Ibid). The systematic review describes challenges and offers solutions; however, it is not known if these issues are relevant or not to ethnic communities. Relational continuity is increasingly recognised as a key pillar in the management of multimorbidity, both in terms of improved outcomes as well as patient perceptions (Salisbury, Tammes & Ridd, 2021, Brown et al., 2022, Mercer et al., 2016, Murphy, Salisbury, 2020, Sandvik et al., 2022). However, there is a steady decline in continuity of care in the UK (Tammes et al., 2021), likely due to fewer

GPs, rising workload and increasing complexity, and policies that prioritise access over continuity (Tammes, Salisbury, 2017, Murphy, Salisbury, 2020, Hobbs et al., 2016, Beech et al., 2019).

#### *2.4.1.4 Managing emotional distress in a context of LTCs*

Emotional distress and the difference between distress and mental health diagnoses was described in chapter 1. Research on management of people with emotional distress within (or outside) the context of LTCs is far less developed. Tools such as the four-dimensional symptom questionnaire  have been developed to distinguish between emotional distress and mental health diagnoses, which may make more appropriate management more effective for the fewer patients appropriately diagnosed with depression, reduced from 28% to 8% in a study, as well as those with emotional distress whereby non-medical interventions such as self-management interventions may be more appropriate (Geraghty et al., 2015). The authors suggest traditional interventions for depression management such as Cognitive Behavioural Therapy and medication (antidepressants) may be less effective in distress (Ibid). Understandings of cultural norms have been identified in the DSM-5 criteria when differentiating depression from culturally approved responses to stressors such as bereavement, which may manifest in distress (American Psychiatric Association, 2013).  A study of older adults reported that few sought help for emotional distress from general practice, and when they did they felt that the treatments offered were unacceptable (Moult, Kingstone & Chew-Graham, 2020). Although it is known that there are variations in the recognition, labelling and interpretation of distress (Kirmayer, 1989), little is known about emotional distress in SAs with LTCs.

## 2.5 Impact of covid-19 for people with LTCs

The covid-19 pandemic as described in chapter 1 had a significant impact on healthcare. The impact of acute covid infection on people with LTCs and SAs is described below, followed by the impact of change in access to healthcare widening existing health inequalities.

### 2.5.1 Impact of acute covid infection

The pandemic has highlighted significant health inequalities with regards to ethnic minorities. Diagnosis of acute covid-19 was found to be highest in people from black ethnic groups, 486 per 10,000 in females and 649 in males, in comparison people from white ethnic groups who had the lowest prevalence, 220 in females and 224 in males per 10,000 (Public Health England, 2020). A study of 8985 patients in London found SAs were found to have almost twice the odds of suspected covid-19 than white adults (Hull et al., 2020). Reasons for increased rates in ethnic minorities include people from ethnic communities having higher rates of deprivation, being more likely to work in professions putting them at risk of contracting covid-19 (such as healthcare), historic racism, poorer experiences of healthcare and cultural practices such as multi-generational households and different social practices (Tang et al., 2019, Sjödin et al., 2020, Bhala et al., 2020). In the Northwest of England, overcrowding in ethnic minority households was found to be 11% in comparison with 1% in the general population (Marmot et al., 2021). Socioeconomic deprivation has an important role within this, and research has shown that people with multimorbidity from lower socioeconomic backgrounds are more likely to have other health conditions, first and foremost mental health and substance abuse problems (Mair, Jani, 2020). However, ethnic disparities in prevalence of covid-19 are still present when socioeconomic disparities are accounted for (Niedzwiedz et al., 2020). Higher levels of chronic disease can be considered a reflection of social and economic disadvantage (Bhala et al., 2020). It has been argued that '*racism is a fundamental cause and driver of adverse health outcomes in ethnic minorities as well as inequities in health'* (Razai et al., 2021a, p2). This includes structural (including institutional) racism, cultural racism and discrimination (Ibid).

Vaccine hesitancy amongst South Asians has been highlighted during the covid pandemic, highest amongst black, Pakistani and Bangladeshi ethnicities (Robertson et al., 2021a). Reasons for his have been explored less, which may include a deep distrust of structural hierarchy due to racism, prejudice and colonialist history and the 2011 United States fake vaccination program in Pakistan as part of its military strategy (Kennedy, 2017, Razai et al., 2021b). These make ethnicity and covid-19 an urgent healthcare priority (Pareek et al., 2020, Morales, Ali, 2021). Public Health England prioritised the importance of cultural competency and provided funding for culturally competent covid-19 education and prevention campaigns in partnership with local ethnic and faith communities (Public Health England, 2020).

There was an increased risk of mortality from covid for people with LTCs such as diabetes and coronary heart disease as well as those with multimorbidity, socioeconomic deprivation and ethnic minority groups (Iaccarino et al., 2020, Williamson et al., 2020). Prognosis for people who contracted covid-19 was worse when these factors, such as LTC, socioeconomic deprivation, and ethnicity, combined (McQueenie et al., 2020).

### 2.5.2 Impact of changes to access to healthcare widening existing health inequalities

The impact of changes to access to health widening existing qualities are described from a physical as well as mental health perspective.

#### *2.5.2.1 Physical health inequalities*

During the pandemic, the management of people with LTCs, primarily based within primary care, became online. Online appointments were found to be easier for some, but for others, in particular those less digitally-literate, the general public perceived that GPs were not ‘open-for-business’ and not to seek help due to healthcare being under pressure, with a message at the start of lockdown to ’save the NHS’ (Healthwatch, 2021). Rates of presentation for diagnoses of depression within primary care decreased by 43% of expected and anxiety 48%, of expected in April 2020 (Carr et al., 2021). This was reflected across clinical areas within primary care as people were reluctant to present to primary care (Khalil-Khan, Khan, 2023). This may be partially explained by the perception of difficulty of access of general practice during the pandemic, greater challenge for people with mental health problems in booking appointments, valuing physical health as the priority and neglecting mental health problems during the pandemic, and perception of limited benefit of GPs helping mental stressors during this time (Carr et al., 2021). In a qualitative study reported in 2022, GPs reported that they were disadvantaging digitally-excluded patients (Turner et al., 2022). In December 2020, 75% of people reported negative sentiments regarding GP access, 20% higher than the same time in the previous year (Ibid). The report highlights those most disadvantaged from these changes, including people to whom English isn't a first language (Ibid). Ethnic minorities are regarded as those who suffered more from the chronic disease management during the pandemic, due to potential digital literacy or access or potentially limited English proficiency (Nouri et al., 2020).

Chronic disease management deteriorated during the pandemic, for example February-March 2020 in comparison with pre-pandemic levels, blood testing decreased by 81–90% and new medication therapy by 52–60% ($P < 0.001$) (Wright et al., 2020). A report from 10 organisations addressing deterioration in people with long-term conditions during the pandemic described how lockdowns, reduced social contact, suspended rehabilitation services, re-deployment of staff to acute services and care moving virtual impacted people with LTCs more than the general population and led to people with LTCs health deteriorating more than the general population (Alzheimer's Society et al., 2021, Hayhoe et al., 2022).

#### *2.5.2.2 Mental health inequalities*

Regional mental health inequalities have been noted during the pandemic, and the North of England has been particularly affected, for example an increase of minor psychiatric disorders 55% in the North compared with 50% in the rest of England and self-reported mental health reducing by 4.4% in comparison with 3.9% in the rest of England (Munford et al., 2021). Mental health has been shown to deteriorate in people with multimorbidity during the pandemic; a study in primary care in Hong Kong found a marked deterioration of psychological health during the pandemic (Wong et al., 2020).

As well as increasing physical health disparities among ethnic minorities, the covid-19 pandemic has increased mental health disparity amongst ethnic minorities (Kapilashrami, Bhui, 2020, Smith, Bhui & Cipriani, 2020). A Canadian study showed ethnic minorities have experienced higher levels of mental distress during the pandemic, potentially related to exposure to the virus, discrimination and stigma (Miconi et al., 2021). A UK study found that mental health deteriorated more in men from ethnic minorities as opposed to white

British men, in particular with distress highest in men from Bangladeshi, Indian and Pakistani backgrounds (Proto, Quintana-Domeque, 2021). There is a need for research in this area as there is a current lack of knowledge of mental health disparities in ethnic minorities during covid-19 (Smith, Bhui & Cipriani, 2020). This highlights the importance of researching mental health amongst ethnic communities during the pandemic, as well as its effects after the pandemic.

## 2.6 Research aims and objectives

The introduction and literature review have highlighted the impact of physical-mental health multimorbidity, emotional distress, and poorer outcomes and research gaps in ethnic community groups, in particular men of SA origin with LTCs. Researching mental health in ethnic minorities can be considered a priority due to the health inequalities.

The research aims were:
To explore how males of SA origin with LTCs understand, experience and seek help for emotional distress.
To explore the perspectives and experiences of GPs working in practices with a high density of SAs.

The research objectives were to explore:

1. *How do males of SA origin with LTCs understand emotional distress, its nature and causes?*
2. *What help-seeking strategies do males of SA origin with LTCs origin use for emotional distress, and do these differ for physical problems?*
3. *What are the facilitators and barriers to GPs supporting males of SA origin with LTCs in identifying and managing emotional problems in SA males with physical-mental comorbidity?*
4. *What services are needed to best support males of SA origin with LTCs for emotional distress?*

5. *How has the covid-19 pandemic affected the mental health of males of SA origin with LTCs, its management and the management of their LTCs, from the perspective of males of SA origin?*
6. *From the perspective of GPs, how has the covid-19 pandemic affected the mental health of males of SA origin with LTCs, its management and the management of their LTCs?*

## 2.7 Chapter summary

The literature review has highlighted the challenges of mental and physical multimorbidity. Addressing this is a priority for the NHS, highlighted by several key policy statements. Ethnic minority groups are under-served by healthcare and have poorer outcomes, such as reduced life expectancy and being more likely to become unemployed, homeless and die by suicide if they have mental health problems. Ethnic minority groups have higher rates of some LTCs, such as diabetes and coronary heart disease in SAs, the largest ethnic minority in the UK.

There is a lack of research in SA males, in particular in a context of LTCs and emotional distress. The research took place within the context of the covid-19 pandemic and the health impact of the covid-19 pandemic was therefore explored. Chapter 3 will provide a systematic review, asking how do people of SA origin with LTCs understand, experience and seek help for emotional distress?

# Chapter 3: Systematic Review

## 3.1 Introduction

This chapter presents a systematic review of qualitative studies which was conducted to explore perceptions of emotional distress in people of SA origin with diabetes and/or coronary heart disease, which has been published in the British Journal of General Practice (Awan et al., 2022).

The chapter begins by describing the background to the systematic review, its aims and objectives and then the methods used. The results are described, initially with overall results, followed by more detailed analysis. A quality appraisal of individual studies as well as overall strength of evidence is included. The discussion follows, which includes implications for research and clinical practice and areas for future research, followed by the chapter summary.

## 3.2 Background

Literature reviews are a key element of research to summarise and synthesise multiple studies on a topic. There are at least 14 distinct types of literature review found within literature (Grant, Booth, 2009), of which systematic reviews are the most well-known. Systematic reviews provide an overview of the available evidence in an area, systematically searching for it, appraising the evidence and synthesising it (Sackett et al., 2000). They adhere to specified guidelines using explicit, systematic methods, to minimise bias and for the data to be more reliable to be acted upon (Higgins et al., 2019). A common alternative is a scoping review, which provides an overview or map of evidence when the potential size and scope of research within an area is not known (Grant, Booth, 2009, Munn et al., 2018). Scoping reviews are less rigorous and are often used to gather further information when it is unclear which questions needs answering by a systematic review (Munn et al., 2018). A systematic review was chosen after reviewing the relevant literature, given the research available in the area and a precise question to be answered. Furthermore, the rigour and robustness associated with systematic reviews is potentially valuable to inform recommendations for policy and practice.

Qualitative evidence synthesis is understood to be increasingly important in health research by providing evidence to inform decisions around healthcare (Tong et al, 2016; Glenton et al 2016; Booth 2017; Carroll 2017). The Cochrane handbook dedicates a chapter to qualitative evidence, explaining how qualitative evidence synthesis can improve health of populations by providing decision makers with a deeper understanding of stakeholder experiences, their values and attitudes, understanding of interventions and variation in context (Noyes et al., 2022). Qualitative systematic reviews not only gather data, but interpret the broader data to form new understandings (Grant, Booth, 2009).

As described in chapter 2 background, mental-physical multimorbidity is an increasing challenge and a key research priority facing 21st century healthcare (MacMahon et al., 2018). People with physical–mental comorbidity have a poorer quality of life, worse clinical outcomes, and increased mortality compared with people with physical conditions alone. Despite being potentially underreported because of stigma (Mercer et al., 2012), there is more mental illness in patients with physical multimorbidity because of a bi-directional relationship (Melis et al., 2014). People with a LTC are more likely to have depression than any other condition (Sinnige et al., 2013).

Research shows that ethnic minority groups are underserved within health care (Derr, 2015, Meyer, Takeuchi, 2014). They are less likely to recognise mental illness, perceive a need for medical intervention, or utilise services  (Villatoro, 2014, Miyasato, 2016), and are undersupported by statutory services (Bhui, Halvorsrud & Nazroo, 2018). Cultural and religious beliefs and stigma influence help-seeking behaviour and willingness to take prescribed medication in people with mental illness from ethnic minority groups (Park, Jang & Chiriboga, 2018). People may present with physical symptoms, rather than identifying an underlying psychological problem (Bhui, Halvorsrud & Nazroo, 2018), which provides a challenge within primary care for diagnosis and management. Clinician understanding and interpretation of different cultures further affects consultations and how the patient's history is obtained and understood, and also how management plans are formulated (Ibid).

To provide effective care for underserved groups, it is argued that GPs must understand the patient's view of themself and also demonstrate this understanding to the patient (Lamb et al., 2012).

SAs make up 24.9% of the world population and have significant populations in different countries throughout the world (Lamb et al., 2012, Worldometer, 2021). SAs are the largest minority group in the UK, with Asians making up 9.3% of the population according to the Census 2021 report (Office for National Statistics, 2023); increased from 7.5% in 2011 and 4.8% in 2001 (Office for National Statistics, 2013). They share cultural features both as indigenous and immigrant populations, which is important given the intrinsic relationship of culture and health (Gopalkrishnan, 2018). SAs have a higher prevalence of LTCs such as diabetes with a prevalence of 14% compared with 6.9% in the general population (Holman et al., 2011) and coronary heart disease prevalence 11% compared with 5% of Europeans (Anand et al., 2000) . Previous research has explored SA women's mental health from both quantitative and qualitative perspectives (Kapadia, Nazroo & Tranmer, 2018, Smith et al., 2019), including exploring British Pakistani women's experiences of depression (Tabassum et al., 2011), and to a limited extent mental health in South Asian males (Bhui, Chandran & Sathyamoorthy, 2002, Lai, Surood, 2008). In addition, a systematic review focused on experiences of mental health problems and stress amongst SAs (Karasz et al., 2019). However, there is a gap in the literature about the experiences of people of SA origin with LTCs, and their experiences of emotional distress, which this systematic review aimed to address.

## 3.3 Systematic review aims and objectives

The systematic review asked, *how do people of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress including depression and anxiety?*

Three specific objectives were set:

1. *How do people of SA origin with LTCs understand emotional distress, its nature and causes?*

2. *What is the experience of people of SA origin with LTCs of emotional distress?*
3. *What help-seeking strategies do people of SA origin with LTCs origin use for emotional distress?*

## 3.4 Systematic review methods

This systematic review was conducted and reported according to the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (see appendix 3.4 for ENTREQ checklist) (Tong et al., 2012) and the protocol was registered with the International prospective register of systematic reviews (PROSPERO ID: CRD42019151217, https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=151217). It was primarily conducted by myself, supported by a five-person review team consisting of the three PhD supervisors and a research student.

### 3.4.1 Eligibility criteria

The inclusion and exclusion criteria are listed below:

Inclusion criteria:

- ‘South Asian’ includes people of origin of India, Pakistan, Bangladesh, Afghanistan, Sri Lanka, Maldives, Nepal, Bhutan, Indian Ocean Islands.
- Population with diabetes and/or coronary heart disease as exemplars of LTCs, as these are some of the most common LTCs in South Asians
- Adults (18 years +)
- Studies that describe understanding, experience, or help-seeking behaviour for emotional distress including depression or anxiety
- Primary care, community care and any community settings worldwide. This is because, as noted in the literature review, there are many elements of SA culture which transcend the country people of SA origin are based in
- Qualitative study design or mixed-methods studies with a qualitative element

Exclusion criteria:

- American Indians, Native Americans, Indigenous Americans
- No formal diagnosis of coronary heart disease or diabetes
- Paediatric only (age ≤17 years) studies
- Studies of schizophrenia, psychosis and cognitive decline such as dementia
- Studies solely exploring carer experiences
- Secondary and tertiary healthcare settings
- Quantitative studies; Conference abstracts; Reviews; Editorials; Opinion pieces
- Full-text not available

### 3.4.2 Search strategy and data sources

Comprehensive searches of eight databases were conducted from inception to 1 September 2021: Medline, Embase, PsycINFO, ASSIA, CINAHLPlus, AMED, Web of Science (Social Science citation index and Conference Proceedings Citation Index — Social Science and Humanities), and Index Medicus for the South-East Asia Region. Searches utilised database subject headings and text words (title, abstract, and keywords) combining terms for 'South Asian' and 'diabetes' or 'heart disease' and 'emotional distress' and 'qualitative research' (DeJean et al., 2016) (see Appendix 1 for the Medline search strategy). The search strategy was developed by myself and reviewed with Nadia Corp (NC) who is an information specialist. In addition, reference checking and citation tracking of included studies was also undertaken. Search results were downloaded and imported into Proquest RefWorks (https:// refworks.proquest.com). Duplicates were removed and screening undertaken within RefWorks.

### 3.4.3 Study selection

Two independent reviewers, myself and Faraz Mughal (FM), screened titles and abstracts according to the eligibility criteria and those that did not meet inclusion criteria were excluded by agreement. A checklist was compiled of inclusion/exclusion criteria for reference, to aid the selection process. Full texts were screened independently by two reviewers (myself and FM) to determine eligibility and reasons for excluding papers recorded. At both stages, disagreements were resolved through discussion or referral to a third reviewer.

### 3.4.4 Data extraction

Included studies were subject to data extraction and quality appraisal. I developed and piloted a data extraction form using Microsoft Excel. Data were extracted from the abstract, results, and discussion sections if relevant. Information was extracted regarding: the study aim, design, data collection methods, method of analysis, participant demographics, setting, number of participants, understanding, experience, help-seeking behaviour for emotional distress, and language of data collection. Data extracted included participant quotes as well as author descriptions of findings. This formed the data for the synthesis.

### 3.4.5 Quality appraisal

Quality assessment of each study was completed alongside data extraction using the Critical Appraisal Skills Programme (CASP) checklist for qualitative data (Critical Appraisal Skills Programme, 2018). Disagreements were resolved through discussion to achieve consensus. Although quality assessment is required to identify biases within the research that could distort findings, studies were not excluded on the basis of quality to allow for broad insights (Carroll, Booth & Lloyd-Jones, 2012).

### 3.4.5 Data synthesis

A thematic synthesis was conducted by myself in collaboration with FM, NC, Carolyn Chew-Graham (CCG) and Tom Kingstone (TK). Thematic synthesis is based on a realist position in which the data is synthesised to provide concrete outcomes which can be more useful in terms of informing health policy (Hannes, Lockwood, 2011). Narrative synthesis was considered, whereby findings are synthesised using words and texts to summarise and explain them and ‘tell the story’ of the findings (Popay et al., 2006); but this was felt to be less appropriate as it is considered more useful in systematic reviews of both qualitative and quantitative data requiring a greater degree of interpretation, and is more useful in the development of new theory (Boland, Cherry & Dickson, 2017). Narrative synthesis is less good at identifying commonality than thematic synthesis and potentially more prone to bias (Lucas et al., 2007, Barnett-Page, Thomas, 2009). The thematic synthesis, based on Thomas and Harden (Thomas, Harden, 2008), involved three stages:

1. Coding of text line-by-line according to its meaning and content.
2. Translatable concepts from the primary studies will then be used to develop descriptive themes.
3. Analytical themes will then be formed which generate new meaning and explanations.

After coding began with initial studies, subsequent studies were coded into pre-existing codes, with new codes created when deemed necessary. An inductive approach was used, allowing the data to determine the themes. I kept a reflexive diary throughout the process and the research team discussed reflections on their backgrounds and preconceived ideas around the topic and its effect on the development of the themes. Descriptive themes were developed, reviewed, and refined iteratively by all members of the research team allowing for members to view raw data and support the generation of analytical themes. The research team consisted of three academic GPs, two of whom are SA, a systematic review specialist, and a social scientist. I initially undertook the coding and thematic synthesis using NVivo (version 12) software analysis to facilitate the thematic synthesis (Lumivero, 2019).

### 3.4.6 Overall strength of evidence

Confidence in the Evidence from Reviews of Qualitative Research (GRADECERQual: https://www.cerqual.org), was used to review the overall strength of evidence, initially by myself and reviewed by all the team. GRADECERQual is based on four components exploring the methodological limitations, relevance, coherence and adequacy of the overall evidence. Methodological limitations assess the extent to which there are concerns about the design or conduct of primary studies supporting a review finding. Relevance looks at the extent to which the body of data from the primary studies supporting a review finding is applicable to the context of the specific research question. Coherence refers to how clear and convincingly the data from the primary studies supports the review finding, such as including contradictory and ambiguous data. Adequacy refers to the level of richness and quantity of data supporting a research finding, for example if the data comes from a number of studies or one or a few studies.

### 3.4.7 Patient advisory group contribution

The study patient advisory group (PAG) played a key role during the systematic review process. Initially, a meeting took place between the PAG in which the systematic review question was refined, core components of the systematic review were discussed along with key search terms and the methods used. Members of the PAG suggested that the systematic review was very much needed, and discussed the benefits and challenges of grouping South Asians under one culture. The PAG was updated throughout the systematic review via email and in a second meeting discussed the results of the systematic review in detail, including the themes that were found and relevancy to themselves. Members of the PAG discussed a number of themes they would have expected to find which were in fact absent from the literature. Reasons for this were discussed. Further details of this are in 3.6 (Patient advisory group feedback).

## 3.5 Results

### 3.5.1 Description of studies

The search identified a total of 3,910 records, which reduced to 3,165 after deduplication. Title and abstract screening led to 37 articles identified for full text screening, and subsequently 21 studies were included for the synthesis. A PRISMA flow diagram has been created depicting this process (see Figure 1).

The characteristics of included studies are reported in Table 1. Studies were from: India (n=7), Nepal (n=2), Pakistan (n=2), Bangladesh (n=1), UK (n=4), Canada (n=1), United States (n=1), Australia (n=1), Norway (n=1) and Qatar (n=1). Eleven studies included people with diabetes, three with diabetes in pregnancy, one with diabetes and heart disease and six studies were of people with coronary heart disease. Four of the studies based in India articles with people with diabetes were based on the same initial cohort of patients and have been considered as one study. Two of the Indian articles with people with diabetes and coronary heart disease were based on the same initial cohort of patients and have been considered as one study. One study included 30 participants of four ethnicities (including non-SA) and did not state how many participants of each ethnicity, and one study had participants with four different diseases and did not state how many had diabetes and heart disease, leading to an approximation of 580-606 participants of SA origin included, 575-601 participants with diabetes, 93 participants with coronary heart disease and 2-39 participants with diabetes and heart disease. Study methods used: semi-structured interviews (n=6), in-depth interviews (n=6), focus groups and in-depth interviews (n=3), focus groups (n=2), semi-structured interviews and case studies (n=1), group story-sharing sessions and individual biographical life narrative interviews (n=1) and narrative interviews (n=1). Ages ranged from 21-88 years old when stated (n=9). Whilst some described ethnicity broadly as SA (n=4), however, the majority of studies gave more specific details. Where ethnicity was mentioned, in order of number largest numbers, participants were from Indian, Bangladesh, Nepal, Pakistan and Sri Lanka.

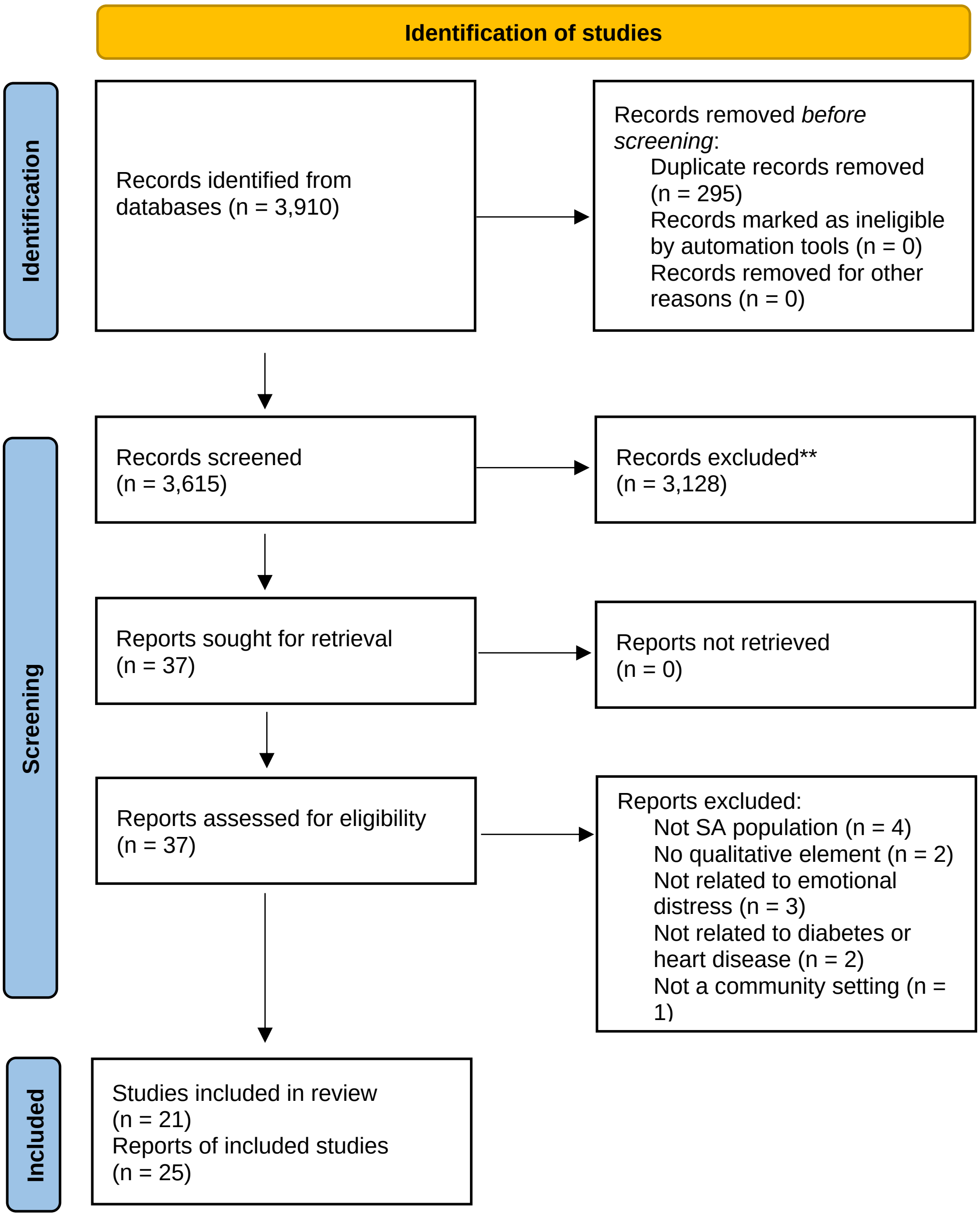


Figure 1 PRISMA flow diagram

Table 1 Characteristics of included studies

| **Study Reference** | **Country** | **Methods** | **Participants** | **Age range (years)** | **Male (%)** | **Language of data collection** |
|---|---|---|---|---|---|---|
| **Diabetes studies** | | | | | | |
| (Bukhsh et al., 2020) | Pakistan | In-depth interviews | 32 Pakistani | 35-75 | 38% | Urdu |
| (Greenhalgh et al., 2015) | UK | Group story-sharing sessions and individual biographical life narrative interviews. | 45 including Bangladeshi, Indian, Sri Lankan, Pakistani<br>Diabetes in pregnancy | 21-45 | 0% | English, Urdu, Tamil, or Sylheti |
| (Ijaz, Ajmal, 2011) | Pakistan | Semi-structured interviews | 4 Pakistani | 40-70 | 50% | Not stated |
| (Islam et al., 2017) | Bangladesh | In-depth interviews | 12 Bangladeshi | 38-66 | 42% | Bengali |
| (Manderson , Kokanovic, 2009) | Australia | In-depth interviews | 30 of different ethnicities, not stated how many South Asian | Not stated | Not stated | English |
| (Mendenhall et al., 2012) | India | In-depth interviews | 59 Indian | Mean 55 ± 10.3 SD | 51% | Hindi |
| (Mendenhall et al., 2016) | India | Focus groups and in-depth interviews | 53 Indian | Mean 54 ± 10.3 SD | 51% | Hindi |
| (Mohamed et al., 2017) | Qatar | Focus groups | 200 South Asians (not stated further) | Not stated | Not stated | English |
| (Nielsen et al., 2020) | India | In-depth interviews | 19 Indian | 24-38 | 0% | Tamil and English |

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
|  |  |  | Diabetes in pregnancy |  |  |  |
| (Rao et al., 2016) | India | Focus groups and in-depth interviews | 52 Indian | 27-67 | 48% | Tamil, Telugu, or Hindi, |
| (Sharma et al., 2021) | Norway | Focus groups | 9 Pakistani, 6 Sri Lankan, 3 Indian<br>Diabetes in pregnancy | Mean 34 plus ± 4 SD | 0% | Norwegian, English, Urdu and Hindi |
| (Thapa, 2014) | Nepal | Semi-structured interviews | 29 Nepalese | 27-77 | 66% | Nepalese |
| (Weaver et al., 2015) and (Weaver, Madhu, 2015) | India | Semi-structured interviews structured around a modified version of Kleinman's illness narrative protocol | 30 Indian | 27-78 | 0% | Hindi and English |
| (Weaver, 2016) |  | Case study | 2 | One participant 62, other not stated |  |  |
| (Weaver, Mendenhall, 2014) |  | Case study | 1 | 54 |  |  |
| (Wilkinson, Randhawa & Singh, 2014) | UK | Semi-structured interviews | 28 South Asians (not stated further) | 34-77 | 52.3% overall (all ethnicities) | Bilingual researchers used, not stated which languages |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Diabetes and coronary heart disease studies** | | | | | | |
| (Singh et al., 2021a, Singh et al., 2021b) | India | In-depth interviews | 41 Indian participants in total who had at least one of 4 diseases. Not stated how many had diabetes and coronary heart disease | Mean 56 | 61% | Hindi, Telegu, Tamil |
| **Coronary heart disease studies** | | | | | | |
| (Bhattacharyya, Stevenson & Walters, 2016) | UK | Semi-structured interviews | 10 Indian, 8 Bangladeshi | 44-88 | 82% | English, Bengali, Sylheti |
| (Jiwani et al., 2017) | US | Interviews based on Leventhal's Common Sense Model (CSM) of self- regulation | 20 including Indian, Pakistani, Bangladeshi | 40% under 55 | 75% | English, Urdu, Hindi |
| (Oli et al., 2014) | Nepal | In-depth interviews | 13 Nepalese | Mean 59.6 ± 13.8 | 46% | Nepalese |
| (Mishra et al., 2021) | India | Focus groups and in-depth interviews | 19 Indian | Mean 51 | 63% | Hindi |
| (Schwind et al., 2016) | Canada | Narrative interviews | 4 South Asians (not stated further) whose primary languages are Gujurati, Tamil or Hindi | All 60+ | 0% | English with translator for Gujurati, Tamil and Hindi |

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| (Webster, Thompson & Davidson, 2003) | UK | Semi-structured interviews | 19 Indian | Mean 65 | 84% | English or Gujurati |

### 3.5.2 Quality assessment

The quality appraisal of the studies according the CASP criteria is outlined collectively in Figure 2 and individually for each study in Table 2. This addresses the 10 questions from the CASP checklist for qualitative data questions based on three areas, if the results are valid, what the results are, and if they will help locally. The questions can be answered as yes (✓), no (x) or partial (p).

Figure 2. Overall quality appraisal based on 10 questions from CASP checklist for qualitative data

Table 2 Quality appraisal for individual studies using the 10 questions above from the CASP checklist for qualitative studies.

| Study ID | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| **Diabetes studies** | | | | | | | | | | |
| (Bukhsh et al., 2020) | ✓ | ✓ | ✓ | ✓ | ✓ | x | ✓ | p | ✓ | Valuable.<br>New insights into the practices and experiences of people with diabetes in urban areas of Pakistan |
| (Greenhalgh et al., 2015) | ✓ | ✓ | ✓ | ✓ | ✓ | x | ✓ | p | ✓ | Valuable.<br>Robust qualitative methodology, clearly presented. |
| (Ijaz, Ajmal, 2011) | ✓ | ✓ | p | x | ✓ | x | x | p | ✓ | Valuable.<br>Interesting findings but lack of methodological clarity. |
| (Islam et al., 2017) | ✓ | ✓ | ✓ | p | ✓ | N | ✓ | x | ✓ | Valuable.<br>Well-described study. |
| (Manderson, Kokanovic, 2009) | ✓ | ✓ | ✓ | p | ✓ | x | ✓ | p | ✓ | Valuable.<br>Improvement of anxiety with time after diabetes diagnosis is a good example of new valuable knowledge. |
| (Mendenhall et al., 2012) | ✓ | ✓ | ✓ | p | ✓ | p | ✓ | p | ✓ | Valuable.<br>The first study to examine the social experiences of men and women with diabetes across income groups in urban India. |
| (Mendenhall et al., 2016) | ✓ | ✓ | ✓ | p | ✓ | x | ✓ | p | ✓ | Valuable.<br>Discourse marketplace model offers unique insight into complexity of healthcare and alternative systems. |
| (Mohamed et al., 2017) | ✓ | ✓ | ✓ | p | ✓ | x | ✓ | p | ✓ | Valuable.<br>Contribution to evidence in Qatar. |
| (Nielsen et al., 2020) | ✓ | ✓ | ✓ | ✓ | ✓ | x | ✓ | ✓ | ✓ | Valuable.<br>Provides insights into the barriers and facilitators to treatment as experienced by women with diabetes in pregnancy in rural and urban areas in India. |
| (Rao et al., 2016) | ✓ | ✓ | ✓ | p | ✓ | x | ✓ | p | ✓ | Valuable.<br>Useful for intervention development and implementation. |
| (Sharm et al., 2021) | ✓ | ✓ | ✓ | ✓ | ✓ | x | ✓ | ✓ | ✓ | Valuable.<br>Contrasting experiences of South Asian and Nordic women. |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| (Thapa, 2014) | ✓ | ✓ | ✓ | p | ✓ | x | ✓ | p | ✓ | Valuable.<br>Unique insights crossing anthropological and medical fields |
| (Weaveret al., 2015, Weaver, Madhu, 2015, Weaver, 2016, Weaver, Mendenhall, 2014) | ✓ | ✓ | ✓ | ✓ | ✓ | x | ✓ | p | ✓ | Valuable.<br>Contribution to existing knowledge as sociocultural and gendered factors in particular 'caretaking activities' protective for mental health.<br>Improvement of anxiety with time after diabetes diagnosis is a good example of new valuable knowledge<br>Using theories, to explore co-morbidity in diabetes. |
| (Wilkinson, Randhawa & Singh, 2014) | ✓ | ✓ | ✓ | ✓ | ✓ | x | ✓ | p | ✓ | Valuable.<br>Contribution to existing knowledge that attitudes to diagnosis of diabetes are not based on ethnicity. |
| **Diabetes and coronary heart disease studies** | | | | | | | | | | |
| (Singh et al., 2021a, Singh et al., 2021b) | ✓ | ✓ | ✓ | ✓ | ✓ | x | ✓ | ✓ | ✓ | Valuable.<br>The first study to investigate the lived experiences of patients with chronic conditions during the COVID-19 pandemic in India. |
| **Coronary heart disease studies** | | | | | | | | | | |
| (Bhattacharyya, Stevenson & Walters, 2016) | ✓ | ✓ | ✓ | ✓ | ✓ | p | ✓ | p | ✓ | Valuable.<br>Well-described study providing important implications. |
| (Jiwani et al., 2017) | ✓ | ✓ | ✓ | p | ✓ | x | ✓ | p | ✓ | Valuable.<br>Clear presentation of interview findings. |
| (Oli et al., 2014) | ✓ | ✓ | ✓ | p | ✓ | p | ✓ | p | ✓ | Valuable.<br>New direction for research identified. |
| (Mishra et al., 2021) | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | Valuable.<br>New insights into experiences of stigma, with non-concordance with medication due to stigma. |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| (Schwind et al., 2016) | ✓ | ✓ | ✓ | p | ✓ | ✓ | ✓ | p | ✓ | Valuable.<br>Excellent reflexivity, such as the first author describing a struggle between her role of acting as a researcher and not care-giver, and holding back from teaching and educating them in her role. |
| (Webster, Thompson & Davidson, 2003) | ✓ | ✓ | ✓ | p | ✓ | x | ✓ | p | ✓ | Valuable.<br>Primary of value to Gujarati community as limited evidence base. |

✓ Reported

P Partially reported

X Not reported

### 3.5.3 Main themes

Three main themes were identified: understanding emotional distress, experience of emotional distress and management of emotional distress. These comprised of 10 sub-themes, which are presented in Figure 3. The GRADE-CERQual assessment of strength of evidence for each theme are presented in Table 3 as well as contributing studies to each theme.

Figure 3 Main Themes

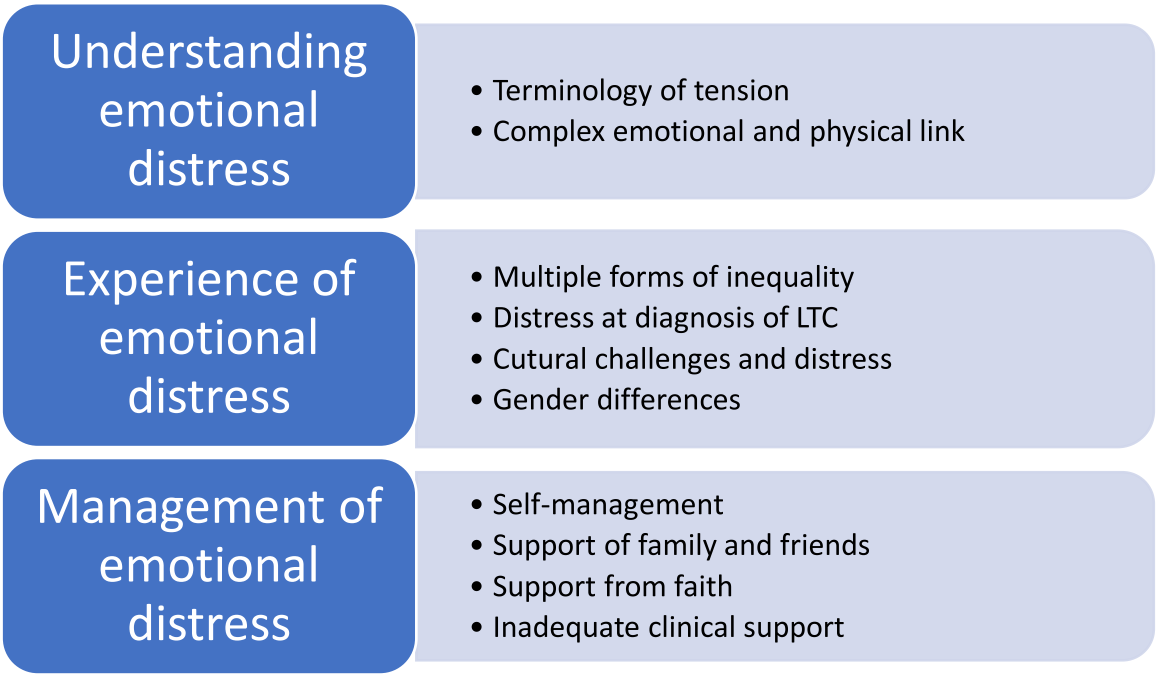


Table 3 GRADE-CERQual assessment of themes

| Sub-theme and contributing studies | Methodological limitations | Coherence | Adequacy | Relevance | CERQual confidence assessment |
|---|---|---|---|---|---|
| **MAIN THEME: UNDERSTANDING EMOTIONAL DISTRESS** | | | | | |
| **Terminology of tension (n=14):** (Greenhalgh et al., 2015, Ijaz, Ajmal, 2011, Islam et al., 2017, Manderson, Kokanovic, 2009, Mendenhall et al., 2012, Mendenhall et al., 2016, Rao et al., 2016, Thapa, 2014, Weaver et al., 2015, Weaver, Madhu, 2015, Weaver, 2016, Weaver, Mendenhall, 2014, Wilkinson, Randhawa & Singh, 2014, Bhattacharyya, Stevenson & Walters, 2016, Schwind et al., 2016, Webster, Thompson & Davidson, 2003, Singh et al., 2021a, Singh et al., 2021b) | 1/14 studies lacked methodological clarity. | Clear and cogent fit between the data from the studies and the finding. No contradictory data. | Rich and large quantity of data from 14 studies. | Spread of studies from a range of different international settings with data highly relevant to the review question. | High |
| **Causation and complexity with emotional and physical illness (n=18):** (Greenhalgh et al., 2015, Ijaz, Ajmal, 2011, Islam et al., 2017, Manderson, L., Kokanovic, 2009, Mendenhall et al., 2012, Mohamed et al., 2017, Rao et al., 2016, Thapa, 2014, Weaver et al., 2015, Weaver, Madhu, 2015, Weaver, Mendenhall, 2014, Bhattacharyya, Stevenson & Walters, 2016, Oli et al., 2014, Schwind et al., 2016, Webster, Thompson & Davidson, 2003, Sharma et al., 2021, Nielsen et al., 2020, Bukhsh et al., 2020, Singh et al., | 1/18 studies lacked methodological clarity. | Clear and cogent fit between the data from the studies and the finding. No contradictory data. | Rich and large quantity of data from 18 studies. | Spread of studies from a range of different international settings with data highly relevant to the review question. | High |

| | | | | | |
|---|---|---|---|---|---|
| 2021a, Singh et al., 2021b, Mishra et al., 2021) | | | | | |
| **MAIN THEME: EXPERIENCE OF EMOTIONAL DISTRESS** | | | | | |
| **Multiple forms of inequality (n=10):** (Manderson , Kokanovic, 2009, Mendenhall et al., 2012, Mendenhall et al., 2016, Thapa, 2014, Weaver, 2016, Weaver, Mendenhall, 2014, Bhattacharyya, Stevenson & Walters, 2016, Schwind et al., 2016, Mishra et al., 2021, Singh et al., 2021a, Singh et al., 2021b, Nielsen et al., 2020) | Ten studies of good methodological quality. | Clear and cogent fit between the data from the studies and the finding. No contradictory data. | Rich data and good quantity from 10 studies in multiple international settings. | Spread of studies from a range of different international settings with data highly relevant to the review question. | High |
| **Distress at diagnosis of LTC (n=10):** (Ijaz, Ajmal, 2011, Manderson, Kokanovic, 2009, Mendenhall et al., 2016, Weaver. et al., 2015, Weaver, Madhu, 2015, Wilkinson, Randhawa & Singh, 2014, Bhattacharyya, Stevenson & Walters, 2016, Schwind et al., 2016, Webster, Thompson & Davidson, 2003, Nielsen et al., 2020, Sharma et al., 2021) | 1/10 studies lacked methodological clarity. | Clear and cogent fit between the data from the studies and the finding. No contradictory data. | Rich and good quantity of data from 10 studies. | Spread of studies from a range of different international settings with data highly relevant to the review question. | High |
| **Cultural challenges and distress (n=14):** (Greenhalghet al., 2015, Manderson, Kokanovic, 2009, Mendenhall et al., 2016, Rao et al., 2016, Thapa, 2014, Weaver, Madhu, 2015, Bhattacharyya, Stevenson & Walters, 2016, Jiwani et al., 2017, Schwind et al., 2016, Webster, Thompson & Davidson, 2003, Singh et al., 2021a, Singh et al., 2021b, Sharmaet al., 2021, Mishra et al., 2021, Nielsen et al., 2020) | Fourteen studies of good methodological quality. | Clear and cogent fit between the data from the studies and the finding. One study displays contradictory findings. | Rich and good quantity of data from 14 studies. | Spread of studies from a range of different international settings with data highly relevant to the review question. | High |

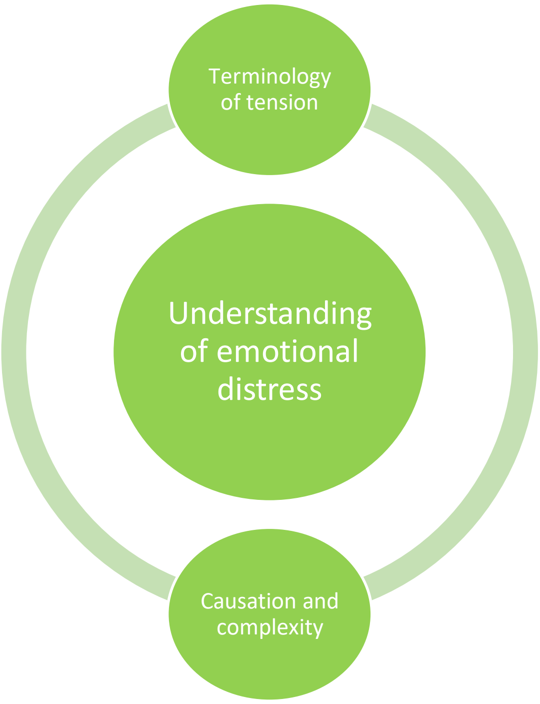
| | | | | | |
|---|---|---|---|---|---|
| **Gender differences (n=8):** (Mendenhall et al., 2012, Mohamed et al., 2017, Wilkinson, Randhawa & Singh, 2014, Weaver, 2016, Weaver, Mendenhall, 2014, Bhattacharyya, Stevenson & Walters, 2016, Schwind et al., 2016, Webster, Thompson & Davidson, 2003, Nielsen et al., 2020) | Eight studies of good methodological quality. | Clear and cogent fit between the data from the studies and the finding when reviewed collectively. No contradictory data. | Rich data but limited quantity from 8 studies. | Few studies addressed this issue directly, however comparing studies, such as female-only studies vs male responses strengthened the relevance of this theme. | Moderate |
| **MAIN THEME: MANAGEMENT OF EMOTIONAL DISTRESS** | | | | | |
| **Self-management (n=13):** (Greenhalgh et al., 2015, Ijaz, Ajmal, 2011, Manderson, Kokanovic, 2009, Mendenhall et al., 2016, Mohamed et al., 2017, Rao et al., 2016, Weaver et al., 2015, Weaver, Madhu, 2015, Weaver, 2016, Wilkinson, Randhawa & Singh, 2014, Bhattacharyya, Stevenson & Walters, 2016, Jiwani et al., 2017, Oli et al., 2014, Schwind et al., 2016, Webster, Thompson & Davidson, 2003) | 1/13 studies lacked methodological clarity. | Clear and cogent fit between the data from the studies and the finding. No contradictory data. | Rich and good quantity of data from 13 studies. | Spread of studies from a range of different international settings with data relevant to the review question. | High |
| **Support of friends and family (n=8):** (Greenhalgh et al., 2015, Ijaz, Ajmal, 2011, Mohamed et al., 2017, Rao et al., 2016, Bhattacharyya, Stevenson & Walters, 2016, Weaver, 2016, Oli et al., 2014, Manderson, Kokanovic, 2009) | 1/8 studies lacked methodological clarity. | Clear and cogent fit between the data from the studies and the finding. Contradictory data in multiple studies present where family | Rich and good quantity of data from 8 studies. | Spread of studies from a range of different international settings with data highly relevant to the review question. | Moderate |

| | | | | | |
|---|---|---|---|---|---|
| | | and friends can be a source of stress. | | | |
| **Support from faith (n=6):** (Ijaz, Ajmal, 2011, Mohamed et al., 2017, Bhattacharyya, Stevenson & Walters, 2016, Schwind et al., 2016, Webster, Thompson & Davidson, 2003, Sharma et al., 2021) | 1/6 studies lacked methodological clarity. | Clear and cogent fit between the data from the studies and the finding. One study displays contradictory findings. | Rich data but limited quantity from 6 studies. | The context of the primary studies included was similar to that of the research question in different international settings. | Moderate |
| **Inadequate clinical support (n=7):** (Greenhalgh et al., 2015, Mohamed et al., 2017, Mendenhall et al., 2016, Weaver et al., 2015, Bhattacharyya, Stevenson & Walters, 2016, Webster, Thompson & Davidson, 2003, Nielsen et al., 2020) | Seven studies of good methodological quality. | Clear and cogent fit between the data from the studies and the finding. One study displays contradictory findings. | Rich data but limited quantity from 7 studies. | The context of the primary studies included was similar to that of the research question. | Moderate |

### 3.5.4 Understanding of emotional distress

Two sub-themes themes emerged regarding understanding of emotional distress: using the terminology of tension to describe emotional distress, and causation and complexity with emotional and physical illness. These are shown below in Figure 4.

Figure 4 Understanding of emotional distress



#### *3.5.4.1 Terminology of tension (high confidence- 14 studies)*

Terminology used regarding emotional distress was noticeable by a lack of use of medical terminology such as *depression, anxiety* or *distress*. In one study the authors described,

> ‘*People rarely described these emotional crises as ''depression.'' They did not necessarily associate their sadness, sense of hopelessness or despondency with depressive illness.’* (Manderson, Kokanovic, 2009, p26)

Not only were episodes of emotional distress not considered as mental health episodes; they were not associated with mental health diagnosis by the SA participants. Emotional distress was instead defined primarily as *tension*:

> ‘*I got it [diabetes] from tension after my husband’s death.’* (Mendenhall et al., 2012, p2525)

Other terminology used to describe emotional distress included specific emotions, such as *stress* (Weaver, L. J. et al., 2015) and *anger* (Mishra et al., 2021). This included situations where patients had clinical symptoms of depression and were treated for it, they still tended to consider it as emotional turmoil within their social construct and not an independent diagnosis of depression. Conversely, participants felt labelling their emotional distress as a diagnosis such as depression minimised their emotional journey whilst having an LTC and its associated ‘*social dislocation*.’ (Manderson, Kokanovic, 2009, p26).

#### *3.5.4.2 Causation and complexity with emotional and physical illness (high confidence- 18 studies)*

SAs with LTCs described a complex and inter-related relationship between emotional distress and physical illness. Emotional distress was described to cause physical illness, from both acute and chronic stress. For example, an Indian participant stated:

> ‘*I got diabetes because of tension only. It’s not because of food habits or lifestyle.’* (Mendenhall et al., 2012, p2525)

Another participant ascribed his heart attack to his perpetual psychological inclination towards anger (Webster, Thompson & Davidson, 2003)

As well as being a causative agent of physical illness, emotional distress was further felt to cause a deterioration in physical illness, as a Bangladeshi participant who had experienced a heart attack stated that ‘*worry make you worst don’t it.’* (Bhattacharyya, Stevenson &

Walters, 2016, p5) Others described how distress not only caused disease, but also affected their ability to manage their illness and influence its progression,

> '*I didn't go for treatment because I was afraid of operation. My children were still small . . . I thought ... if I die ... what would happen to them?'* (Oli et al., 2014, p6)

One participant described how a stressful event would impact their physical health for days,

> 'G*ive me any stressful situation even now and my sugar levels shoot up. It takes me days to bring it back to normal.'* (Manderson, Kokanovic, 2009, p25)

The link between causation of physical illness and emotional distress was described in one study to be stronger in middle and higher socioeconomic groups (Mendenhall et al., 2012). The cause of emotional distress was also different, with participants from middle and higher socioeconomic groups describing intra-family tension as a key causer of emotional distress, such as the mother-in-law and daughter-in-law relationship,

> '*My in-laws were not reasonable people. They were biased for one thing or another. They scolded me all the time. She [mother-in-law] never let me leave; all the time I was busy with housework.*' (Mendenhall et al., 2012, p2526)

Whilst not in poverty, they were still stressed by the pursuit of wealth and status,

> '*The major reason for tension in today's world is the status factor: we need to have a car, a bungalow, so much money to survive. I guess people are running behind [in status] and [they belief that] if you don't have all this, you would not be respected in society.*' (Mendenhall et al., 2012, p2526)

People from lower socioeconomic groups described poverty, including inter-generational poverty, as a greater source of stress (Thapa, 2014). Participants based in India described restrictions on land ownership and lack of access to education and employment opportunities as a significant cause of stress causing diabetes. However, having money without purposive employment could also be a source of stress from feeling empty, as one participant explained,

> '*God has given me so much that three generations of my family can eat without doing any work, just sitting. But I feel empty.'* (Weaver, 2016, p507)

Physical illness was felt to cause emotional distress. One study described how:

> '*Participants also considered that diabetes ''caused'' stress in relation to controlling the condition and preventing complications, and in response to doctors' comments.'* (Manderson, L., Kokanovic, 2009, p24)

Numerous elements were thought to lead to physical illness causing emotional distress. This included regret and not making lifestyle change earlier (Jiwani et al., 2017), symptoms of the LTC such as physical restrictions caused by shortness of breath (Oli et al., 2014), stress of making lifestyle changes (Rao et al., 2016), anxiety around tests such as checking blood sugar (Weaver, Madhu, 2015), and taking medication, in particular insulin (Mohamed et al., 2017) For women with diabetes in pregnancy, distress stemmed from the stress of health consequences for the participant, their baby, and managing a busy schedule of multiple clinic appointments and regular testing (Greenhalgh et al., 2015, Sharma et al., 2021, Nielsen et al., 2020).

Participants reported that positive emotional health reduced physical illness (Wilkinson, Randhawa & Singh, 2014b). When physical health was good, this also had a positive impact on emotional wellbeing,

> '*When my blood sugar level is normal I become very happy*.' (Ijaz, Ajmal, 2011, p51)

This led to a level of stoicism in some participants, carrying on with their lives with as much normality as they could, without letting themselves feel upset by their illness,

> ‘*Diabetes is non-curable you just have to live with it and do the best you can, it will not go away by feeling sorry for yourself you know.’* (Mohamed et al., 2017, p630)

Other causes of distress included *Kismet* (destiny), which was often linked to a belief in sin as a cause of illness,

> ‘*Fate brings illness but still ... it’s our sins*.’ (Webster, Thompson & Davidson, 2003, p293)

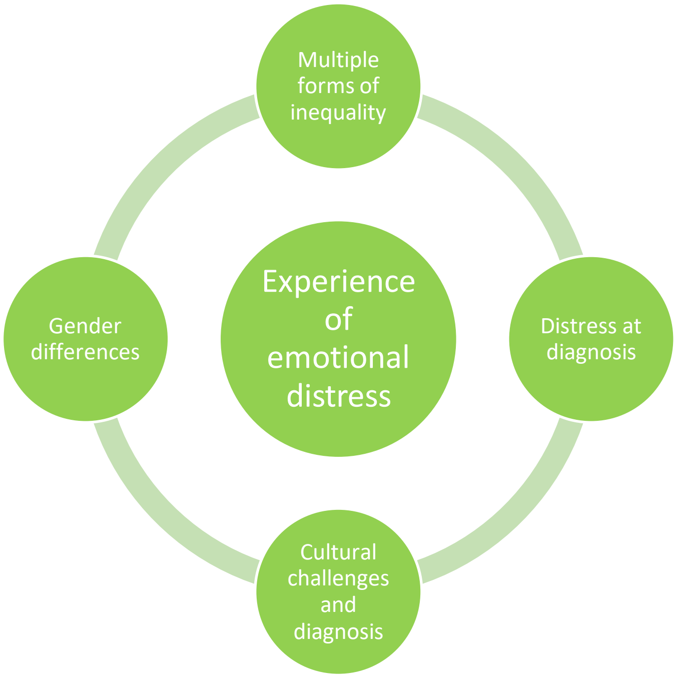
A fatalistic perspective could also lead to a resignation to poor health,

> ‘*I’m going to die anyway, so I might as well eat what I like*.’ (Weaver, Mendenhall, 2014, p100)

### 3.5.5 Experience of emotional distress

Four sub-themes emerged regarding experiences of emotional distress: multiple forms of inequality, distress at diagnosis of the LTC, cultural challenges and distress, and gender differences. These are shown in Figure 5.

Figure 5 Experience of emotional distress



#### *3.5.5.1 Multiple forms of inequality (high confidence- 10 studies)*

SAs described multiple forms of inequality as a source of distress throughout studies of different contexts worldwide, as well as a direct cause of physical illness. Poverty was described throughout all studies internationally.

> ‘*Poverty causes illness and illness causes poverty, it is a cycle in this way… in my experience chhinta* (angst/anxiety) *and poverty gave me the gift of sugar.’* (Thapa, 2014, p433)

As well as limited access to medication, and health clinics, these participants described how healthier foods and vegetables were more expensive than unhealthy foods which they knew would worsen their illness,

> '*Another financial suffering is that I cannot afford the food that I need to eat nor can I afford medicines and blood tests. Always money is going and going; for a poor person like me this is a big suffering*.' (Thapa, 2014, p435)

Poverty was exacerbated by loss of employment due to the LTC, as one participant stated,

> '*I was laid off from my work after my heart problem.*' (Schwind et al., 2016, p4)

The extent of suffering from poverty was so severe that a female Nepalese participant described attempting suicide due to severe poverty and not being able to manage her diabetes,

> '*It (diabetes) doesn't kill you and it doesn't allow a comfortable life. In other words, I cannot live or die. Therefore, very often I used to think about committing suicide and look for the easy way out. . . . I don't want to live such a painful life and I don't want to be a burden to anybody else. I was longing for and shouting for my death. . . . I went near to the forest when I was ready to be to hang myself. One of my neighbours, who I did not see, was watching me and I stopped (when I saw him) . . . still death is far better than this suffering for me.'* (Thapa, 2014, p436)

The concept of living with a chronic disease being *worse than death* was also felt with heart failure, with one participant describing how

> '*I feel myself a liability ... internally I pray to God that please take me, I've had enough now.'* (Webster, Thompson & Davidson, 2003, p293)

A participant explained how caste-based discrimination causes '*unbearable psychological pain.'* (Thapa, 2014, p434) . Another described how,

> ‘*We were oppressed and suffered discrimination, and the reason for our poverty was that we were the serving caste to the high caste. We became landless and poverty has become the cause of our suffering now. . . . The main reason that I believe I have sugar is chhinta… We as Dalit people experience poverty and poverty causes chhinta and this makes the blood sugar go up*.’ Another described how ‘*in my experience chhinta and poverty gave me the gift of sugar.’* Another elaborated that ‘*the domination and discrimination and disregard created low self-esteem, anger, anxiety, and chhinta, and Dalit became at high risk of developing sugar.’* (Thapa, 2014, p434) .

A combination of being SA, having a LTC, poverty and covid lead to feelings of helpless and emotional distress from loss of income. (Singh et al., 2021a)

> *‘The income is stopped so this is natural worry. That’s the tension which I have on every 3rd or 4th day.’* (Singh et al., 2021a)

Participants were anxious about attending hospital care due to their higher risk of mortality with covid given their LTC. A participant with diabetes described,

> *‘Everyone scares us saying that it is difficult for the diabetic. So I didn’t want that to happen. Because they had the spread the awareness that diabetics, old aged people have a problem during this corona. And yes I was scared.’* (Singh et al., 2021a, p4)

#### *3.5.5.2 Distress at diagnosis of LTC (high confidence- 10 studies)*

Participants reported a wide range of emotions relating to the initial diagnosis of a LTC; this was felt to be a life-defining moment. These included being ‘*scared’* (Nielsen et al., 2020, p7) *‘shocked’* (Wilkinson, Randhawa & Singh, 2014, p183), *‘fear*’ (Oli et al., 2014, p6) and *‘a disaster’* (Mohamed et al., 2017, p629). An emotional journey was described in one study were participants initially felt shock, followed by low mood, anxiety and resentment at their impaired physical ability (Bhattacharyya, Stevenson & Walters, 2016). Some participants described a negative change in aspects of their personality after diagnosis, such as lacking confidence and motivation, which was more profound in participants with coronary heart disease (Bhattacharyya, Stevenson & Walters, 2016, Manderson, Kokanovic, 2009). This was linked with perceived vulnerability,

> '*If anybody wants to hit me for nothing, or to push me, I would say, 'I'm right,' but I would say, 'I am sorry.' Because mentally I thought I am not strong enough, I've got a weak heart.'* (Bhattacharyya, Stevenson & Walters, 2016, p4)

One participant described how a change in personality after diagnosis impacted his personality and therefore relationships,

> *'Before, I had so much energy. I could take on a lot, lot more. I was a 'Yes, I'm a go-ahead person,' and now I have sit back and think whether I can really live up to that commitment. And no-one's happy with that because they can't accept that change in me all.'* (Manderson and Kokanovic, 2009, p26)

Emotional distress related to the LTC tended to reduce over time with participants '*getting used to'* (Weaver, Madhu, 2015, p2336) their illness. A participant described how,

> *'Initially I used to get tensed [by my diabetes]. But I have accepted it.'* (Mendenhall et al., 2016, p302).'

### *3.5.5.3 Cultural challenges and distress (high confidence- 14 studies)*

Culture was found to play an important role in experience of emotional distress. One participant described how it was part of Indian culture to have high levels of stress,

> '*Yes in our Indians we take on a lot of tension*.*'* (Webster, Thompson & Davidson, 2003, p294)

Acculturation (the process of adjusting to a new culture) was described in many forms; one example of this was from people of SA origin who were in a higher socioeconomic demographic in their country of origin who had to adapt to changing roles and more manual work in their country of destination,

> '*I came to Canada from India 25 years ago with my husband and two children. I was a teacher in my home country so I never had to do any physical work. In Canada I worked very hard in the factory for fifteen years to support my family. My husband did not work much. I looked after my old mother, brought up my children and looked after my grandkids. I started having heart trouble one day when I was at work. I told my supervisor and he sent me home. I came back to work the next day. The pain returned and I was taken to the hospital. I think I had a heart attack.'* (Schwind et al., 2016, p4)

They described stress due to conforming to expectations of the country they migrated to, which were different from their country of origin. Participants also described a lack of support systems which were available in their countries of origin as a greater compounder of stress (Schwind et al., 2016).

Some elements of South Asian culture contradicted medical advice regarding healthy lifestyles, potentially causing tension. One participant described how

> '*I try to eat right, but it's hard since I like Indian food. I cannot eat salt, sugar, oil and fat, which is hard to do.'* (Schwind et al., 2016, p4)

Within SA culture, there was a greater level of stigma felt for people with LTCs, such as gestational diabetes being viewed as a occurring as a result of lack of self-discipline (Sharma et al., 2021), and discrimination felt by participants with coronary artery disease (Mishra et al., 2021) and if they contracted covid (Singh et al., 2021a). One participant described that

> '*Near my home in my area they speak very bad about diabetes people.*' (Rao et al., 2016, p6)

Cultural differences were identified. Indian men were found to normalise symptoms of cardiac events, for example stating after a heart attack , '*I feel that nothing happened to me,'* (Bhattacharyya, Stevenson & Walters, 2016, p4) whereas Bangladeshis experienced more anxiety, low mood, less positivity and a greater fear of lifting heavy objects (Bhattacharyya, Stevenson & Walters, 2016). This caused a stress based on cultural expectations of males being the providers for their families, as a Bangladeshi participant described,

> '*Obviously as a man, obviously if you have family, obviously the first thing you think about is money...So that's why I'm worried. So money worries financial worries sometimes. If you are very badly problem in financial then it makes you upset and you can put yourself in depression...I don't want to be dependent. I don't want for someone to support me. I feel humiliated...Like I'm just sitting down, sleeping, working, smoking, eating, and she's earning money and she's buying food for me. I don't want to do that.'* (Bhattacharyya, Stevenson & Walters, 2016, p5)

#### *3.5.5.4 Gender differences (moderate confidence- 8 studies)*

Differences were found between the experience of male and female people of SA origin with LTCs. Females tended to have stronger emotional reactions, in particular to diagnosis, and related negative feelings to experiences of family members. One female participant stated,

> '*Yes it was shock, because I saw my brother [who had diabetes], he was really bad* (Wilkinson, Randhawa & Singh, 2014, p183)

Resilience against mental health was described as related to their caring and domestic roles within the family, yet these same roles impeded their self-management of their chronic illness (Weaver et al., 2015).

Men perceived having less control of their health, describing an external locus of control in different manners (Mohamed et al., 2017) and greater emotional distress with regards to their employment,

> ‘*Obviously as a man, obviously if you have family, obviously the first thing you think about is money… I don’t want for someone to support me. I feel humiliated.*’ (Bhattacharyya, Stevenson & Walters, 2016, p5)

### 3.5.6 Management of emotional distress

Four sub-themes emerged regarding management of emotional distress: self-management, support of family and friends, inadequate clinical support, and support from faith. These are shown in Figure 6.

Figure 6 Management of emotional distress

### *3.5.6.1 Self-management (high confidence- 13 studies)*

A key area described prior to seeking help for emotional distress was self-management. Self-management began with having a positive mindset. One participant described the power of positive thinking, stating

> '*It's your thinking that makes your body feel sick. It's all in the mind*.' (Weaver et al., 2015, p127)

Some participants made proactive lifestyle changes after coping with emotional distress from their LTC, such as going from multiple jobs to one job after a coronary event,

> '*I get chest pain with stress but I did change. Before, I was working 3 to 4 jobs at a time, but now - 1 at a time.'* (Jiwani et al., 2017, p5)

Other lifestyle modifications included stress reduction techniques, such as exercise, yoga, prayer, voluntary work, listening to music and reducing smoking and alcohol intake (Oli et al., 2014). Participants also tried to avoid situations which would make them '*emotional and hyped up.*' (Manderson, Kokanovic, 2009, p28)

### *3.5.6.2 Support of family and friends (moderate confidence- 8 studies)*

Family and friends were described as great sources of support during distress, in particular children who were active in their parents' lives.

> '*My son lives not far from my house. I see him every day. We're a close family. I've got brothers, sisters-in-law, nephews. We are very close. Just a phone call and they'll all be there. So that way I'm really happy. Lucky anyway...When you can count on somebody, even in the back of your mind, you relax. At least you know somebody cares and they are there when you need them. That makes all the difference to me.'* (Bhattacharyya, Stevenson & Walters, 2016, p5)

One study found the involvement of family and friends the most important mechanism of maintaining emotional wellbeing and physical health (Oli et al., 2014). They also described how family and friends accommodated to their mood and lower energy levels, usually in terms of excellent support. Health was viewed as a family responsibility, with family members giving support with the management of their LTC, keeping them away from stress and negativity from others, and supporting them financially (Oli et al., 2014). Advice from peers was '*familiar, meaningful, and morally resonant*' (Greenhalgh et al., 2015, p1). Work colleagues were also described as supportive (Bhattacharyya, Stevenson & Walters, 2016). This helped raise patients' emotional state as well as providing practical support with domestic and work chores. One participant explained how

> '*We want to belong to a group to share our feelings*.' (Mohamed et al., 2017, p630)

When family and in particular children were not involved, this caused negative emotions,

> *'I have kids, but they don't visit; they are too busy with their own children and with work. I am now separated from my husband*. *I am lonely*.' (Schwind et al., 2016, p4)

Whilst the majority of participants described support of family and friends, some described that their family's approach caused greater stress due to the added burden upon the family,

> *'When my family came to know about my disease they became stressed because they had to cook separately for me from now on.'* (Oli et al., 2014, p7)

Perceived help and support from family and friends was interpreted by some as a source of their distress by singling them out. One participant described feeling '*being watched'* (Mohamed et al., 2017, p628) whilst another stated that

> *'When I call my daughter to check my blood sugar, she asks me why it's so high. . . . She says, what did I eat? And she starts fighting with me about it.'* (Weaver, 2016, p508)

Participants felt distress from aspects of their children's lives, including issues with children such as gambling and drug-taking behaviour, as well as unfulfilled expectations such not getting married or being able to support them. One participant described

> '*Whether they're doing good in school or not, that has a lot to do with my sugar levels staying there as well*.' (Manderson, Kokanovic, 2009, p28)

Another described how marriage of children was a source of distress,

> '*I am tensed about my children's marriage. We have been searching for a good match for my daughters for two years. We are not getting our choice in grooms. We want our daughters to be happy after marriage.*' (Mendenhall et al., 2012, p2526)

#### *3.5.6.3 Support from faith (moderate confidence- 6 studies)*

A strong theme across ethnic groups was a faith in a higher being and emotional support from the higher being as well as their spiritual community, be it from the temple or mosque community (Schwind et al., 2016). This was strongest amongst the Bangladeshi community, as one participant stated,

> '*It all depends how much faith you have on the Almighty… people who, they have weak faith they're more worried...If you have strong faith that gives you strength in order to endure the situation and overcome it and adjust to it.'* (Bhattacharyya, Stevenson & Walters, 2016, p5)

Practically, acts of worship such as 'Dhikr,' (saying formulas of remembrance of God), were felt to reduce distress,

> '*Dhikr of Allah gives relief to hearts and because of this our sugar is under control. Whatever it is, it is from Allah and we have to accept it heartedly*.' (Ijaz, Ajmal, 2011, p52)

Attendance at faith centres such as the temple, or community centres was described as a source of psychological support. In the context of being lonely, one participant described how

> ‘*I try to go to the community centre and to the Temple whenever someone can take me there*.’ (Schwind et al., 2016, p4)

Participants found strength in belief that the disease was from a higher being and gave them the strength to manage it,

> ‘*Disease is from Allah, I have to face it*.’ (Ijaz, Ajmal, 2011, p52)

Whilst the majority of participants described support of faith, some displayed reticence and frustration with the higher being. One participant struggling with eyesight complications of diabetes described how,

> ‘*Now I feel sad with the thought that Allah is depriving me from many things with time.’* (Ijaz, Ajmal, 2011, p51)

#### *3.5.6.4 Inadequate clinical support (moderate confidence- 7 studies)*

Participants of all ethnicities were critical of clinical support, for both their psychological issues and their medical issues, for example,

> ‘*Doctors are not helping us.’* (Mohamed et al., 2017, p628)

Another participant described how *'doctors never explain why I am feeling down’* (Mohamed et al., 2017, p629). Some participants described clinicians being rude, discriminatory and uncaring (Bhattacharyya, Stevenson & Walters, 2016, Nielsen et al., 2020). Health education advice was felt to be unfamiliar, using medical jargon and devoid of empathy and cultural meaning (Greenhalgh et al., 2015). This led to a scepticism of clinicians,

> ‘*I stopped going to the doctors because there was so many problems with the medicines… He was creating problems about my blood pressure medicine. I must take it, my blood pressure medicine but he was making difficulties.’* (Webster, Thompson & Davidson, 2003, p293)

Others complained of family members being used as interpreters, or poor quality of NHS interpreters (Bhattacharyya, Stevenson & Walters, 2016). One explained how clinicians were perceived to be problem-orientated and not solution-focused,

> ‘*Nobody talks about how to protect yourself , but they are good at pointing out that I will be blind, I will have a heart attack.’* (Mohamed et al., 2017, p629)

Conversely, participants from all ethnic backgrounds who had a heart attack stated they would like access to psychological support following the event (Bhattacharyya, Stevenson & Walters, 2016). Participants also described visiting traditional healers for psychological as well as physical problems in SA countries (Mendenhall et al., 2016)

## 3.6 Patient advisory group feedback

The findings were discussed with the patient advisory group (PAG), providing a further layer of credibility (i.e. confidence in the ‘truth’ of the findings) as the PAG members agreed with all of the themes. However, some members of the PAG discussed a number of culturally common beliefs which were not found in the review, such as ‘black magic’ and ‘envy’ as causes of emotional distress, and faith leaders as a source of support. The group discussed how these concepts may not have been mentioned due to censorship, participants may not have felt comfortable discussing such concepts with the interviewer, and they may not have been considered in interview questions. They also discussed cultural help-seeking behaviours such as using scripture and religious leaders, which again were absent from the existing literature. The group felt that these concepts may not be elicited except through direct questioning with interviewers who understand SA culture. The PAG views cannot be said to be representative of views of people of SA origin with LTCs and further research would be needed to assess representability.

## 3.7 Reflexivity

During my meeting with the PAG I felt a significant level of embarrassment. When they discussed SA concepts such as black magic and envy causing distress, I realised that these were concepts of SA culture I am very aware of, yet I had not considered them as my focus was thinking primarily as a researcher, and to an extent I had disregarded my SA roots. This made me realise the value of a PAG.

A second point of note is regarding the publication of the systematic review, which changed ‘gender differences’ to ‘sex differences,’ explaining this is according to the journal’s style. For the thesis chapter, ‘gender differences’ were preferred as the male/female differences can be viewed from a lens of a social construct, as opposed to purely biological differences which the term sex differences may indicate (World Health Organisation, No date.a). The differences between men and women found in this systematic review are deeper than purely biological factors and SA social and cultural interpretations of gender influence the findings, hence the term gender used here.

## 3.8 Discussion

The discussion begins with the summary of the key findings, strengths and limitations, comparison with current literature and the implications for research and clinical practice.

### 3.8.1 Summary of key findings

This review synthesised evidence regarding the understanding, experience, and help-seeking behaviour for emotional distress, depression and anxiety in people of SA origin with LTCs. Distress is understood in terms of tension and emotions such as stress and anger, with medical terminology such as depression of less relevance. Emotional distress and physical illness have a complex and inter-related relationship. With regards to experiences of emotional distress, multiple forms of inequality lead to emotional distress, such as poverty, being SA, and having a LTC. The time of diagnosis of the LTC is particularly difficult. Adapting from specific aspects of SA culture is a significant cause of emotional distress. Gender differences have been identified. With regards to management, people of SA origin self-manage via activities such as stress reduction exercises, prayer and exercise. Family and friends are reported to be an excellent source of support. Generally, spiritual and religious support is felt to be important and clinical support is felt to be of limited benefit and devoid of cultural meaning.

### 3.8.2 Strengths and limitations

This is the first systematic review to explore the understanding, experiences and help-seeking behaviour for emotional distress of people of SA origin with LTCs. It highlights a gap between the need of this group for support for emotional distress and the services offered by clinicians. The GRADE-CERQual assessment of themes ranged from high to medium, providing greater confidence in the evidence of the review. The review has the potential to lead to improvement in the recognition and management of emotional distress. This study has the potential to influence policy-makers and commissioners about service provision for this patient group. An ethnically-appropriate PAG was another strength of review. The PAG discussed causes of potentially missing data, such black magic, envy and faith leaders as a source of support. The group suggested these concepts may not have been mentioned due to censorship, participants may not have felt comfortable discussing such concepts with interviewers, or they may not have been considered in topic guides. The group felt that these concepts may not be elicited except through direct questioning with interviewers who understand SA culture.

A limitation is the challenge of comparing the experiences of SA within and outside of South Asia. Whilst cultural aspects may remain consistent, different contextual factors mean that comparisons must be made with caution. Furthermore, whilst there are many similarities across SAs, they encompass a diverse group with different geographical areas, languages and religions, and there is a level of heterogeneity and difference between the experience of SAs of different backgrounds which could be further explored.

### 3.8.3 Comparison with previous literature

This review builds upon previous systematic reviews of emotional distress and mental health problems in SAs (Karasz et al., 2019) and experiences of living with LTCs in SAs (Sohal et al., 2015, Garrett et al., 2012, Galdas, Ratner & Oliffe, 2012). It provides new understanding in exploring emotional distress in people of SA origin with LTCs by bringing together multiple studies. The review shows that the relationship between emotional distress and physical illness is complex and inter-related. This leads to more than purely the addition of two (or more) separate illnesses, but instead a new entity of comorbidity which is greater than the sum of its parts, and is directly affected by the cultural context and social factors within a person’s life. This is consistent with the concept of syndemics, in which the social reality a person experiences shapes their experience of their illness, based on social, cultural and economic factors (Sharma, A., 2017, Weaver, Mendenhall, 2014).

This review highlights how multiple forms of inequality act as a key contributing factor to both emotional and physical distress in people of SA origin of with LTCs. The social determinants of health are intertwined with ethnicity, for example, the Marmot report describes the lower life expectancy of people of Pakistani and Bangladeshi origin in the UK is primarily due to poverty, with some of the highest poverty rates of up to 50% (Marmot, 2020). Ethnic minority groups with mental health problems may require greater attention as part of ‘proportionate universalism’ to reduce this health inequality and improve the health of the society.

The NHS Long Term Plan (NHS, 2019a) prioritises the reduction of health inequality and the NHS Mental Health Implementation Plan 2019/20 – 2023/24 (NHS, 2019b) calls for increased funding and to develop a Patient and Carer Race Equality Framework (PCREF) to improve ethnic minority health outcomes. However, there is a significant policy gap to integrating physical-mental health services; The King’s Fund’s report (The King's Fund, 2019) highlights the need for a more integrated approach and ‘joined-up services’ for the significant number of people with both mental and physical multimorbidity after years of underinvestment and neglect to mental health services funding. Until these multiple forms of inequality are addressed, gains in health improvement may be minimal.

Religion as a coping mechanism for emotional distress has a rich history within SAs as well as other communities (Dein, 2020) and is being increasingly researched as a potential area of intervention and improving care, such as culturally adapted psychotherapy for depression (Anik et al., 2021). There is potential for such developments to be situated in primary care. However this review found that people of SA origin with LTCs experiencing emotional distress generally found clinical services of little benefit, and had a significant scepticism to medical professionals due to a lack of cultural awareness and understanding. Mistrust of medical professionals and clinicians in ethnic minorities has been described African Americans for example, due to a historical narrative of persecution (Gopalkrishnan, 2018), which parallel some historical narratives with SAs and may be a cause of mistrust of healthcare professionals found in SAs (Ivey et al., 2018) A qualitative study looking at barriers to managing depression in people with LTCs in primary care found uncertainty in labelling depression in patients with LTCs that would facilitate shared understanding and future management (Coventry et al., 2011). Developing cultural competency in clinicians could potentially reduce health inequalities, (Institute of Medicine, 2003) which is a mandatory aspect of medical education in the United States; (Liaison Committee on Medical Education, 2019) but not in the UK.

### 3.8.4 Implications for research and clinical practice

There is a lack of research around males of SA origin with emotional distress, yet clear gender differences have been identified. A priority for future research is to explore the understanding, experience and help-seeking behaviour of men of SA origin with emotional distress, in particular regarding areas that members of the PAG felt were missing from the systematic review. Furthermore, given that primary care is perceived by people of SA origin to be culturally inappropriate in supporting them, the perspectives of clinicians within primary care, in particular general practitioners (GPs), is needed to understand this perceived gap and perspectives from clinicians trying to support this group.

A key implication for practice is the need for clinicians within primary care to develop a level of cultural competency so that people of SA origin with emotional distress feel comfortable and willing to seek help from them. To a higher degree, cultural safety is needed whereby healthcare professionals examine their own culture and its impact on healthcare delivery, including their own biases, assumptions, stereotypes etc, to influence healthcare to reduce bias and achieve equity (Curtis et al., 2019). Public health education must have a meaning within the culture of the patient for it to be of value. Until this happens, this group of people may not engage with primary care and services available to support them.

There is the need for clinicians to consider emotional distress in people of SA origin with LTCs when patients use culturally-specific terminology such as ‘tension’ to describe their mental state. The management of emotional health is not just to provide quality clinical services in primary care, community and secondary care, which is undoubtedly a necessity, but rather addressing root causes of poor emotional health. Policy makers must address challenges such as poverty and health disparities leading to different communities, such as South Asians, may be more adversely affected by this, and mechanisms of supporting this group and others out of poverty.

## 3.9 Chapter summary

This chapter presents a systematic review to explore perceptions of emotional distress in people of SA origin with diabetes and/or coronary heart disease. Three main themes were identified, understanding of emotional distress, experiences of emotional distress and help-seeking behaviour. This review provides a greater understanding of the conceptualisation of emotional distress in the context of LTCs by people of SA origin, to support improvement in its recognition and management. This review was published in BJGP (Awan et al., 2022) and is included in Appendix 2.

Research gaps highlighted informed the qualitative studies reported in this thesis - interviews with SA males with diabetes and/or coronary heart disease and GPs - which are reported in the following chapters.

# Chapter 4: Methodology

## 4.1 Introduction

Chapter 3 provided a greater understanding of the conceptualisation of emotional distress in the context of LTCs by people of SA origin. Findings from the systematic review showed that SAs with LTCs used non-medical terminology to describe distress and there was a complex relationship between emotional and physical illness, however a conceptualisation of distress specific to this population is limited within the literature. Gender differences were found, related to cultural factors such as SA men's roles as 'breadwinners' and a greater focus on work stress, yet little further was known regarding the experiences of SA men with LTCs specifically. Help-seeking behaviour focused around perceived inadequate clinical support, and seeking support from faith, family and friends, however the reasons as to why this was the case, or perspectives of GPs and family doctors serving this patient group, had not been previously researched.

The systematic review demonstrated a gap in the literature which a qualitative study could address. This chapter describes the methodology for the qualitative study. This chapter begins by restating the research objectives, followed by ontological and epistemological underpinning of the research paradigm and qualitative methodology. The theoretical underpinning of the selected methods are discussed, followed by a justification of methodological rigor applied in this doctoral research. Patient and public involvement and engagement is discussed with respect to the qualitative study, followed by ethical issues considered and chapter summary.

## 4.2 Research objectives

The research aims have been described previously. The objectives of the qualitative study were to explore:

1. *How do males of SA origin with LTCs understand emotional distress, its nature and causes?*

2. *What help-seeking strategies do males of SA origin with LTCs use for emotional distress, and do these differ for physical problems?*
3. *What are the facilitators and barriers to GPs supporting males of SA origin with LTCs in identifying and managing emotional problems in SA males with physical-mental comorbidity?*
4. *What services are needed to best support males of SA origin with LTCs for emotional distress?*
5. *How has the COVID-19 pandemic affected the mental health of males of SA origin with LTCs, its management and the management of their LTCs?*

## 4.3 Research paradigm

Research paradigms are explored below, including my own research paradigm, leading to qualitative methodologies being chosen and then the choice of methods described.

### 4.3.1 Research paradigms

A research paradigm was defined by Kuhn as '*the set of common beliefs and agreements shared between scientists about how problems should be understood and addressed*' (Kuhn, 1996). These can be related to the fundamental belief systems that define the world-view of a person and are based on our ontological, epistemological and methodological assumptions (Guba, Lincoln, 1994). This provides a lens in which the world is thought about, and hence guides the research. It is crucial for a researcher to understand their own research paradigm, as this relates to their philosophical assumptions of knowledge (Berry, Kincheloe, 2004) which will directly influence their methodology, methods, results and ultimately what is understood from any research inquiry. Awareness of the philosophical underpinning of research as well as one's own assumptions about the world and what can be known is essential to ensuring the quality of the research produced (Ormston et al., 2014).

Ontology can be considered as '*the study of being,'* i.e. what we know (Crotty, 1998, p10) and what constitutes reality. This refers to what *is* and therefore what can be known (i.e one's epistemological position). Crotty finally discusses the theoretical perspective, *'the philosophical stance informing the methodology'* (Ibid*,* p3*).* Epistemology can be considered as '*how we know what we know,'* i.e. how meaning is derived (Ibid, p8). This refers to the theory of knowledge itself and what kind of knowledge can be learnt (Jackson, 2013). Two main theoretical perspectives can be broadly considered, inductive logic where knowledge is built from observation from a bottom-up approach, and deductive logic whereas a theory is tested by hypotheses which can be confirmed or rejected (Ritchie et al., 2013). The methodology refers to how one can approach finding out what they believe can be known (Guba, Lincoln, 1994), i.e. the approach taken to the research design (Jackson, 2013) or a theory of how inquiry should proceed (Schwandt, 2014). This then influences the methods, which refer to the techniques used for data gathering and analysis (Crotty, 1998).

Different approaches and ways of thinking about research philosophy have informed my philosophical stance in this doctoral research. The linear model described by Crotty (1998), which connects ontology, epistemology, theoretical perspective, methodology and methods along a single line informed my early thinking. The work of Saunders et al. (2019) has helped me to explore, interrogate and identify my own philosophical thinking. The model described by Saunders et al. - the Research Onion - considers research philosophy as a series of layers, each influencing the other and related to a core research aim/question (Ibid). This was developed from a business management perspective, but has relevance for health research. The research onion resonates with my paradigm of research, as the layering of the onion and cross-over between layers is more reflective of how research paradigms influence and direct research in practice. The onion from outer to inner is of: the philosophy (which includes both epistemology and ontology), the approach to theory development, the methodological choice, the strategy, the time horizon, and finally the data collection and analysis. It takes away a linear process and appreciates the different layers, in particular how a person's beliefs and assumptions, philosophy and research design all interact and influence each other. It also considers axiology, the role of values and ethics, which builds on the work of Crotty (1998).

Epistemologies were traditionally split between objectivist and interpretivist positions. An objectivist position such as positivism and, progressively, post-positivism argue that meaning and reality are independent of human existence, and reality is unaffected by the research process (Ritchie et al., 2013). Positivism argues that an objective and singular reality can be known through emotional neutrality (Murzi, 2007), whereas post-positivism evolved to argue that whilst there is a singular objective reality, it can only be measured imperfectly by limited human perception (Alvesson, Sköldberg, 2017). Positivism, and then post-positivism, has primarily been the positions of quantitative research, identifying a hypothesis and testing it empirically to find the truth. Positivism is criticised when studying social phenomenon as this approach searches for laws governing the phenomenon, akin to the natural sciences, which may be too rigid to apply to research involving relationships, consciousness, human choice, personal histories and experiences, their environment and so on. It has been considered as reductionist, attempting to reduce social reality to biological and physical events and universal laws. Interpretivist positions such as constructionism argue that knowledge is produced by exploring and understanding the social world, focusing on meaning and interpretation (Alharahsheh, Pius, 2020, Ritchie et al., 2013). Researchers construct meaning based on their interpretations, and the research process affects reality, which cannot be considered as a singular truth. Therefore, from this perspective, reality needs to be interpreted to acquire meaning. Hence there are multiple forms of truth. Qualitative research has traditionally been viewed as based on interpretivist positions, and takes consideration of differences such as cultures and circumstances. This gives richness of insight as opposed to searching for definite and universal laws (Alharahsheh, Pius, 2020). A key criticism of interpretivism is if there is no singular reality or truth, findings may be purely subjective, lack reliability and have no applicability in other areas. Explanation and causation are lost to the focus on interpretation and description. It is increasingly understood that this split may not be so clear, and there are increasing cross-overs between these two positions. A different approach to research paradigms can be a pragmatic approach of choosing a research paradigm which is best appropriate to generate rigorous findings, dependent on the research question and information being sought (Robson, 2002, Kaushik, Walsh, 2019).

My philosophical position is also influenced by my professional role and training. In my role as a GP, I recognise how I work to manage individual patients, who often present complex illness experiences that are shaped and influenced by their own backgrounds and exposure to inequalities, with disease classifications and guideline-led treatments and systems informed by evidence (usually based on quantitative trial data). This has given me a wider appreciation of the need to be pragmatic and to explore and validate problems experienced by patients and to offer practical and available solutions. When approaching research, I ask myself about the problems I see and ask what solutions can be found, before thinking deeply about ontological and epistemological perspectives, hence a pragmatism-based approach to research aligns with myself.

The methodology I applied in this study is underpinned by a position closest to critical realism (Gorski, 2013, Robson, 2002, Bhaskar, 2013), which sits between positivism and interpretivism and deals with some of the challenges of both. Critical realists argue that reality exists independently of observation, yet is influenced by the research process, and cannot wholly be understood by humans due to our limited intellect and faculties. My research relates primarily to social constructs, understanding experiences and help-seeking behaviour for emotional distress. In my clinical experience and reading of the literature, I have found that emotional distress can differ from individual to individual and at the same time be influenced and have some similarities across culture. Knowledge can be interpreted as to how to support and improve care, without a boldness to look for scientific rules that can be applied to all irrespective of background. Critical realism builds upon the realist position that reality is independent of the human mind, yet is critical with respect that that reality cannot be observed directly, as what is observed is dependent on perceptions, theories and constructs. Bhaskar described three different domains; the empirical domain is what is known through human senses, the actual domain is its existence irrespective of observation, and the real domain which is that of underlying processes and mechanisms. In my view, emotional distress can be considered as a part of the empirical domain, in which it is experienced in different ways by different people, with no singular experience, yet is based upon actual and real domains. Bhaskar made an important distinction between intransitive entities, objects that exist without knowledge about them, and transitive entities social products, which are knowledge and understanding of the conceptual world (Bhaskar, 2013). Being SA can be considered a transitive entity, considered as people born in or originating from SA countries, yet a social product which is not independent of interpretation. My research paradigm is more interpretivist than positivist in the respect that whilst there may be a singular reality, this is experienced differently by individuals and is open to subjectivity and interpretation. Critics of critical realism consider it to be both too positivist, in claiming that there is reality and trying to identify causal mechanisms, and too interpretivist, in claiming that that reality cannot be known. It is methods-neutral, and has been criticised for being methodologically weak, therefore not fulfilling the purpose of providing meaningful insights (Karlsson, Ackroyd, 2014). Whilst it is unsurprising that an approach between positivism and interpretivism is criticised by both sides for being too positivist and at the same time too interpretivist, I believe that there is a truth and reality independent of human existence, which is experienced partially by human perception. Being methods-neutral can also be viewed as an asset to critical realism at it is flexible to be used for different methods. This also reflects my pragmatic approach.

In this research, I chose a qualitative methodology to gather the depth and meaning from the experiences and understandings of SAs with LTCs and GPs who see them. I gathered different perspectives and layers of meaning in an exploratory manner. Hence the epistemological and ontological position of both my personal outlook to knowledge, as well as its relevance to the specific research topic, converged towards qualitative methodologies. When considering axiology and my own values and ethics, I chose the topic of emotional distress as it is something I feel is has a significant impact on people’s lives and is something I would want to improve the care of people for. SAs with LTCs are an underserved group as previously described in chapter 2, and my values of helping those most in need guided my decision to research this group. My values directed the research topic, as well as the methods, as I value listening to the voice of people one is trying to support. The people one is trying to support are those I believe to have the truest voice of the situation and context to which they live and what treatment and management they are willing to take and why. This correlates with Heron’s view that values and beliefs guide the reasoning and decision-making of human action (Heron, 1996). My interest in people’s stories reflects a theoretical framework informed by narrative theory, which places an emphasis on understanding people’s accounts and experiences of the world, and how they narrate their experiences (Moen, 2006). However, my interest in not only hearing people’s expressions of the stories of their lives, but also how these perspectives as well as others can be used as a means of change. Narratives provide a window into the experiences of participants, but other windows need exploration. Further reflexivity on my own role as a clinician, research, being

SA and an active community member are discussed later in this chapter in 4.4.2 Reflexivity. Methodologies stemming from a positivist epistemological position, whereby knowledge is produced through observation and reality can be known accurately, or a post-positivist position, whereby knowledge is produced through testing propositions and reality can be known approximately and is unaffected by the research process, were not considered appropriate. This is because of the exploratory nature of the research; there is richness in people's perspectives and diverse experiences and an approach looking for a 'correct' answer would be inappropriate. The qualitative methodology will be described in further detail in the following section.

### 4.3.2 Qualitative methodology

Qualitative research offers an interpretive approach to research, typically utilising methods such as interviews, focus groups and participant observation to generate data in order to make sense of or interpret phenomena in terms of the meaning people bring to them (Denzin, Lincoln, 2011). Qualitative research contributes to health service and health policy research by developing depth of knowledge and a more comprehensive theoretical base in which the '*why'* questions are dealt with as well as the '*how*' questions (Sofaer, 1999), asking open questions provide a platform for voices to be heard of people who may not otherwise be heard. This facilitates both descriptive as well as exploratory research. A qualitative approach is suitable for this study due to the exploratory nature of the research questions, seeking to reveal perspectives and understandings, interpreting the experience of GPs and males of SA origin whose experiences have not been adequately captured in previous health research (Sofaer, 1999). By exploring perspectives of males of SA origin with LTCs about understanding and conceptualisation of emotional distress, as well as GP perspectives, richness of data regarding their experiences and understanding was best gained from such qualitative methodology (National Cancer Institute Division of Cancer Control & Population Sciences, 2020). This is informed from my perspective which relates to critical realism; qualitative methods facilitate interpretation and insight into different aspects of reality.

The value of qualitative research has been questioned by, from what I perceive as, a positivist perspective. The British Medical Journal (BMJ), a key journal of clinical research based in the UK, rejected all qualitative research as recently as 2016, stating qualitative work to be low priority, unlikely to be cited, and lacking practical value (Greenhalgh et al., 2016). One may ask, are qualitative methodologies, which tend to step from interpretivist positions supposing no single answer can be gained from observation health care questions, helpful to health research? If research cannot be known except through interpretation, can it be of value to health research? The intended outcome of research is to improve patient care in some way and not left purely within the realm of theory. A clear answer is needed to these questions for any health care researcher conducting qualitative research such as this study, and has been provided from important bodies. A World Health Organisation (WHO) bulletin stated the importance of qualitative research to improve guidelines and health decision-making, to assess the needs, values, perceptions and experiences of stakeholders, as well as informing the acceptability of recommendations and implementations (Langlois et al., 2018). The WHO describe qualitative research as *crucial* for complex health decision-making (Langlois et al., 2018). Greenhalgh and colleagues provided the example of a surgical checklist reducing complications after non-cardiac surgery from 11% to 7% and perioperative mortality from 1.5% to 0.8%, however this was not replicated in other settings until qualitative research unearthed how new forms of cooperation and communication were needed (Greenhalgh et al., 2016). A relevant recent example is that of the development of the NICE long covid guidelines, in which holistic care was emphasised in the guidelines, covering not only symptoms but also how they feel overall, due to patient experiences evidencing people felt their symptoms were not taken seriously (Health Improvement Scotland, 2020, NICE, 2020). The qualitative systematic review which I conducted, described in chapter 3, provides an example of how this research can contribute to health research and provide clear clinical implications, such as using culturally specific terminology and developing cultural competency (Awan et al., 2022). The qualitative study using semi-structured interviews to explore the perspectives of SA men with LTCs regarding their understanding and conceptualisation of emotional distress as well as perspectives of GPs is hoped to provide in a similar vein an increased evidence base to support complex health decision-making that funders and policy-makers take with regards to community interventions for emotional distress in SA men with LTCs.

### 4.3.3 Choice of methods

The choice of methods includes data generation and approach to analysis.

#### *4.3.3.1 Data generation*

Semi-structured interviews were the methods chosen as best suited to answer the research question. Semi-structured interviews are considered as ‘conversations with a purpose,’ (Burgess, 2002) positioned between an unstructured conversation and a structured survey. Semi-structured interviews explore a certain area, whereby there are ‘*conversations where the outcome is coproduction of the interviewer and the subject*’ (Kvale, Brinkmann, 2009). Semi-structured interviews are the setting for these purposeful conversations. Within this setting, the interviewer facilitates dialogue through which knowledge is shared and an understanding is generated between interviewer and interviewee. This production of data is based upon perceptions of SA men with LTCs and GPs perceptions as well as interpretation of these perceptions by the researcher and research team. Semi-structured interviews are congruent with my critical realist position of constructing understandings of perspectives of reality from different participants, as a reality exists independent of the mind, but can only be partially known through human perception (Bhaskar, 2013). Semi-structured interviews fly on two wings of flexibility and structure; there is a topic guide of open questions as well as prompts which the researcher applies to guide the interviews, yet there is flexibility with respect that the researcher can ask further questions and dig deeper when participants discuss areas of particular relevance to the research. They are beneficial in gaining ideas, opinions and experiences. These are all very relevant to this research whereby exploration of a previously unknown topic was done, specifically regarding understandings, experiences and help-seeking behaviour for emotional distress of SA males with LTCs. Semi-structured interviews are also helpful when researching sensitive matters such as emotional distress whereby participants may not be willing to discuss openly due to cultural taboos and stigma associated with distress. When interviews are undertaken, the position and culture of the researcher should be considered, as these may influence participant responses. Hence reflexivity and considering my own positionality were therefore crucial during the research process.

Semi-structured interviews are flexible in format, they can be face-to-face, telephone and online interviews. As described in 4.3.2, there is a topic guide of open questions as well as prompts which *guide* the interviews, yet there is flexibility with respect that the researcher can ask further questions and dig deeper when participants discuss areas of particular relevance to the research. Open questions are important when exploring experiences to allow for participants to explain their understandings with depth, and provide the opportunity for them to discuss areas that the researcher has not considered. I came with layers of knowledge and experience as a researcher given my background reading of literature and systematic review on the topic, as well as personal experience as a GP serving the South Asian community and being a member of the South Asian community; this is described further in the reflexivity section 5.5.5. The data and analysis drove the iterative development of the topic guide and main areas of questions. Interviewing SA men with LTCs and GPs at the same time allowed for integration of themes and areas that were brought up by participants of one group to be explored with the other. To allow for participants to bring up areas that were not covered in the topic guide, questions were kept as open questions with flexibility to ask about and explore further areas raised by participants.

Open-ended or unstructured interviews may have facilitated in-depth exploration and richness of data. They would not have been appropriate as there were specific areas of consideration that warranted exploring based on areas suggested by the previous research and considerations from the patient advisory group. Furthermore, open-ended interviews are more challenging in terms of setting and timing, and may be less relevant to my clear overriding question of healthcare utility- how can these interviews potentially shape and provide direction to service development. Structured interviews are helpful for consistency and ease of comparison. However, they were not appropriate as they would not have allowed to research to explore areas brought up by interviewees and go into depth regarding relevant points discussed. As there is little known is this area, a detailed topic guide would have been more difficult to produce to incorporate asking relevant questions. Biographical narrative interviews are an alternative whereby in-depth interviews facilitate participants to tell their life stories. Interviews generate rich data about individuals, but would be less relevant to interviews focusing specifically on emotional distress and specifically around understanding, experiences and help-seeking. Semi-structured interviews enabled comparison of analysis between research participant types, i.e. SAs and GPs, as I was able to ensure comparable topics were discussed by providing a level of structure.

Focus groups were considered and can be useful in different data coming out based upon group dynamic and interactions. By listening to others, participants have the opportunity to refine their thinking and input (Davidson, Halcomb & Gholizadeh, 2013). However focus groups do not allow for more detailed understandings of individuals or their personal experiences and history, which was relevant with regards to emotional distress. Focus groups can be less helpful with sensitive issues such as emotional distress if these are stigmatised within the community as they give a collective perspective whereby participants may be less comfortable to reveal personal experiences (Green, Thorogood, 2018). Focus groups may have in particular stifled SA male participants from discussing their experiences given stigma around mental health in the SA community  (Karasz et al., 2019). It is also a challenge to gather GPs together at a specified time in a specified place, given their busy schedules as well as increased time required from them to include their travel.

#### *4.3.3.2 Approach to analysis*

Data analysis can be considered as the process by which researchers develop primary data into findings, to understand what the data *means* (Green, Thorogood, 2018). According to critical realism, these are *demi-regularities*, rather than finding *laws* which always occur and is a positivist position, there is a search for *tendencies* (Fletcher, 2017). Data analysis provides insight into these *demi-regularities*. It is increasingly recognised in health research to demonstrate that inferences are sound. Health inequalities and experiences and outcomes for SAs may be related to demi-regularities that can be changed. Since qualitative research tends to be more interpretative, it is extremely important for researchers to be aware of, and describe, their approach to data analysis and the rigor of their research. As described earlier, there are two broad theoretical approaches, deductive and inductive analysis. Deductive analysis uses a priori concepts developed from existing theory which are tested to develop themes, whereas inductive analysis looks to identify patterns and relationships within data to build theory. In my personal opinion, analysis is not purely deductive or inductive, yet sits on a spectrum, based upon the epistemological and ontological position. Analysis is not purely deductive, as a priori concepts are influenced and interpreted differently by researchers' findings from the data. Analysis is not purely inductive, as the patterns of themes which researchers develop are based on their a priori thoughts and experiences. Given the qualitative exploratory nature of the research, the analysis is more inductive than deductive. I explored the data to develop themes without existing developed theory. However, there was also a deductive element to the analysis considering my background reading of the research area, experience working in primary care mental health and culture. As well as deduction and induction, critical realists may also include abduction, whereby empirical data is redescribed using theoretical concepts, and retroduction, in which one looks for the contextual conditions for causal mechanisms to take effect and result in what is observed (Fletcher, 2017, Blaikie, Priest, 2019). In principle, with qualitative analysis there are three main steps involved. There is a description of the data, interpretation of the data and it's analysis. The analysis provides theoretical insights. These processes do not occur in a linear fashion but instead at the same time and there is an interconnectedness between the different steps to provide the insights.

Thematic analysis was selected as the chosen analysis method which fit both by epistemological and ontological position as well as an appropriate approach to answering the research question. Thematic analysis is a common method of analysing qualitative data, focusing on meaning across a data set. It involves construction, interpretation and reporting of patterns to allow researchers to understand collective and shared experiences (Braun, Clarke, 2014). The approach involves systematically reviewing texts to identify codes which integrate into higher-order themes. I appreciate that understandings of emotional distress and culture are fluid concepts and has similarities and differences amongst people of SA origin, first and second generation SAs, and on an individual level every human has their own perspective of the actual reality given their understanding and experience of culture. From a critical realist perspective, thematic analysis can be used to develop themes searching for tendencies which can influence health provision and policy. Thematic analysis has been argued to be a generic method rather than an approach in itself, lacking in an epistemological base, as it can be used with different forms of analysis (Ryan, Bernard, 2000). Whilst it is true that thematic coding can be used in different approaches, I follow the understanding that it can be used as an approach within itself, and in fact is commonly used so (Braun, Clarke, 2006). Braun and Clarke describe reflexive thematic analysis as rooted in epistemological assumptions about meaningful knowledge production, focusing on researcher subjectivity, organic and recursive coding processes, and the importance of deep reflection on as well as engagement within data (Braun, Clarke, 2019). The researcher's role lies at the heart of knowledge production, in collaboration with participants, the patient advisory group and other members of the research team, and I have reflected in reflexivity sections throughout the thesis. By using thematic analysis, the gathering of shared meaning through themes is useful in research relevant to healthcare policy due to its transferability (Braun, Clarke, 2014). Constant comparison was also used, in which data is systematically compared to all other data within the data set. Whilst constant comparison emerged from grounded theory (Glaser, Strauss, 1967), it is increasingly used with other methods (Fram, 2013). It adds to analysis by comparing data from different interviews, highlighting similarities and differences, and discovering patterns. Whilst a purist thematic analysis may not include constant comparison, I found this process useful in re-analysis of older interviews based on new data and the development of themes throughout this process.

Other forms of data analysis were considered and felt less appropriate. Grounded theory is a primarily inductive approach in which theory is generated purely from the data (Glaser and Strauss, 1967); it proposed that prior knowledge can be withheld in order to ground the analysis in participant data alone. Modern approaches to grounded theory can be constructionist in approach whereby interviews are not meant to mirror reality but rather a mutual exploration of the perspectives of the interviewee (Charmaz, Thornberg, 2021). Grounded theory is less consistent with critical realism as it is inductive and concepts are not drawn from other data, whereas critical realism is more flexible as it engages with existing theories to find the best explanation of reality (Fletcher, 2017). I came to the research with both clinical experience as a GP working in a practice with a high density of people from SA origin as well as personal experience as a member of the SA community driving my interest, as well as significant review of the literature including having conducted a systematic review, hence a grounded theory approach would be less consistent with my background. Theory is available from the literature, as described in the literature review, which has therefore been used in the development of topic guides the semi-structured interviews, in conjunction with discussion with the research team and patient advisory group. Furthermore, grounded theory is less generalisable given its primary focus on depth of data, and my primary intention for doing the research was potential clinical benefit. The area of inquiry was determined prior to the qualitative interviews based upon the literature and my experiences, again making grounded theory less applicable. Interpretive phenomenological analysis (Eatough, Smith, 2017), another interpretivist approach which focuses on people's lived experience and provides a more in-depth analysis of fewer cases in which comparing and contrasting cases is not undertaken, is heavily influenced by the researcher's interpretation. Phenomenology takes shared experiences such as culture and cultural expectations less into account, which was a key concept based on the previous literature. It is potentially less transferable or relevant to this study which aims to influence healthcare policy (Stoller, 2009). Further details of the choice of analysis method as well as concepts around theoretical saturation are described in chapter 5.

## 4.4 Research quality

Research quality refers to the rigor in carrying out research, i.e. how good the quality of the research is. From objectivist positions such as positivism, a deductive belief in a single reality where hypotheses can be tested, as well as more nuanced post-positivist positions where it is believed that the background of the researcher can influence the results and objectivity can be achieved by recognising biases, quantitative methodologies have tended to define research quality according to validity and reliability. Validity refers to how well a method measures a phenomenon of interest. Reliability asks if the study was exactly replicated, would the same results occur? (Seale, 2004) These provide a challenge to qualitative research in which a more interpretivist epistemological position is found. With regards to validity, questions conducive to qualitative enquiry such as *why* questions and exploration of experiences cannot be measured in the same way as quantitative research, with statistical analyses and tests. With regards to reliability, if two researchers independently worked to answer the same research question, even using the same methodology and methods, they would end up with different results. This is not because of poor research rigor. It reflects the interpretivist understanding that there is no single objective truth, and the research process itself affects reality, which is interpreted by the research (Alharahsheh, Pius, 2020, Ritchie et al., 2013). Yet there is certainly qualitative research that is robust, that follows transparent and robust methodology, as well as qualitative research of poorer quality, such as analysis that is not comprehensive, interpretations not supported by data, biases not taken into account and opacity in methodology.

The question arises of how to measure quality in qualitative research. Lincoln and Guba (1985) answered this question by asking how trustworthy qualitative research is, i.e. the quality, authenticity and truthfulness of findings, how much the research can be trusted (Cypress, 2017). Lincoln and Guba derived four main components of quality in qualitative research to define trustworthiness, these are credibility, dependability, confirmability and transferability. Credibility refers to the confidence in the 'truth' of the findings. Truth within research is usually based on theories, the correspondence theory of truth that whatever corresponds to observable reality is true, the coherence theory of truth that claims are true if they follow logically and coherently from axioms or propositions, and the pragmatic theory of truth, that what is true is what is pragmatically useful (Brüssow, 2022). Critical realism recognises a difference between empirical observation and theoretical explanation and may align closer to the correspondence theory of truth as theories developed approximate reality, although they will not perfectly match reality. Transferability relates to the applicability of the findings in other contexts. Dependability shows that the findings are consistent and can be repeated. Confirmability refers to the degree of neutrality or the extent to which the findings are shaped by the respondents as opposed to researcher bias. However, there are critiques of this approach, primarily that by moving the terms with regards to rigor away from reliability and validity, this approach makes qualitative research appear to be unreliable and invalid, and in fact the problem is with a rigid application of the terms themselves (Robson, 2002). Reliability is considered as the stability of the findings i.e. how stable they are if multiple coders used the same data sets, and validity as how authentic and credible the findings are, this can be applied appropriately to qualitative research (Ritchie et al., 2013). A more middle approach has been argued to consider the quality of qualitative research in terms of reliability, validity and generalisability (Morse, 2015). My understanding is that the main principle is that research quality must be prioritised, otherwise it is of little use or applicability to different contexts, and either approach can be taken. I have followed the approach of Lincoln and Guba (1985) in discussing research quality in chapter 5 due to its ease of applicability to qualitative research, rather than the latter approach of maintaining the same terms of quantitative research, yet using them in very different ways. I have kept a reflexive diary throughout the research and reflexivity is discussed later in this chapter. Whilst there are many crossovers in quantitative and qualitative research, in particular with the construction of knowledge, I believe that qualitative research can be rigorous in its own right without needing to pigeon-hole itself into quantitative approaches to rigor.

### 4.4.1 Researcher's positionality

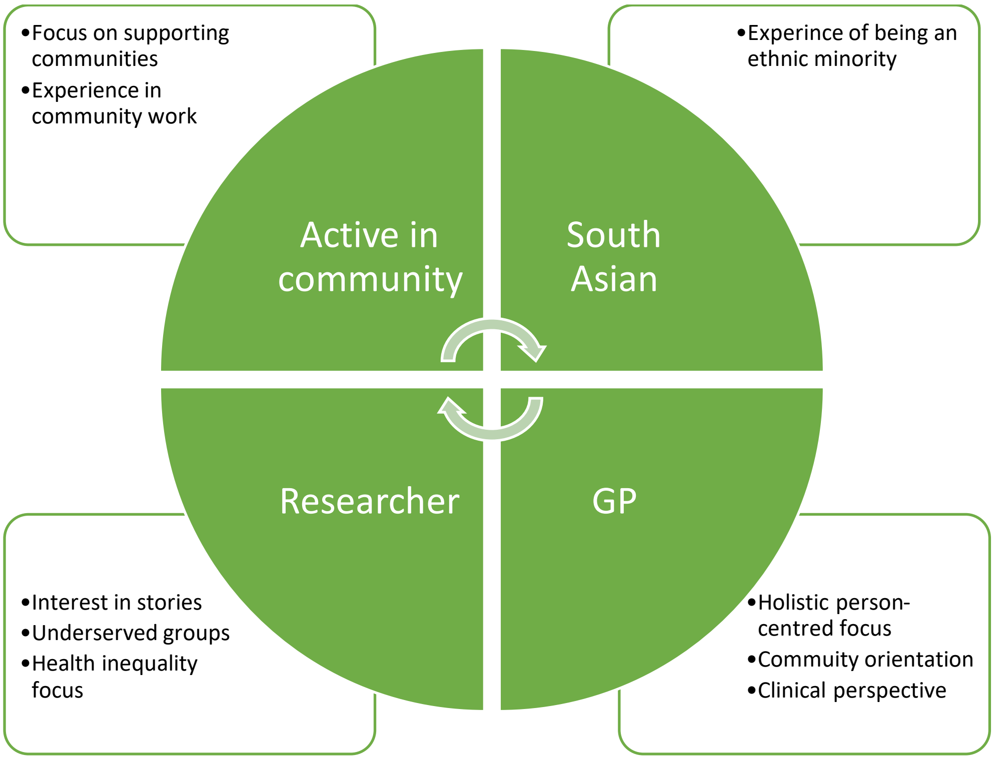
The positionality of any researcher is important to reflect upon given my critical realist position that any research will be affected by the researcher, their background, experience and thoughts; rather than falsely trying to stop this process, one should minimise bias by being aware of their positionality an how this may affect research. My axiology is that of understanding my own world views and experiences influence the research process. Key areas of consideration to the research include my clinical and research experience, cultural upbringing and world outlook.

I am approaching this research from multiple perspectives based on my personal and professional roles and identities. Clinically, I am General Practitioner, graduating from medicine in 2011 and completing GP training in 2017. My professional background is primarily being educated in a clinical world that focuses heavily on biomedical understandings of illness and health. I have vast experience of managing men of SA origin with LTCs for a variety of issues, including both physical health as well as mental health problems. My experiences of challenges faced in trying to support this group to have better outcomes directly lead to undertaking this research. Hence, my clinical exposure and challenges in clinical practice directly lead to undertaking this research. However, this was not from a perspective of having 'the answer' or 'answers' to the problem, but from a position of seeing a problem and asking what solutions can be found. General practice training and practice has given me a community-orientated and holistic focus, with an interest in supporting people with illnesses to live better in their own community environments, providing my community-orientated and culturally-sensitive approach. Being a GP also provides me with experience of life serving this patient cohort within primary care and both lived experience of challenges faced within general practice which may hinder optimal care as well as access to and insight from colleagues and friends working in primary care, from a professional and personal capacity. Whilst I aimed to undertake the research which open eyes and a fresh mindset, I was very aware of how my clinical experience may influence my thought processes during the research, and I regularly wrote a reflexivity journal throughout.

From an academic perspective, I consider myself an early career researcher. I was fascinated by research in medical school, and gained a distinction in my first research exposure as a Special Study Component in my first year of medical school, examining the ethics of 'Designer Babies'. However, I prioritised clinical work over the following decade, until as a GP trainee I completed an academic clinical fellowship and research Masters which included interviewing people with severe mental illness about brief interventions for physical health. My interest has always been qualitative research, borne from a fascination in people and their stories, which led to myself undertaking medicine and choosing general practice. My research background and interests influenced the design of the research.

Personal aspects of my life also were reflected upon during the research. I am a male of South Asian origin, born and brought in the UK, and have maintained and developed my community links through language, culture, faith and community involvement such as being actively involved in a local charity and engaging in community events. Being raised in a family that valued equity, fairness and compassion at the core of its principles led to my interest in research as a means of benefit on a potentially larger scale than solely from the community I serve as a GP and community member. My interests aligned most closely to health inequality and supporting underserved communities and those whose voices have been less heard, or heard but not listened to. Mental health has always been my area of most clinical interest, and I applied for both GP and psychiatry training as a junior doctor, eventually choosing general practice due to my perception that general practice was more holistic, and involved helping support and manage people living within their communities with physical and mental health problems, person-orientated with continuity potentially from the cradle to the grave and not disease-orientated. Working in general practice further nurtured and directed my experience and interest towards community mental health.

Figure 7 summarises my research positionality.



### 4.4.2 Reflexivity

Reflexivity can be considered one's challenging of their own assumptions and finding strategies to minimise bias, whereas positionality relates more to one's understanding of themselves and what they bring to the research. My epistemological and ontological viewpoint is that all research is influenced by the researcher and other factors, both in qualitative and quantitative research, and there is no such thing as completely neutral or objective research. Hence researchers must reflect upon themselves as well as potential areas of bias. Reflexivity can be considered as a researcher turning their researcher lens onto themselves, to recognise and take responsibility for their positionality with research and how it influences and affects the research (Berger, R., 2015). One's positionality may lead to assumptions which remain tacit and hidden until they are purposefully reflected upon. Reflexivity increases the credibility of research, given the researcher's diligence in examining their own perspectives and views and how it affects the research (Dodgson, 2019). Reflexivity further deepens the understanding of the research (Dodgson, 2019). It is considered a vital part of qualitative research, whether or not the researcher is researching people from similar backgrounds (Teh, Lek, 2018). My reflexivity diary was essential to note down thoughts and feelings throughout the research, as discussed in the following chapters.

### 4.4.3 Triangulation

Triangulation involves the use of different sources of information to confirm and improve the clarity and precision of research findings (Ritchie et al., 2013). It involves looking at a phenomenon in diverse ways to add credibility and strengthen the confidence in the findings (Patton, 2002). There is debate within the literature whether triangulation improves the validity of research or if it instead widens understanding via gathering data from different sources (Ritchie et al., 2013). From a critical realist perspective, it is impossible to perceive a single truth, however research of a specific phenomenon is better understood with triangulation. Different forms of triangulation can take place, such as methods triangulation (comparing data from different methods), triangulation of sources (such as from different qualitative methods), triangulation through multiple analysis (such as different interviewers and analysts) and theory triangulation (looking at data from different theoretical perspectives) (Ritchie et al., 2013). Different forms of triangulation of understanding, experiences and help-seeking behaviour for emotional distress took place within this research which are described further in chapter 5. These include triangulation of sources by comparing SA and GP interviews and triangulation of data through multiple analysis with different members of the research team and PAG involved in analysis as well as conference presentations where analysis was discussed. Methods triangulation did not take place, such as mixed methods approaches, as the research focused on understandings and experiences, to which quantitative data would not have been appropriate.

## 4.5 Patient and public involvement and engagement

As described in chapter 1, in order to ensure the relevance and effectiveness of research, it is crucial to incorporate the perspectives and voices of those individuals for whom the research is intended to benefit  (Chief Scientist Office, Health and Care Research Wales, Public Health Agency and National Institute for Health Research, 2018). The National Institute of Health Research (NIHR) described in its vision for public involvement in 2025 the need to prioritise engaging with PPIE with people from underserved backgrounds (NIHR, 2015). It's 2018/2019 paper evaluating progress on *Going the Extra Mile* describes an area of improvement to involve minority ethnic groups more in research, with Asian ethnic groups making up 3% of those involved in public involvement, in comparison to the Asian population of 7.5%  (NIHR, 2019). It was reported that only 35% of PPIE involvement included men (Ibid), making the need for the engagement of men in PPIE greater. A systematic review of studies with PPIE involvement from ethnic minorities found them to be primarily based in the USA focusing on Afro-Americans and indigenous populations (Dawson et al., 2018). PPIE with South Asian populations is much more limited than these USA-based ethnic minorities. An exploratory study of SAs with asthma reported a number of barriers to SAs taking part in research, including a lack of cultural and religious sensitivity around gender segregation as well as the need for incentives to take part in research (Rooney et al., 2011). Hence there is a greater need for PPIE involvement with SAs, with a sensitivity and awareness to their cultural and religious sensitivities. They should not be viewed as 'hard to reach', but due to a number of societal factors these groups may find it 'hard to trust' health researchers, due to barriers related to research culture such as language, barriers related to healthcare, such as structural health inequalities and racism, and barriers related to society and heritage such as mistrust of institutions and healthcare providers, and barriers within communities such as socioeconomic status (Islam et al., 2021).

An ethnically appropriate patient advisory group was convened through reaching out and engagement with the SA community, as described in chapter 1. They were involved throughout the research according to the National Standards for Public Involvement (Chief

Scientist Office, Health and Care Research Wales, Public Health Agency and National Institute for Health Research, 2018). The six standards used are ‘inclusive opportunities’, ‘working together’, ‘support and learning’, ‘communications’, ‘impact’ and ‘governance’ and further details of engagement with the standards and the patient advisory group working are in chapter 5. Furthermore, the toolkit for increasing participation of black, asian and ethnic minority ethnic (BAME) groups in health and social care research informed the approach to PPIE (Farooqi et al., 2022). Of note, the terminology of BAME is now considered outdated after the 2021 Commission on Race and Ethnic Disparities (Commission on Race and Ethnic Disparities, 2021). Hence for this research the term ethnic minorities is used.

## 4.6 Ethical considerations

Ethics can be considered as the branch of knowledge that deals with moral principles. Ethical considerations are integral to research, if not the most integral aspect of research. One may value ethics by considering when ethical considerations are not prioritised, as the Arabic proverb states *bididihaa tamayyazul ashyaa,* consideration of the opposite of a concept makes the concept clearer. The Nuremburg Trials involved experimentation of prisoners of war without any concept of consent or many other issues (Taylor, 2012). The Tuskegee Syphilis Study involved the experimentation for 40 years on African Americans by injecting a proportion with Syphilis to see if black people reacted the same as white people and determine how long they could live if untreated  (Brandt, 1978). These are not isolated cases in research. The development of anthropology came from colonialism, studying ‘others’ such as Africans and South Asians, so that they could be subdued and controlled during expansion of imperialist empires  (Lewis, 1973).  Ethical considerations are therefore essential when considering any research, and particularly sensitive in my research when specifically researching groups like SAs where research has previously been used a tool against them.

Ethics is very much dependent upon theoretical perspectives (Ritchie et al., 2013). Universalism takes the approach of ethical rules and moral principles are universal and should never be broken. In research there would be a clear black and white with rules. It is traced back to ancient Greek philosophers Socrates, Plato and Epicurus, and later on by

Jeremy Bentham and John Stuart Mill (Schlenker, Forsyth, 1977). Utilitarian approaches are based on weighing up the consequences of any action, and balancing the benefits and harms. For example, what is the benefit and harms of the research participant being involved in the research, what are the benefits and harms to society, and so on. Criticisms of utilitarian approaches to research include how well the consequences can be predicted, infringing upon rights of some to achieve the greatest benefit for most, and the applicability of universal rules to nuanced situations (Noble-Adams, 1999). It can be challenging when trying to establish overall benefit with different competing benefits and harms. Deontological approaches are based on duty (*deon* in Greek) and the morality of an action as opposed to its consequences, advocated by Immanuel Kant amongst others (Kant, 1873). It is rules- based but focused primarily on duties; an action is ethical if it accords with set of rules. Deontological approaches can be difficult to apply when in a situation where rules conflict. A purely deontological and rules-based perspective may lack the flexibility needed at times with qualitative research. Virtue ethics is person-based, focusing on the characteristics an individual should possess to live virtuously. A researcher must possess the right character to make correct decisions in the ethical situations they face, and to know what a correct decision is. Relational ethics is related to this, focusing on the ethics of relationships, such as that of the researcher and research participants, and intentions behind relationships such as collaboration and empowerment. Virtue and relationship-based ethics may not ensure the safety of participants and others involved in the research due to their primary focus on the researcher or relationships. Situational or principled relativism approaches advocate a case by case approach, without as moral absolutes, looking for the unique solutions to individual contexts. Researchers in this case would need to analyse every ethical situation without looking for principles or rules. Situational perspectives become cumbersome to analyse each situation and may make it difficult for researchers to maintain consistency of ethical decisions. The different theoretical perspectives have their benefits and challenges to research, and pragmatically different approaches can be used within a study (Biagetti, Gedutis & Ma, 2020). A utilitarian approach was crucial to this research when considering and planning the research, to consider the intended and unintended consequences of the research on participants, considering emotional distress can be an upsetting topic. Practical codes of ethics were also considered, as described below.

To support researchers to work in an ethical way, and safeguard research participants, different ethical codes have been created. The 1964 World Medical Organisation Helsinki Declaration (Rickham, 1964) provided a key international set of guidelines for research with human participants. Multiple guidelines have followed since. Ethical principles of respect for autonomy- respecting the rights of the individual, beneficence- doing good, non-maleficence- not doing harm, and justice- including equity, are considered key principles, adapted from *Principles of Biomedical Ethics* (Beauchamp, Childress, 2001). Prior to undertaking this research, ethical issues were carefully considered and ethical approval was achieved from Keele University's Faculty of Medicine and Health sciences Research Ethics Committee (FMHS FREC project reference MH-200132) as well as Health Research Authority (HRA) and Health and Care Research Wales (HCRW) Approval (Integrated Research Application System (IRAS) project ID 293272). The consideration of ethical issues was at the heart of this research and is further described in chapter 5.

## 4.7 Chapter summary

The chapter began with a review of the research aim and objectives, followed by the exploration of different research paradigms and qualitative research. The methods were discussed from a methodological perspective as well as research quality within qualitative research, including the researcher positionality, reflexivity and triangulation. These were followed by patient and public involvement and engagement and ethical considerations. Chapter 5 will discuss the research methods in further detail.

# Chapter 5: Methods

## 5.1 Introduction

The previous chapter laid the philosophical and methodological foundation for the qualitative study. This chapter explains the methods of the qualitative study, including the choice of methods, how primary qualitative data were collected, the methods used, ethical considerations and implications, and patient and public involvement and engagement. The chapter concludes with a discussion around research quality and reflexivity.

## 5.2 Choice of methods

The methodology and methods are described below, followed, participants, study setting, sampling and recruitment, data generation, data analysis, theoretical saturation and data storage.

### 5.2.1 Methodology meets methods

The research paradigm as discussed in 4.3 directly influences the methodology and methods. My research philosophy is closest to that of critical realism in which reality exists independently of observation, yet is influenced by the research process, and cannot wholly be understood by humans due to our limited intellect and faculties. The empirical domain which is known through the human senses is dependent on perceptions, theories and constructs, in contrast to the actual domain which exists irrespective of observation, or the real domain of underlying processes and mechanisms. It is imperative for a choice of methods to have congruence. Based on this position, this qualitative study researched the level of the empirical domain, exploring different perspectives to gather the depth and meaning from the experiences and understandings of emotional distress of SAs with LTCs and GPs who support them. I undertook semi-structured interviews; section 4.3.3.1 details why I chose these and not other methods.

### 5.2.2 Participants

Two sets of participants were interviewed, males of SA origin with LTCs who are the group of interest, and GPs who serve them within primary care.

#### *5.2.2.1 Males of SA origin*

Males of SA origin were interviewed. ‘*South Asian origin’* is a term used to include people of origin of India, Pakistan, Bangladesh, Afghanistan, Sri Lanka, Maldives, Nepal, Bhutan and Indian Ocean Islands. Semi-structured interviews were undertaken with males of SA origin with diabetes and/or coronary heart disease, to explore their understanding and conceptualisation of emotional distress in the context of physical health problems.

Inclusion criteria:

- Male
- SA ethnic origin
- Diabetes and/or coronary heart disease
- 18 years of age or older
- English-speaking (due to a lack of funding for translation services)

Exclusion criteria :

- Lacking capacity to provide consent
- Currently receiving inpatient care

The above exclusion criteria were operationalised by being clearly defined on the recruitment poster (Appendix 3 Recruitment poster for SA men) and information leaflet (Appendix 4 Participant information sheet for SA men). During the consent process the inclusion and exclusion criteria were checked. Capacity was assumed unless there is a clear reason to suspect a lack of capacity in accordance with the General Medical Council guidelines on decision making and consent (General Medical Council, 2020). If any concerns arose around capacity, I am competent to assess capacity according to the GMC principles that the participant can understand, retain, weigh up, and communicate their decision to be involved in the research. If I had concerns regarding capacity, the interview did not go ahead, or was terminated. This did not occur.

#### *5.2.2.2 GPs*

GPs in areas of higher density of SAs were invited to be interviewed as it was anticipated they would be well positioned to explore perceived needs of males of SA origin with LTCs. Public Health England's Strategic Health Asset Planning and Evaluation (SHAPE) atlas tool (Public Health England, No date) was used to identify areas of higher density of SAs. The SHAPE atlas is a web-based platform linking data for clinical analysis, public health, primary care, demographic data, healthcare estates performance and facilities location, based on geography. It is free for NHS professionals and Local Authority professionals with a role in Public Health or Social Care and provides information on densities of different ethnicities, in addition other indicators and data. The ethnicity of 'Asian/Asian British' was used to find areas of higher densities of these ethnicities and practices in those areas were emailed.

Inclusion criteria

- GP working in clinical practice, either as a partner or salaried doctor
- Working in a practice where South Asians are registered

Exclusion criteria

- GP trainees; due to limited clinical experience
- Locum GPs; due to not being embedded in practices and less likely to be involved in long-term management of patients
- Primary care clinicians who are not GPs (whilst there are many different clinicians in primary care who see patients for physical and mental health problems, this study was restricted to GPs who traditionally have been seen as the first point of contact for health problems)

The above exclusion criteria were operationalised by being clearly defined in the recruitment email (Appendix 5 Email to GP Practices) and information leaflet (Appendix 6 Participant information sheet for GPs). During the consent process the inclusion and exclusion criteria were checked.

### 5.2.3 Study setting

The study took place in three regions, Staffordshire, Manchester and Lancashire. These three regions were selected based on two main principles. The first factor was that they are areas of high densities of SAs (Office for National Statistics, 2013), and the research is very relevant to such populations. Secondly, an important factor when dealing with ethnic community groups is building trust (Waheed et al., 2020); areas were selected where I have built trusting relationships with the community. Keele university, the host institute, is based in Staffordshire in close proximity to areas with large SA communities, such as Stoke-on-Trent. I live and work clinically in Manchester, and am an active member of the wider community there. I also work in Burnley and have some connections with the Lancashire general community as well as GP practices within the locality. Hence these three areas were chosen as the study setting.

### 5.2.4 Sampling and recruitment

The patient advisory group fed into all aspects of recruitment; they advised how recruitment should take place, suggesting a poster in shops frequented by SAs and which shops specifically and in which areas. They also suggested community and faith centres of different backgrounds and reaching out to local media, in particular for SA communities.

#### *5.2.4.1 Males of SA origin*

Purposive sampling is when researchers deliberately choose which cases to sample to include a predetermined range or information-rich samples for in-depth study (Green, Thorogood, 2018). This is in contrast to probability sampling which is used more in quantitative studies whereby a sample is selected from a population based on randomisation to achieve a representative sample. Recruitment was purposive with respect that sampling was undertaken given the inclusion and exclusion criteria via community channels such as community and faith centres and shops frequented by SA communities to reach men of SA origin with LTCs. This was to gain a better understanding of the SA community's views of emotional distress rather than solely those patients who attend the

GP for treatment or support for their emotional distress. This included linking with 'gatekeepers,' respected members from the community such as those who are active from an organisational perspective in community or religious running committees or community or faith leaders, whose voice may be more likely to be listened to, to gain participants from community groups. A research poster and participant information leaflet was distributed to support this as well as via social media, such as twitter and Facebook accounts including Keele Mental Health Research Group. Snowball sampling (Atkinson, Flint, 2001), in which interviewed males of SA origin were asked to encourage other males of SA origin with diabetes and/or heart disease who may be willing to be interviewed, was also used in order to utilise existing networks of SAs. Convenience sampling is when the most available and easiest to recruit cases are interviewed, such as by asking people in a clinic waiting room if they would like to take part (Green, Thorogood, 2018). The lines between convenience and purposive sampling can be blurred. When displaying posters in public areas, it depended on who walked past the poster and noticed it, which can be considered convenience. The sampling was purposive with respect to the inclusion and exclusion criteria being clearly defined as well as efforts made to engage specific ethnic groups who did not initially volunteer to be interviewed. There was not a luxury of a list of masses of potential participants which was reviewed and selected participants chosen based on maximum variation, which is a sampling strategy in itself, i.e. maximum variation sampling.

#### *5.2.4.2 GPs*

I emailed practice managers at practices with high densities of SAs around the Staffordshire, Manchester and Lancashire regions as identified from Public Health England's SHAPE atlas tool (Public Health England, No date). They were asked to distribute study information to GPs within their practice via email. GPs known to the research team, who work in areas with high densities of SAs, were emailed directly. Snowball sampling (Atkinson, Flint, 2001) was also utilised, in which interviewed GPs were asked to share the study details with other GPs who might be willing to take part.

Local media were engaged with to support the recruitment strategy and promote the research; I appeared on Radio Stoke and BBC Radio Lancashire and Indus to discuss the study and encourage recruitment. I contacted radio stations specific for Asian communities contacted but they did not respond to allow time on their stations. To increase visibility for the study and support recruitment, I wrote a blog for the School for Primary Care Research (SPCR) (Awan, 2020b), Society for Academic Primary Care (SAPC) (Awan, 2021), and a video for the British Journal of General Practice (BJGP) Live (Awan, 2020a).

#### *5.2.4.3 Interested Potential Participants*

Two stage consent took place; an expression of interest followed by written consent (Appendix 7 Interview consent form for males of SA origin with diabetes and/or heart disease and Appendix 8 Interview consent form for GPs). The recruitment poster for males of SA origin and participant information leaflet for males of SA origin and GPs summarised the study and invited potential participants to contact myself via email or phone to express their interest in taking part. At this point of contact, I provided the potential participant with the participant information leaflet if they did not already have it. Information packs were be distributed by email or post depending on what the potential participant stated was their preference at the initial point of contact.

Information within the pack directed potential participants (SA males and GPs) to contact the myself to confirm willingness to participate and arrange an interview time. Potential participants who agreed to participate were invited via phone or email to arrange an interview. If no response has been received two weeks after initial distribution of the participant information pack, then a reminder letter or email was sent by myself together with further copy of the information sheet. Consent was obtained by email or post in advance of the interview, and consent reconfirmed (and recorded) at start of the interview.

All participants who had been interviewed received a thank-you letter or email (Appendix 9 Participant thank-you letter). Males of SA origin were offered a £20 voucher to recompense time and GPs were reimbursed for their time at the rate of £88 per hour (NHS Employers, 2019). Field notes were taken during the interviews.

### 5.2.5 Data generation

All interviews took place online in accordance with Keele University's advice for conducting research interviews during the pandemic. As part of the consent process, participants were asked if they agree for interviews to be digitally-recorded (for accuracy) and transcribed, and for direct quotations to be used, after having been anonymised, in the dissemination of the work. A record of consent was kept online on password-protected computers on Keele university's network and encrypted accordingly.

Demographic information from males of SA origin was collected to contextualise the data and support the description of the sample in publications. This includes age, ethnicity, educational attainment, occupation, religion and household composition. These details were gathered to provide contextual understanding of participants to interpret and analyse data within the broader contexts. If appropriate, comparisons were made such as first versus second generation SAs. Variation was considered, such as making active effort to recruit from participants from different SA countries.

For GPs, age, gender, years of experience working in General Practice, number of clinical sessions worked per week, job role (GP partner or salaried, as well as other relevant clinical roles) as well as practice demographics was collected. These details were gathered to provide contextual understanding of participants to interpret and analyse data within the broader contexts. If appropriate, comparisons were made such as SA versus non-SAs. Variation was considered, such as making active effort to recruit from participants from female as well as male participants.

Two interview topic guides, one for interviews with males of SA origin with diabetes and heart disease (Appendix 10 Topic Guide for males of SA origin with diabetes and/or heart disease) and one for interviews with GPs (Appendix 11 Topic Guide for GPs), were developed from the literature and discussion with the research team and patient advisory group. Initial interviews were used to pilot and refine the interview topic guide. The latest topic guides have been included in the appendices, which with small amendments included 10 versions for GPs and 15 for SAs. Each interview was expected to last around 45 minutes with males of SA origin, and half an hour with GPs. At the end of the interviews, participants were asked whether they would like to be sent a summary of results and if via email or post. This was recorded in a password-protected spreadsheet. The audio recordings of the interviews were transcribed; by myself and some by Way With Words (https://waywithwords.net/), a transcribing company used by Keele University. Interviews were continued until data saturation had been achieved (Saunders et al., 2018). The approach to data saturation is discussed further in 5.2.8. The topic guides remained flexible and were modified as data generation and analysis proceeded to respond to developing themes.

Topic guides were designed to facilitate the conversation and exploration of the following six areas:

1. *How do males of SA origin with LTCs understand emotional distress, its nature and causes?*
2. *What help-seeking strategies do males of SA origin with LTCs origin use for emotional distress, and do these differ for physical problems?*
3. *What are the facilitators and barriers to GPs supporting males of SA origin with LTCs in identifying and managing emotional problems in SA males with physical-mental comorbidity?*
4. *What services are needed to best support males of SA origin with LTCs for emotional distress?*
5. *How has the covid-19 pandemic affected the mental health of males of SA origin with LTCs, its management and the management of their LTCs, from the perspective of males of SA origin?*
6. *From the perspective of GPs, how has the covid-19 pandemic affected the mental health of males of SA origin with LTCs, its management and the management of their LTCs?*

With interviews taking place online due to the COVID-19 pandemic, the impact of the pandemic was considered. Online interviews can have the positive of greater flexibility in time and location, whilst challenges of security of the platform, confidentiality of the interview (for example with other members of the family at home) and the logistics (internet, camera etc) (Lobe, Morgan & Hoffman, 2020). Online interviews provided a number of benefits, namely that there was no travel time and much more accessible as participants may have found it easier to participate in interviews from wherever they were (de Villiers, Farooq & Molinari, 2022). They have given a further sense of privacy for participants which is important when discussing topics that may be stigmatised. Furthermore, for those able to manage internet and technology, interviews took place via Microsoft Teams which allowed for video interviews where body language could still be picked up. Notably, online interviews have been found to have similar interview lengths, subjective interview ratings and substantive coding in comparison with in-person interviews (Johnson, Scheitle & Ecklund, 2021).

Online interviews also provided a set of challenges. Online interviews can exclude populations who do not have access to the internet (Vicary, 2021). A number of South Asian participants were unable manage the technology or internet to have video interviews, so phone interviews often took place in which body language and nuances in communication were lost. In-person interviews provide more opportunities to establish rapport, with moments such as walking in, meeting each other and asking how the journey was, and other small conversation build up to a more comfortable setting when the interview starts (Saarijärvi, Bratt, 2021) . Online interviews did not have these in-person opportunities, but may have facilitated participants to feel more comfortable and open in the safe space of their homes with an interviewer online and not encroaching in their safe space. Whilst interviews provided great depth in terms of data and experience, one can consider if they were in-person if greater depth could have been gained. Some interviews began as online interviews but finished as telephone interviews due to poor internet connection. This impacted the rapport and flow of the interview. Furthermore, there were often disturbances from GPs who would have to leave the interview for a few minutes for an urgent task. One can consider that when being interviewed in-person they block that time out in a different way to when they are interviewed in person. Issues of confidentiality are greater in online interviews where it is more likely for third person to be in the room of the participant without the interviewer being aware (Saarijärvi, Bratt, 2021); this occurred during one interview with a SA participant where a relative began to answer a few questions on his behalf. It was explained that it was important to hear the viewpoints of the participant, and the interview continued to run smoothly. The conversation of the other person was not used in the interview and the relative was not asked to leave the room due to the participant's preference for them to be there. This could potentially provide different data to a completely confidential setting to one in which a person may speak without any relatives or others listening. Of note, some SAs may feel intimidated by interviews with researchers and having a familiar face present may have facilitated them to participate in the interview.

### 5.2.6 Data analysis

Transcripts formed the data-set which was thematically analysed using constant comparison (Fram, 2013). Each data-set was analysed separately before analysis conducted across the two data-sets. Thematic analysis focuses on meaning across a data set, allowing researchers to understand collective and shared experiences (Braun, Clarke, 2014). The gathering of data to create overall meaning through themes is useful in health research, and relevant to healthcare policy due to its transferability (although not all themes may be transferable beyond the context of a specific research study). It is increasingly used with other methods (Fram, 2013). It adds to analysis by comparing data from different interviews, highlighting similarities and differences, and discovering patterns. I undertook six phases of thematic analysis based on Braun and Clarke's approach to thematic analysis, and specifically according to reflexive thematic analysis (Braun, Clarke, 2019) as shown below in Table 4. Data were then inspected for commonalities using a constant comparative model, in which data is systematically compared to all other data within the data set, which has been done in studies with participants from different groups (Coventry et al., 2011). As described in the methodology chapter, constant comparison emerged from grounded theory (Glaser, Strauss, 1967), and it is increasingly used with other methods (Fram, 2013). Whilst Braun and Clarke advocate that thematic analysis is enough in itself, I feel that constant comparison adds to analysis by comparing data from different interviews, highlighting similarities and differences, and discovering patterns. SA and GP data-sets were separately analysed; once analysis was completed for both data sets they were compared to find similarities and differences (see Appendix 12 Example of coding of separate groups for data analysis).

Table 4 Phases of data analysis

| **Phase of data analysis** | **Steps taken** |
|---|---|
| 1. Familiarisation with the data | Initially, I familiarised myself with the data by reading and re-reading the data to note down ideas. |
| 2. Generating initial codes | I coded transcripts individually and then a selection of transcripts were also analysed by members of the supervisory team. Codes can be considered as an analytical tool to provide a summary or the content of a small portion of data (Braun, Clarke, 2014). |
| 3. Development of themes | I identified themes. Themes are considered to be broader topics to which groups of codes can be clustered together which show patterns of meaning (Braun, Clarke, 2014). I used constant comparison to develop the initial themes by comparing later data sets with earlier sets. |
| 4. Reviewing potential themes | Potential themes were reviewed and discussed collaboratively with the supervisory team as well as the patient advisory group. The supervisory team consisted of clinical as well as non-clinical members brought different perspectives when viewing the data. |
| 5. Defining and naming themes | Themes were defined and named in discussion and collaboration with the supervisory team and patient advisory group to ensure that they were focused, related without excessive overlap and answered the research question. |
| 6. Producing the report | Finally, the synthesis was written up for the thesis and for publication. |

### 5.2.7 Approach to saturation

There is a debate in qualitative research as to whether data saturation is a useful concept given. Braun and Clarke argue that the concept of saturation refers to a redundancy of information is neo-positivist and inconsistent with reflexive thematic analysis (Braun, Clarke, 2021); codes are never finally fixed but evolve, expand, contract and are renamed as part of deeper engagement with the data and are not describing ontological real things. They argue that numbers for theoretical saturation cannot be known in advance, challenge the use of theoretical saturation in thematic analysis, and discuss other terms used such as theoretical sufficiency and conceptual depth (Ibid). Proponents of data saturation in qualitative research describe it in nuanced ways, and rather that data saturation and the final themes reported are not to be considered an objective truth but rather themes developed from established processes that is open to scrutiny. Subjective data will always be able to find another view, another experience in another time and place, hence a line may need to be drawn at some point. Four types of data saturation have been argued to exist, *theoretical saturation* using the development of categories and emerging theory in analysis to determine data collection, *inductive thematic saturation* which focuses on analysis of new codes and themes, *a prior thematic saturation* in which refers to the degree in which codes and themes are exemplified in the data based on pre-determined theory, and *data saturation,* referring to the degree in which new data repeats in what was expressed in previous data (Saunders et al., 2018). Inductive data saturation was used as a means of data saturation when I was confident that the themes were sufficiently well-established and coherent, which took place after 17 SA and 18 GP interviews.

### 5.2.8 Data storage

Data storage procedures followed the university of Keele’s Standard Operating Procedures for research, in particular ‘HSCR-POL01 - Policy for Health and Social Care Research Participants.’ Personal data was only accessible to the research team during the data collection phase of the study. A study database containing participant information was housed on Keele University’s secure network in a password-protected folder. Personal data was kept for up to six months after the end of the study. There were secure physical storage arrangements for hard copies within the School of Medicine in lockable filing cabinets. The School building operates a key code entry system to ensure only appropriate persons can enter the building. In addition, any hard copy research data that was printed for checking was destroyed by shredding. Research data was pseudo-anonymised prior to analysis through the use of a unique study code; only I had access to the link to identify data. Electronic copies of anonymised transcripts will be stored for ten years on a secure university network to be accessible for future research (where participant consent has been obtained). For archiving at the end of the study, all data has been maintained in such a form that they cannot be linked with identifiable participants and will be anonymised in the reports.

## 5.3 Ethical considerations

Ethical approval for interviews with men of SA origin with LTCs was attained via Keele University's Research Ethics Committee (REC) (project reference MH-200132 and Appendix 13 Ethical Approval from Keele University). For GP interviews, Health Research Authority (HRA) approval was also obtained, as NHS services facilitated NHS staff recruitment for interviews (IRAS ID 293272 and Appendix 14 IRAS and HRA Approval). Prior to data collection, written informed consent was obtained by myself, using a consent form, and I have completed Good Clinical Practice (GCP) training (November 20th 2019). Participation in the study was kept confidential and data pseudo-anonymised through the use of a unique study identifier.

I considered deontological approaches consistent with codes of ethics. Relational ethics was important to this research, as I built a relationship with participants from an underserved group (SAs) as well as a GPs and made efforts to ensure the research was culturally relevant and appropriate for all participants. I asked sensitive questions and reflected upon how that could impact our relationship and participants' relationships with research and healthcare in general, considering my multiple roles which participants were aware of. Virtue ethics is something I ascribe to on a personal level, trying to act in a way which is 'of virtue.' Situational ethics was important in qualitative interviews in which people could have potentially disclosed thoughts of self-harm or suicide, whereby a plan was in place in advance if such occurred, yet each situation would be discussed with my lead supervisor and acted upon given the situation. Furthermore, anything unplanned for would have been dealt with by this approach.

If, during interviews, participants became upset or distressed they were offered the opportunity to discuss their concerns at the end of the interview or to stop the interview altogether. Participants had the option to leave the interview at any point. As a GP, I have undertaken training on how to deal with distressed individuals and would have advised participants to seek help from appropriate services such as their General Practitioner (GP). A risk protocol was in place to guide decision-making should the safety of participants (for example risk of self-harm or suicide) or others be identified as at risk (Appendix 15 Risk Protocol). If any difficulties arose, the risk protocol was that I should contact CCG (supervisor and academic GP) for advice. No instances occurred in which interviews had to be terminated or the risk protocol initiated.

The School Lone Working policy would have been used with any interviews conducted face-to-face outside Keele University premises, however all interviews took place online/telephone. The research protocol was written and public-facing documents were agreed with the supervisory team after feedback from the patient advisory group, including the recruitment poster, information leaflets, email to GPs, consent form, topic guides, thank-you letter for taking part, and risk protocol.

The study took place in a context of the COVID-19 pandemic; all UK government guidelines were followed to ensure neither myself nor study participants were put in any risk. All interviews took place via telephone or online. The first patient advisory group meeting took place in person prior to the pandemic, subsequent meetings took place virtually, using both video and audio and presentations via Microsoft Teams. Anyone from the patient advisory group who could attend the meetings virtually or was unable to manage the online element was contacted via telephone to enable them to contribute to the study. During one interview, a participant's relative was in the room and started to answer questions. The approach to resolving this was previously discussed in 5.2.6 data generation. No further ethical issues occurred.

## 5.4 Patient and Public Involvement and Engagement in methods

Patient and public involvement and engagement (PPIE) is an integral part of this research. In any study, the voice of those to whom the research is trying to benefit is critical to ensure that the research is relevant and effective  (Chief Scientist Office, Health and Care Research Wales, Public Health Agency and National Institute for Health Research, 2018). A systematic review in 2017 found only one study in the UK whose PPIE focused around ethnic monitories (Dawson et al., 2018). This highlights the lack of PPIE work focusing around ethnic minorities; conversely, the need for research within people from ethnic minorities has been discussed in chapter 2 highlighting a clear mismatch between needs and action. Involving and engaging people from ethnic communities in patient advisory groups for research is both a challenge and priority (Ekezie et al. 2021). Involvement of people from ethnic groups such as SAs has been described as a need, yet the involvement should not be tokenistic and should involve the community in all stages of the research, to make the research relevant to their communities (Ibid).

To ensure the ethnicity of the patient advisory group is most appropriate for the study, the *Student-Link* initiative was utilised; this was a Keele University initiative to support ethnic diversity within PPIE within the School of Medicine. I attended a workshop in which students and staff at Keele University explored ways of increasing diversity within the Research User Group (RUG) by acting as *community champions* encouraging diverse community members to join. I attended further meetings about developing the *Student-Link* project and became a *BAME champion* (as termed at the time) and actively engaged with BAME networks to establish a patient advisory group of six SA males from a variety of social and economic backgrounds. I wrote a blog for the SPCR regarding lessons learnt whilst setting up a culturally sensitive patient advisory group  (Awan 2020b). Key points learned included:

- Undertaking research that ethnic minority groups feel is relevant to them
- Building trust with ethnic minority communities
- Using existing networks within ethnic minority groups to establish the group

In the initial meeting, the patient advisory group group felt the research was very relevant to them and their communities. They discussed components of the proposed systematic review and reviewed public-facing study documents for the qualitative study. They suggested improvements to support cultural relevancy and to support participant recruitment. The group suggested recruiting from particular areas of Stoke-on-Trent, local community and faith centres, and advised on times to speak at religious and cultural events to capture the largest audience; these suggestions were acted upon during recruitment.

The patient advisory group was utilised throughout the research according to the National Standards for Public Involvement (Chief Scientist Office, Health and Care Research Wales, Public Health Agency and National Institute for Health Research, 2018). The six standards were used, which are ‘inclusive opportunities’, ‘working together’, ‘support and learning’, ‘communications’, ‘impact’ and ‘governance’, described in Table 5 below.

Table 5 Patient advisory group input into the National Standards for Public Involvement

| **National Standards for Public Involvement** | **Patient advisory group** |
|---|---|
| Inclusive opportunities | An ethnically appropriate patient advisory group of five SA males was recruited to reflect the study participants as described in 5.4. |
| Working together | The patient advisory group acted as colleagues reviewing the research four times during the different stages of the PhD project and provided input which affected the research. This was facilitated by encouraging the patient advisory group to provide direction to the research and provide critical input to any work presented to them. This included developing the key components for the systematic review, recruitment, developing public-facing documents and interview topic guides, analysis of themes, |

| | |
|---|---|
| | dissemination priorities and development of an animation video. |
| Support and learning | The patient advisory group underwent some training to support their participation in the research, such as in developing themes. |
| Communications | The patient advisory group reviewed all public-facing documents to ensure they were culturally sensitive and clear.<br>Engagement was maintained between meetings via email. Engagement was maintained within meetings by ensuring any work presented was in lay terminology and taking consideration of cultural and religious norms. Care was taken to ensure the group had a space where they felt safe to discuss and challenge thoughts during discussions. |
| Impact | The patient advisory group played a crucial role in identifying dissemination activities and providing input into these activities, including co-creating an animation video, further described in Table 6. |
| Governance and leadership | Progress was regularly reported to the patient advisory group with opportunity for the patient advisory group group to provide input and feedback to the research team outside of the meetings via email. I acted as a facilitator to allow for the patient advisory group to input into processes and infrastructure. |

The patient advisory group met six times, the outcomes of the meetings are provided in Table 6.

Table 6 Patient advisory group meetings

| **Date** | **Patient Advisory Group Meeting Agenda** | **Outcome** | **Impact** |
|---|---|---|---|
| Meeting 1: July 2019 | Research ideas were presented to the group.<br>The systematic review key terms were discussed.<br>Public-facing documents for the qualitative study were discussed. | Members of the group felt that the research was relevant and needed in particular for SA men. They discussed differences in approaches such as emotional distress versus mental health problems and felt that emotional distress would be more helpful, describing a significant amount of emotional distress within the community but rarely diagnosed. They also discussed researching SAs versus researching people from a specific SA country such as from India or Pakistan and the challenge of the heterogeneity. They felt overall that SAs share significant cultural, religious and geographical similarities and that it would be helpful to research SAs rather than people from a specific countries. They discussed components of the proposed systematic review.<br>Public-facing study documents for the qualitative study including the recruitment poster and participant information leaflets were amended to ensure they were clear and concise to people in whom English may be a second language. | Research ideas finalised.<br>Systematic review key components confirmed.<br>Public-facing documents for the qualitative study developed and confirmed. |

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|  |  | Improvements to make the documents more culturally relevant were suggested as well as to support participant outcomes. |  |
| Meeting 2: May 2020 | Focus on the preliminary systematic review results, discussing the qualitative study including recruitment plans | The group were in general agreement with the overall systematic results, but discussed areas they expected from the data which was missing, in particular around cultural health beliefs. They described surprise at a lack of description of terms such as black magic as a source of emotional distress, and the use of faith-based practitioners in the management of emotional distress. The group advised to include these and other culturally relevant questions in the topic guides.<br>Recruitment plans were adapted to include approaching community and faith centres, radio, and putting posters up in shops in named streets that were frequented by SAs. The group emphasised the importance of getting the views of the community, and not to neglect people who do not go to the GP, hence not to recruit from GP settings but instead community-related venues. | Systematic review themes discussed and finalised, as well as themes not included which were expected; this was included in the systematic review publication.<br>Topic guides refined for qualitative study.<br>Recruitment plans adapted. |
| Meeting 3: May 2021 | Discuss the qualitative analysis from the SA interviews and review of topic guides. | Discussion and development of qualitative themes of SA interviews and refinement of topic guide for GP interviews based on this as well as further areas for exploration with SA interviews. The group challenged some suggested terms. For example, I suggested a theme of navigating cultural beliefs. A | Refinement of findings. |

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| | | member of the group challenged this theme explaining that SAs beliefs are not hurdles that GPs have to navigate around, and secondly that GPs have their own beliefs that have to be considered. Both perspectives need to be navigated to come to shared decision-making. Hence the term co-navigating care was suggested. | |
| Meeting 4: January 2022 | Discuss and develop the themes from SA and GP interviews, dissemination plans and discussion of next steps of the research and conclusion of the study. | Amalgamated themes were finalised with the patient advisory group and dissemination plans agreed, including different means of community engagement such as an animation video and/or infographic. Research priorities were discussed, including developing culturally adapted services, training in cultural sensitivity and how to change systems within primary care to make them culturally relevant. | Themes developed for qualitative study.<br>Dissemination plans agreed.<br>Future research priorities discussed. |
| Meeting 5: September 2022 | Co-create animation video | The main study findings were reviewed and then the PAG built an animation video in conjunction with HA. The main points for the video were agreed, a transcript, voices, animations, colour schemes and text. The PAG felt that a slow pace of speech would be helpful, and that whilst an animation video in multiple different languages would be helpful, for simplicity one video would be made with simple English. The PAG requested myself to be one of the speakers in the video to add authenticity to the | Animation video co-created. |

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| | | project, as well as a SA male voice. They suggested a dim colour scheme which then developed in colour. They did not want music in the video. | |
| Meeting 6: October 2022 | Review animation video | The transcript was further simplified in terms of English language and speech in the transcript became more positive (from ‘GP gave advice’ to ‘GP gave good advice’ and from ‘I trusted my GP’ to ‘I trust my GP’). They decided the parting text- Don’t suffer in silence, see your GP. The SA voice was agreed to be a SA voice but without a strong accent. Symbols of the major faiths in SA countries were all requested to be included. The initial colour contrast was felt not to be strong enough and the PAG wanted the final images to be more smiling. | Animation video reviewed and finalised. |

The guidance *Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project* (National Institute for Health Research 2020), which was published after this study started, was also reviewed to ensure the research involved under-served groups. For example, the paper describes *Questions to guide research teams in designing inclusive research*, including *How will your recruitment and retention methods engage with under-served groups?*; this was answered by the patient advisory group in details. A toolkit similarly published in 2022 for increasing the participation of Black, Asian and minority ethnic communities in health and social care research (Farooqi et al. 2022) was also reviewed. Some of the key results of this study had already been acted upon, such as adequate attention to recruitment strategies and planning, researchers engaging with communities and individuals in a cultural competency manner, and linking with community networks (Ibid). All of the six good practice guidelines had been considered; considering the communities which the research needs to involve, undertaking effective patient and public involvement (PPI) in research, conducting effective recruitment in BAME communities, Ensuring cultural competence in the conduct of your research, providing effective feedback to research participants, recognising the importance of recruiting BAME communities in research: preparing a grant application. I had already acted upon the three main advices of Farooqi et al (2022)- effective patient and public involvement (as per the PAG group of SA men), culturally competent researchers (myself in this case) and providing effective feedback (with regular meetings and emails between meetings). Whilst the toolkit was helpful, some areas of my approach differed to the toolkit. For example, I used the term people from ethnic minorities and not BAME, as it groups diverse ethnicities into one group and emphasises certain groups over others.

## 5.5 Research quality

The methodology chapter (section 4.4) described how research quality in qualitative research can be defined as to how trustworthy it is, based on four areas of credibility, dependability, confirmability and transferability. They are discussed below in further detail.

### 5.5.1 Credibility

Credibility refers to the confidence in the ‘truth’ of the findings. Credibility was maintained by monthly meetings with the research supervisors, and research themes, categories and codes were developed from quotes and evidenced according to them. As described in 5.2.7, inductive data saturation occurred whereby I was confident that the themes were sufficiently well-established and coherent. Triangulation, the assumption that different sources of information help confirm, improve and clarify a research finding (Ritchie et al. 2013) took place. Triangulation of sources took place via comparison of interviews from GPs and SAs. Triangulation through multiple analysis took place with different members of the research team involved in analysing the data, as well as the patient advisory group. A supervisory team of different clinical and non-clinical backgrounds further helped the credibility of the themes. Negative case analysis occurred whereby findings not consistent with the overall data were sought out and discussed, such as some SA preferences not to see a SA GP. Different aspects of the results were shared at a number of conferences, including the Royal College of General Practice Annual Conference in conjunction with

WONCA Europe,  Society for Academic Primary Care North Conference 2021, the Society for Academic Primary Care Annual Scientific Meeting 2022 and 2021, Primary Care Mental Health Research Conference 2022 and 2021. Throughout these conferences, preparation for the conferences and discussion and questions and answers after the conferences further refined the analysis. These can be considered a form of external peer review. Appendix 16 contains the list of conferences and titles (Appendix 16 List of outputs resulting from PhD).

### 5.5.2 Transferability

Transferability relates to the extent to which the findings can be applied in contexts beyond those of the research setting. Interviewing SA males and GPs from three different geographical areas in England makes the research potentially transferable to different geographical settings. Sampling included a purposive element with efforts made to engage specific ethnic groups who did not initially volunteer to be interviewed. Semi-structured interviews provided detailed accounts which thematic analysis and constant comparison sought to look for transferable themes. Engagement with existing literature and theoretical constructs helped support abstraction in the analysis; I developed the themes from initially descriptive to higher level themes of patterns of shared meaning which underpinned by a central meaning-based concept (Braun, Clarke 2019) which supported the transferability of the themes to different contexts.

### 5.5.3 Dependability

Dependability shows that the findings are consistent and can be repeated. During all stages of research meticulous detailing of the research process took place in accordance with the research protocol. The methodology and methods were followed in detail. The research process was reviewed by the research supervisors and patient advisory group and coding tables and themes were reviewed, with a clear audit trail to all of the research. Data collection included transcripts and a reflexivity diary was kept throughout and shared with the supervisory team, increasing the transparency of the research (see section 5.5.5 for further details).

### 5.5.4 Confirmability

Confirmability refers to the degree of neutrality or the extent to which the findings are shaped by the respondents as opposed to researcher bias. A researcher's background and experience directly affect their choice of the research question, approach to the research, analysis and dissemination of findings (Malterud 2001). A reflexivity diary was kept throughout to ensure I was aware of personal feelings and thoughts and how these could potentially influence the research and how they could be minimised (5.5.5). Patient advisory group meetings were used as opportunities for sense-checking and self-reflection. Triangulation of sources via constant comparison and triangulation through multiple analysis as described in 5.5.1 also supported confirmability.

### 5.5.5 Reflexivity

Based on my epistemological perspective, it is an impossibility to have research which is not influenced by a researcher. Hence I aimed for *empathic neutrality*, in which one strives to avoid bias and be as neutral as they can (Ritchie et al. 2013). There are challenges and experiences for a researcher who shares experiences of study participants, a researcher who moves from being an outsider to an insider during the study, and a researcher who has no personal familiarity with what is being studied (Berger, 2015). A reflexivity diary was written throughout. I return to this in Chapter 6 (section 6.6).

## 5.6 Chapter summary

The chapter began with a description of the choice of methods. This was followed by details of the participants, setting and then the sampling and recruitment strategy. Data generation and data analysis including theoretical saturation was discussed, followed by data storage, ethical considerations and patient and public involvement and engagement in research. The chapter concluded with a brief discussion around research quality and reflexivity. Chapter 6 will discuss the first chapter of the findings from the qualitative research study.

# Chapter 6: Contextualising and conceptualising distress

## 6.1 Introduction

The findings from the qualitative study are presented in two chapters. Two sets of participants were interviewed, males of SA origin with LTCs, and GPs who serve them within primary care. As described 5.2.6, topic guides were designed to facilitate the conversation and exploration of the following six areas:

1. *How do males of SA origin with LTCs understand emotional distress, its nature and causes?*
2. *What help-seeking strategies do males of SA origin with LTCs origin use for emotional distress, and do these differ for physical problems?*
3. *What are the facilitators and barriers to GPs supporting males of SA origin with LTCs in identifying and managing emotional problems in SA males with physical-mental comorbidity?*
4. *What services are needed to best support males of SA origin with LTCs for emotional distress?*
5. *How has the covid-19 pandemic affected the mental health of males of SA origin with LTCs, its management and the management of their LTCs, from the perspective of males of SA origin?*
6. *From the perspective of GPs, how has the covid-19 pandemic affected the mental health of males of SA origin with LTCs, its management and the management of their LTCs?*

The first findings chapter begins with a description of characteristics of the participants interviewed. Two overarching themes of contextualising distress and conceptualising distress are discussed. Contextualising distress encompasses distress experienced around diagnosis of a long-term condition (LTC), adjusting to life with a LTC, social factors and perceptions of prejudice. Conceptualising distress encompasses ‘distress not depression’, negotiating multiple identities and alternative paradigms of health. The contributions of the patient advisory group and reflexivity in relation to the development of themes are presented at the end of the chapter, followed by the chapter summary.

Most interviews of both males of SA origin and GPs lasted approximately an hour. The potential implications of longer interviews were considered and participants were asked if it was ok to continue beyond the expected time

## 6.1 Characteristics of participants

Seventeen SA men with LTCs and 18 GPs were interviewed one-to-one and all virtually. The interviews took place between November 2020 and October 2021, allowing for topic guides to be iteratively changed to incorporate the areas discussed by participants in each group and alongside initial analysis. Data were initially analysed separately as per participant group, and then the two data-sets were compared and contrasted to develop a more nuanced understanding of the data, as described in 5.2.7 (Data analysis).

### 6.1.1 SA participants

SA participants broadly represented ethnicities from the largest SA countries, with 10 participants of Pakistani origin, four of Bangladeshi origin and 3 of Indian origin. Religion was less diverse, with 16 SA participants ascribing to Islam and one to Hinduism. Eleven SA participants had self-reported diabetes, one had heart disease and five had both diabetes and heart disease. Nine described other comorbidities, such as hypertension and hypercholesterolaemia. The mean age of SA participants was 54.5, with an age range of 30-83. Educational attainment levels ranged from university degree to no formal schooling. Thirteen participants described themselves as first generation immigrants, and four as second generation, although all had been in the UK for over 20 years. Table 7 provides the main characteristics of the SA participants, all who were interviewed virtually.

Table 7 Characteristics of SA participants:

| **Participant ID** | **Ethnicity** | **Age (years)** | **Index LTC** | **Comorbidities** | **Educational attainment** | **Occupation** | **Religion** | **How many years has been in the UK** | **Generational status** |
|---|---|---|---|---|---|---|---|---|---|
| SA01 | Pakistani | 60 | Diabetes Type 2 | None reported | College | Taxi driver | Islam | 42 | First |
| SA02 | Pakistani | 54 | Diabetes Type 2 and heart disease | None reported | College | IT consultant | Islam | 51 | First |
| SA03 | Indian | 62 | Diabetes Type 2 | None reported | University | Operations manager | Islam | 55 | First |
| SA04 | Indian | 67 | Diabetes Type 2 | None reported | No schooling | Retired factory worker | Islam | 22 | First |

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|---|---|---|---|---|---|---|---|---|---|
| SA05 | Pakistani | 60 | Heart disease | Hypercholesterolaemia and prediabetes | University | IT consultant | Islam | 50 | First |
| SA06 | Pakistani | 39 | Diabetes Type 2 | None reported | University | Unemployed | Islam | Born in UK | Second |
| SA07 | Bangladeshi | 42 | Diabetes Type 1 | Hypercholesterolaemia, hypertension | College | Security worker | Islam | 40 | Second |
| SA08 | Pakistani | 57 | Diabetes Type 2 and heart disease | Hypercholesterolaemia, hypertension | Secondary school | Factory worker | Islam | 45 | First |
| SA09 | Bangladeshi | 33 | Diabetes Type 2 | Asthma | University | Teacher | Islam | 32 | Second |
| SA10 | Bangladeshi | 37 | Diabetes Type 2 | Paranoid schizophrenia | University | Unemployed | Islam | 26 | First |
| SA11 | Pakistani | 83 | Diabetes Type 2 and heart disease | Osteoarthritis | Secondary school | Retired travel agent | Islam | 60 | First |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| SA12 | Pakistani | 50 | Diabetes Type 2 and heart disease | None reported | University | Post office and taxi driver | Islam | 25 | First |
| SA13 | Pakistani | 66 | Diabetes Type 2 and heart disease | None reported | Secondary school | Businessman | Islam | 52 | First |
| SA14 | Pakistani | 62 | Diabetes Type 2 | Partially blind | College | Driver on sick leave | Islam | 35 | First |
| SA15 | Indian | 63 | Diabetes Type 2 | Dystonia | Partial secondary school | Post office | Hinduism | 22 | First |
| SA16 | Pakistani | 62 | Diabetes Type 2 | Hypercholesterolaemia | Partial secondary school | Shopkeeper | Islam | 31 | First |
| SA17 | Bangladeshi | 30 | Diabetes Type 1 | None reported | College | Underwriter | Islam | Born in UK | Second |

### 6.1.2 GP participants

Fourteen GPs were male and four were female. The majority of GPs who took part in interviews were of SA heritage, 16 participants as opposed to 2 non-SA. Again, ethnicities of the three most populous SA countries were represented, 8 GPs of Pakistani ethnicity, 5 of Indian and 3 of Bangladeshi ethnicity. Fifteen GPs interviewed spoke a SA language, such as Punjabi or Urdu. The mean age was 41.9, with a range of 31-64. There was a variation in clinical sessions worked, from 2 to 10 a week. Table 7 provides the main characteristics of the GP participants.

Table 7 Characteristics of GP participants

| Participant ID | Age (years) | Gender | Ethnicity | SA languages spoken | Numbers of clinical sessions worked | Years of experience as a GP | Roles |
|---|---|---|---|---|---|---|---|
| GP01 | 64 | Male | Indian | Gujarati | 3 | 32 | Partner; Academia |
| GP02 | 40 | Male | Pakistani | Punjabi, Urdu | 3 | 11 | Partner; Leadership |
| GP03 | 55 | Male | English | Nil | 4 | 29 | Salaried; Medical education |
| GP04 | 39 | Male | Pakistani | Urdu, Punjabi | 6 | 10 | Partner; Medical education |
| GP05 | 50 | Male | Pakistani | Urdu | 9 | 20 | Partner; Leadership |
| GP06 | 38 | Male | Indian | Gujarati | 6.5 | 11 | Partner; Medical education |

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|
| GP07 | 43 | Male | Pakistani | Urdu, Pashto | 6 | 8 | Salaried; Other clinical roles, medical education |
| GP08 | 33 | Male | Pakistani | Urdu, Punjabi | 6 | 4 | Partner; Medical education |
| GP09 | 32 | Female | English | Nil | 4 | 2.5 | Salaried; Academia, medical education |
| GP10 | 44 | Male | Bangladeshi | Bengali | 3.5 | 16 | Partner; Leadership, medical education |
| GP11 | 38 | Female | Indian | Nil | 6.5 | 6.5 | Salaried |
| GP12 | 42 | Male | Pakistani | Urdu, Punjabi, Hindko | 8 | 5 | Salaried (and locum); Medical education |
| GP13 | 30 | Female | Indian | Tamil | 10 | 1 | Partner |
| GP14 | 33 | Male | Indian | Hindi | 2 | 4.5 | Salaried; Other clinical roles |
| GP15 | 49 | Male | Pakistani | Urdu | 7.5 | 18 | Salaried; Other clinical roles |
| GP16 | 45 | Male | Bangladeshi | Bengali | 9 | 16 | Partner; Leadership |
| GP17 | 49 | Female | Pakistani | Urdu | 6 | 7 | Salaried; Other clinical roles |
| GP18 | 31 | Male | Bangladeshi | Bengali | 6 | 3 | Salaried; Leadership |

## 6.3 Contextualising distress

A key overarching theme was contextualising distress, i.e. the circumstances within which distress was experienced. These included multiple challenges, such as social, financial, relationships and families, and healthcare challenges. When asked about what distress is, one SA participant emphasised that distress had to be considered within the context of an individual's life and the challenges they face.

> *Somebody's going through a bad time in their life, if some experience has happened to them, that's anxiety. That can lead a person to mental health issues temporarily. You see lots of people in the [SA] community going through that, whether it's social, financial, domestic, or health, or whatever it is.* (SA03)

Within the context of having a LTC, SA and GP participants described distress around the diagnosis of the LTC, living with the LTC and social causes of distress.

### 6.3.1 Distress around diagnosis of a LTC

The reported experiences of diagnosis of a LTC focused around stress and shock around diagnosis. One participant described how he felt '*betrayed'* by his body, having had previous good health and being active. The shock and stress around diagnosis was often related to fear of complications, awareness of poor health outcomes of others, and fear of further heart attacks in the case of heart disease.

> *The diabetes at first, it was very depressing, that I felt my body had let me down. Obviously, from being quite active, bouncing about and football and whatever, whenever I could. I think I was 49 or something like that at the time. I felt a bit betrayed by my body. I know it's silly. But then I got used to it and I find that it didn't really affect me that much. I was okay, pretty much, within myself after a couple of months. And then with this heart attack now, it's very depressing. Again, because now, I'm always worried about the next event.* (SA02)

This experience of the initial diagnosis period as a distressing time was echoed by the majority of GPs:

> *I think one is the diagnosis of the condition. I think the simplest thing there is once you've got a new diagnosis I think automatically it will affect their mental health.* (GP07)

Distress around diagnosis was described by some SA males as lessening over time as they described getting used to managing their illness and adjust to their new circumstances.

> *Because I've heard cases where a lot of people have died from diabetes, so I think my mood has been affected as a result… Short term… I think what it is, I've learnt just to pull myself back up. I think I've learnt to adjust with it in time.* (SA06)

Other SA males described longer term distress which had not improved over time, with a feeling of helplessness, and ongoing worry at the potential deterioration of the body. Diabetes was considered an invisible disease, impacting the body in a way no outsider could see.

> *You could feel quite helpless as well because there's something going on with your body. You can't see it going on but… Like, for example, diabetes. You can't see the diabetes, the effects of it are in your blood. And it can be quite stressful in that way. Stressful in the sense that there's a lot of physical reasons there's something wrong with you and you can't fix it quickly. You have to go to the GP or take medication or, if the worst comes to the worst, you have to go to the hospital to get it checked out.* (SA10)

Distress around diagnosis of the LTC has been discussed. As well as this, SAs and GPs described adjusting to life with a LTC, which will be explored below.

### 6.3.2 Adjusting to life with a LTC

SAs and GPs described challenges making lifestyle changes, discipline and family support, and some issues with Asian diet. One participant described how he made little lifestyle change after a diagnosis of diabetes, and when he was therefore started on medication he became even less engaging with healthy lifestyle choices due to feeling that the medication was doing the job of looking after his health.

> *I was very, let's say, lackadaisical with regards to the diabetes when I was first diagnosed. And then when I started going on the medication, I became even less.* (SA02)

Lifestyle changes caused a sense of distress not only by making the changes themselves, but also by how making lifestyle changes impacted their lives. One participant, who attempted to quit smoking, described frustration and isolation after subsequently losing contact with members of his social network who continued to smoke.

> *When you're constantly being told that you have to make a whole U-turn in your life in terms of your lifestyle, in terms of… Because a lot of my friends smoke. So, when we do socialise, we go out, smoke and then go out for a meal. So, it's almost letting go of your social group. That in itself can bring you… Everyone around you is smoking. It looks like they're having fun, sitting there, gossiping.* (SA07)

Family were described as a means of support in making lifestyle changes, in particular wives who tended to do the majority of the cooking. Children were also described as a source of support. When asked if household members supported a SA participant in managing his LTC, he replied:

> *Oh, very much so. Yes, very much. They [household members] are always on the case. Even now, today, my wife cooks very healthy in terms of home cooking. So, less salt so it's going to be a bit of pink salt instead of the white salt. Hardly any oil in the*

> *cooking, probably more water than oil. If it's meat, very lean. There is no fat added at all in the meat. Balanced diet throughout the week. So, the family is very supportive, yes. That helps, yes. Then my daughters keep an eye on me to make sure I'm not being naughty and try to bypass all of the household procedures.* (SA05)

Family support for helping a person manage their LTCs was similarly described by GPs.

> *They know they should take the treatment and their families know about it. Families support them in doing that.* (GP01)

Often it was family that initiated appointments for review of LTCs, and were more interested in the medication taken by the patients themselves. This ensured they were provided care when needed yet at the same time potentially reduced their autonomy.

> *Often, when a patient is brought in by their daughter, you know, can you have a look at dad's foot? He doesn't really speak much English. He's type one diabetic, all these different things. You can see a lot more other things going on. You can address a lot more, check their understanding. Sometimes they don't even know what tablets they're taking or what different tablets are for. I think they're just put in front of them by the family. Here are your meds. Take them. And things which are sometimes…PRN [as needed] tablets, for example, things like co-codamol, they're just taken for a very long time. And then when I've said to the daughter… For example, the one gentleman recently had a very long list of medications, and she was asking about each and every one.* (GP13)

SA males described a fear of complications of their LTC and deterioration in health, primarily based on experiences of family members. Both taking medication, as well as reliance on God at the same time, was felt to be needed to manage the LTC.

> *I know that there's a lot of people in my community that are suffering from generally looking after their sugar levels and diabetes. Then their kidney fails and then their heart fails. There are a lot of problems that I can see myself. Then there is suffering, a*

> *lot of illness. So, that's why I just sometimes think that's bad. My dad had a problem with diabetes as well in the last couple of years. He had a disease. So, I mean, the last couple of months was bad anyway. My mum had diabetes as well. I mean, that's why I can see some of my family and my relatives are suffering. Sometimes they have dialysis in the kidney and then a lot of vital organs inside the body are giving a problem. So, sometimes, I said Allah, help me as well and I look after myself. But it's a bad thing anyway, diabetes. If you don't look after it, then it will be a problem for your life.* (SA04)

Actual complications experienced related to LTCs caused further distress. One participant described how erectile dysfunction and visual problems related to diabetes caused distress for him, both in terms of managing his life as well as implications for relationships and having children.

> *You feel depressed when you're not able to do the things you were able to do. Even sexually, when you're not able to… Because I did have erection problems that through my diabetes as well, we had to seek medical help, go back to the doctor and see how they could help. I was told it can reduce your pressure as well as your diabetes, your level of your sugar almost right in terms of holding erections. That mood went right down. Is this going to last forever? Am I always going to be like this? If I was to get in a relationship, what would the partner think of me? What if I were to get married? Would I be able to ever have kids? When I do have kids, is it going to impact him or her? So, a lot of things do tend to play on your mind. Even in terms of driving or just your eyesight, you're just not able to come to terms with the fact that this is going to cause eyesight problems.* (SA07)

The burden of having a number of LTCs was described which caused people to tire of managing their LTC. Reasons for this included the constant management of their LTCs, dietary and lifestyle changes, and the impact of these changes on their individual lives, family lives and within their friendship and community circles. This was reported to lead to distress in different ways such as frustration and anger. SA males described the emotional fatigue of persistently having to manage a LTC which could lead to anger, hopelessness and a defeatist attitude:

> *Sometimes you almost erupt. We're trying to sort out dietary needs and trying to do everything right concerning diabetes. When a diabetes nurse speaks to you, they tell you, you have to do this, you have to exercise, you must do this and you must do that. Certain things in your life can happen where you just think, forget this, I've had enough. How much longer am I going to put up with all this, or do I have to do this all my life? Those kinds of thoughts come in your head, where you're like, should I just give up? And then there have been times where I have thought I've had enough of this or I can't do this anymore. Those kinds of thoughts.* (SA07)

Another SA participant described tiring from the burden of attending appointments and therefore stopping attending appointments due to the expected multiple attendances and constant need to actively manage the LTC.

> *It's fluctuating. Sometimes I'm really good with my diet, sometimes I'm not, and the Nurse has been telling me to come and do a check-up. I did initially, in the first few years, but now, for the last couple of years, I haven't really checked myself into the Nurse to see how it is.* (SA09)

GPs also recognised that SAs may tire of the burden of managing a LTC, or lose interest in maintaining care for their condition. In this instance, it was felt the role of the GP was to challenge this.

> *They might present to me because the nurse has said she doesn't know what to do with them. Their diabetes is getting worse and worse control. You look and you realise that they haven't been taking their tablets. Their compliance has been really low. When you challenge them on that they deny it completely and go, oh no doctor I take my tablets all the time. And you say, look, I'm looking at the computer screen and it's telling me that you've only ordered three sets of prescriptions in the last year. And they'll often still deny it, and again that's part of their concentration is very poor.*

> *But actually, it's because they just lost interest in looking after themselves. And they just go with the flow. Which can make it very difficult.* (GP05)

Concordance as explained in chapter 2 refers to agreement after negotiation between clinicians and patients, whilst respecting patients' beliefs, about medication and whether/when/how it is taken. A number of GPs described poor concordance with medication due to different health beliefs, describing a lack of understanding of the underlying LTC or need for ongoing treatment.

> *I find a lot of the time that compliance with treatment can be an issue, in terms of the understanding of why a certain say, medication is indicated. And therefore, having that on a consistent basis. The other thing that I've found is general lack of understanding in terms of the condition [a LTC such as diabetes and heart disease] itself, and what types of symptoms that might manifest on a day-to-day level.* (GP08)

Several GPs described SA males with LTCs as generally a harder group to manage than the general population and more resistant to making changes, related to a cultural understanding of healthcare and wellbeing being something that is done to them rather than something that they do.

> *It's probably a cultural thing. So in some Asian cultures, obviously, approaches to healthcare is more paternalistic where they see the physician as somebody who does something for them and gives them something. Whereas self-management strategies are more emphasised in a Western environment.* (GP14)

The word 'acopic' was used by a few GPs to described SAs, a potentially pejorative term, with respect that if they were dealt with stress for example from a LTC they would not be able to cope with the stress. SAs were felt to be more hopeless and helpless and likely to suffer from emotional distress. GPs also thought that SAs were less able to discuss their distress with family or with clinicians.

> *My experience is that often those patients suffer a worse reaction from an acute stress reaction, for example, when they have a chronic condition they become far more acopic as a result of that. But at the same time, they are far less likely to discuss their emotional needs either with family members or with clinicians.* (GP04)

A mismatch between care offered and care wanted

The majority of GPs felt there was potentially poor concordance due to a lack of appropriate healthcare support within the NHS. They described how interventions were tailored to other populations and therefore not relevant to SAs. This potentially led to health outcomes of SA males with LTCs being worse than the general population.

> *And then one of the other sides of that as well is in terms of the diet. Dietary advice, it's only relative recently that you have dietary advice which is tailored more for South Asian diets, or other alternative diets, of the traditional western one. So, the system itself has some, what's the word, institutional bias is probably a bit too strong. But some systemic of biases because of the nature of how most evidence-based research was done. It was usually white male, with single condition issues, and of a different socioeconomic background, being researched on, and not your average South Asian male instead. So, that's obviously led to issues as well in terms of how they're ending up being marginalised maybe to some extent, or not intentionally. But I think there is that institutional bias there that needs addressing.* (GP07)

Some SAs described that the tailored care they wanted was unavailable.

> *I've not found anything as of yet in my own community. I live in [location]. I don't know if you know of it. My family there. I live in [location]. So, in [location], I don't think there's any kind of charity or organisation that works for people's mental health. And that's something that, in the future, I'd like to set up. Something like a support network for people with mental health problems. Because just even talking about it with some like-minded people, even that is so therapeutic. Just being able to*

> *share your experiences and not be judged by people. That in itself is so therapeutic.* (SA10)

A lack of tailored care was felt by SAs and GPs to be due to limited interest in the NHS to serve ethnic minorities and provide services appropriate to them, in comparison with other countries.

> *The whole system in place, in terms of even if you look at healthcare for the South Asian community, it's disproportionately very broad outcomes… NHS-funded services to meet the needs of the minority, so there's very limited service, very limited support measures compared to other countries healthcare.* (SA06)

Due to the potential mismatch between care offered and care wanted, GP felt that SAs had poorer outcomes than the general population.

> *And unless they [SA males] find themselves in a place where they've got some support, some active, proactive support, often, their trajectory on this is really, really rapid. They get to the point of complications and they become disabled and it's only at that point, sadly, that they're able to look after themselves. Or attempt to look after themselves.* (GP02)

Adjusting to life with a LTC was described as a cause of distress due to challenges around lifestyle factors, family adjustment, fear of complications, actual complications, treatment burden and a lack of services specific for this group. Other social factors were also described within the context of distress which will be discussed below.

### 6.3.3 Intersections of social factors contributing to distress

A number of social factors were described as contributing to distress of SA males with a LTC additional to living with a LTC, namely family matters, financial stress and social isolation.

<u>Family dynamics</u>

SAs described family challenges as the greatest source of distress, linked with cultural expectations and pressures of multigenerational households.

> *A lot of tension is tension with the family. 99% of problems of tension is with family. It's a family killer, these problems because we're living with our families so much.* (SA02)

SAs described the greatest source of family distress to be marital breakdown when this occurred, and even led to feelings of suicidality

> *Actually, I had this problem in my life. What it is, I had a first wife and the marriage was broken, and I was feeling suicidal.* (SA01)

Another cause of family stress was around children, and the expectation of them looking after their parents within SA culture, which did not always happen within UK culture that they lived. This included an expectation of children being proactive and looking after their parents' health and externalising responsibility as described previously,

> *South-Asian people, like I said to you, because they're so close, I think we rely too much on our family, when we get old as well. And if we can't work, we don't get the right treatment, like the way our children should look after us, then obviously you get more and more stressed and then more worrying. And angry, you get more angry then.* (SA13)

Conversely, if family relationships were perceived as positive, they were perceived by SA males to be protective to wellbeing and distress.

> *But Mashallah, I'm okay with everything. I have good kids, my wife, my family. I have got no tension from my family. Sometimes, your lad is ignoring you, your family is ignoring you and then you have tension. Your wife looks after you. Sometimes your wife gives you problems, so I'm okay. I have a good family and they're helping a lot*

> *for me as well. They're really understanding as well, my family, my kids, everyone. So, I've got no tension… But I have, Mashallah, good kids. They look after me as well. My wife is so good. We both have a good understanding. She helps me a lot, Mashallah.* (SA04)

*Money is more important than health:* Financial pressures

Financial pressures were described as another key source of distress in SA men with LTCs, at times synonymous with distress. One participant described how financial pressured directly cause worry and then then high-level anxiety.

> *If somebody's got financial stress, they'll be worried, and they'll have a source of high-level anxiety.* (SA03)

Another SA participant described the relationship between a lack of work and finances causing distress.

> *That is most of it, because like I said, if they can't work, finance will be a problem, because if you don't work, you don't get no money. So then, you can't pay the bills and whatever then you will get distressed.* (SA13)

GPs described low-paid jobs as a primary reason for SAs developing distress and being unable to cope with the challenges of life.

> *It's part of the reason why people thought this group of people were acopic, because there's always going to be a greater level of unemployment. They're more likely to be in jobs that are not permanent. Zero-hours jobs and all stress that comes with that.* (GP05)

GPs described how some SAs did not seem able to prioritise their health due to other competing problems, such as finances and poor housing. They described the challenging context of social factors, in particular living in deprived areas.

> *Sadly, many present, and the triggers to their presentation tend to be, again, socio-economic reasons. So, they've got financial issues, employment issues, problems within their relationships. And, sadly, lots of addiction problems… And the thread that links all of this across communities, beyond south Asian communities, I think, is deprivation.* (GP02)

The multiple social factors were described by GPs to cause a context of distress from an early age for SAs, such as having unstable jobs, living in high areas of deprivation, poor housing and dental care:

> *I think one is the diagnosis of the condition. I think the simplest thing there is once you've got a new diagnosis I think automatically it will affect their mental health. The second I would say with that is their own… I think that on top of that are the social stresses they have around them, like issues to do with their general health. And not being aware of their own health issues in terms of improving things like control over their diet, or lifestyle. Often they're working in frontline jobs, self-employed jobs with little job security. They're more statistically likely to be in areas of high deprivation, with poor housing, and poor dental care. And the list of things that are working against them is significant really. The odds are really stacked against them in many ways from very early on.* (GP07)

Due to the social factors, GPs described how SA males with LTCs were not able to prioritise health and therefore poorer outcomes, leading to a perception of helplessness.

> *Health is right at the bottom of the list for a lot of south Asian males because of the responsibilities that they feel they hold and, in fact, often, they do hold, almost that defeatist mentality of, right, well, I've got it now.* (GP02)

> *And again, a lot of these patients have got a lot of things going on in life and they're maybe working all hours of the day, trying to provide for their family and they just don't have the time or the availability to look after their own health in a way.* (GP03)

SAs described prioritising other issues such as finances over health, due to living in possible poverty.

> *Financial thing is the main issue. If you don't have the money, without money you can't live. They say that health is more important, I always say money is more important than health, because if you don't have the money, your health will go down anyway. You can't eat the proper thing, you can't pay the bill, your stress will come, you are short of everything.* (SA13)

GPs described that with SAs living in deprived areas, social factors were exacerbated by healthcare inequality. This included fewer and overworked GPs in such areas.

> *And there's something called inverse care law, which you're probably aware of, which highlights that. It says basically the people that need the most get the least. And that applies, because you can see the difference in the level of pressures that are put on doctors. It doesn't naturally attract loads of people who work there as well. They struggle with recruitment in those areas, because they're dealing with such complexity.* (GP07)

Conversely, there was one deviant case whereby a SA suggested that distress was based more on individual personality as opposed to their external circumstances and social factors. He described stoicism whereby people should go through hardships without complaint. This illustrates the heterogeneity of SAs, as different members of SA community experiences distress due to and in different ways.

> *A lot of it's to do with how a person manages the tension in their life… It's me, it's my personality, and your DNA, who you are, isn't it? It's down to each individual, isn't it? Coping… In my life, I have the expectation that I'll be able to deal with and cope with pressure, analyse things in a calm way, and never get flustered, and don't get angry. So, that's what teaches you. Whatever happens, just take it in your stride.* (SA03)

The financial impact of the covid pandemic was felt in particular during the lockdown, with worsening of the social determinants of health in a group experiencing significant amounts of poverty.

> *Before, I was working, but now I don’t work because of this whole covid situation. I was laid off work, because of the organisation being in problems financially.* (SA06)

GPs described how SAs were adversely impacted due to the multiple inequalities faced. When asked how the pandemic affected SA men with LTCs, a GP replied

> *GP03 Badly… I haven’t read it but I glanced through the newspaper reporting about the Marmot report commissioned by Greater Manchester Health. And the reporting says that there’s evidence of reduction in longevity of life in Manchester residents up until March, I think it was, 2021. And yes, I think if you are a South Asian man with Ischemic heart disease or diabetes or epilepsy or rheumatoid arthritis or whatever it is. I can’t imagine that covid has done anything other than impact you more adversely than someone in the population who isn’t South Asian and that doesn’t have a long-term condition morbidity and mortality-wise.* (GP03)

Social isolation

Social isolation was felt to be a particular trigger for distress. This was exacerbated during the covid lockdowns, with some SAs describing themselves as prisoners which led to distress.

> *Yes, corona, honestly I feel like a prisoner. I mean to say, afraid, mentally, honest, I'm not happy.* (SA11)

During the pandemic, there was were lockdowns with almost total bans on social gatherings and households were not able to mix. The impact of lockdowns on SAs included frustration and loneliness. Places of worship provided a place for community support as well religion and their closure impacted on SAs as they were central areas of support prior to covid restrictions..

> *We can’t go to masjid. That’s really bad… It’s just dreadful.* (SA01)

SAs described how not being able to see family members during the lockdown impacting on them, potentially related to the impact of support of close-knit family ties.

> *Not being able to see my family face-to-face. That was definitely depressing, and it definitely made me pessimistic. It was hard to be optimistic at that time.* (SA10)

One aspect of distress was described by a patient who suffered from a heart attack during the pandemic. As a consequence of experiencing social isolation, his engagement in various activities was hindered, resulting in a heightened fixation on the occurrence of the heart attack, devoid of any available avenues for diversion.

> *So, it has been a very isolating situation and time. It's been quite depressing. Summer was bad enough, but just the last couple of days, me and my wife have been saying that I'm finding it hard to focus on much else apart from the recent heart attack, because there's not much else to do.* (SA02)

Isolation was perceived to lead to boredom and frustration due to a lack of regular activities such as work, seeing friends and hobbies. This directly impacted wellbeing.

> *The pandemic has affected me mentally because of lockdown, not being able to go outside. Because before, I would go outside and also work. Now, because I’m no longer in work, I have a lot of time during the day, and just feeling very bored, very isolated. All the issues around mental wellbeing. You speak to your friends, you speak to your mates, but you can’t go anywhere. You’re restricted from going to places.* (SA06)

SAs with LTCs described increased distress during the covid pandemic due to a perceived limited ability to undertake other activities.

> *It has been a very isolating situation and time. It's been quite depressing. Summer was bad enough, but just the last couple of days, me and my wife have been saying that I'm finding it hard to focus on much else apart from the recent heart attack, because there's not much else to do. I go out for shopping. The nurse has advised against getting on the bike just yet, and I'm reluctant to do anything until the heart scan. So, there's not much else I can do with the kids apart from play a couple of board games at home and just go for a walk to the shops or a walk to the park. So, it has been a very depressing, feeling isolated time.* (SA02)

SAs described feeling increasingly vulnerable and fearful during the pandemic due to having heart disease or diabetes. A SA with a LTC who previously experienced covid requiring admission and oxygen therapy described a persistent anxiety at the risk of catching covid again.

> *It's just like even trying to go out and help your health, you're just afraid and you're cautious. Because when you go out you have to look out for everything else, and be careful that you won't get Covid again, or might be in touch with something that you shouldn't be. And then that's it, you've got Covid. So it always gives you that anxiety.* (SA17)

GPs similarly felt that there was more distress due to isolation and SAs not being able specifically to engage with families and friends. They noted seeing patients deteriorating due to this.

> *People have been isolated, haven't been able to meet friends and family as much, so I am noticing a lot more deterioration of mental health in the last few months as well.* (GP16)

GPs perceived the isolation to have a bigger impact on the SA community due to pre-existing issues of trust.

> *It's made everybody more isolated, but I think it made these sorts of communities more isolated, because they've not known who to trust, and not known perhaps where to go for support.* (GP09)

Of note, there was a deviant case whereby a participant felt that the pandemic did not impact his mood, due to working from home prior to covid with his role as an operations manager and being with family. The participant appreciated it may have been more difficult for people living alone.

> *To be fair, it doesn't affect me anyway, because I work from home, I'm with my daughter and my wife, and then I go for my daily walks anyway, so it doesn't affect me that much. But it can be. I can imagine people who live on their own and they're positive, probably go through a tough time. You have no one to talk to, and you're within four walls, isolating.* (SA03)

A second deviant case was identified, whereby the participant described lockdown, rather than being a source of emotional distress, being one of the best times of his life due to being able to focus on family relationships and charitable activities.

> *It was last year, just being locked up and not being able to go outside the house to do anything. I've got used to it let's put it that way. It's helped me. For example, last year was probably the best that I have had in my entire life… So, I finished work in April, so that's one thing I wasn't working. Even if I was, I would have been at home. I probably wouldn't have had to do that much. The fact I was just home purely focusing on mostly charity and so were the family. So, for me personally and as of the family, it was fantastic in terms of what we got out of it.* (SA05)

The experience of distress, as described above, has been significantly impacted by the social circumstances SAs lived within.

### 6.5.4 Perceptions of prejudice

The approach of media was described by SA males as a significant contributor to distress, due to perceptions of prejudice from the perceived biased nature of coverage of SAs within the media.

> *But sometimes, the media makes a lot of mental illness. I don't listen to media much. I said to my wife, don't open the television because you will get all bad fake news, and then give more tension to yourself. Don't listen to the news. It's not correct. Sometimes, it's 99.9% fake. [IV And the media you think is one of the causes of mental illness and stress and these things?] 100%. They're all interest. Who gives you this disease? Repent to him. Allah. Don't go to the media. Don't listen to the media. That's why there's all the problems. It's causing problems in the media in this country, everywhere in the world. In the world, media makes a lot of problems.* (SA04)

One SA participant described how he felt Muslims in particular and their faith was constantly attacked by the media.

> *The way that Islam and Muslims are being portrayed, at least they were up to the point of the beginning of the pandemic although it has quietened down a bit massively, but up to that point in time, it's always in the media attacking Islam, attacking Muslims all the time. This word terrorism is synonymous to Islam and Muslims which is completely wrong.* (SA05)

The social media experience during the pandemic was associated with feelings of distress. This included multiple untrue messages being circulated within the SA community around the pandemic. SAs described focusing on death rates leading to significant distress and being unable to focus on other aspects of their lives. Further to this, frustrations with political decisions as well as funding levels for the NHS in comparison with other countries were also described.

> *First of all, at the beginning of the lockdown, it was these ridiculous conspiracy theories that I was getting through WhatsApp every single day. It was infuriating that grown up people could think that this was this and that was that. And then it was just all the other conspiracy theories around that. Then it was a case of being obsessive about the news, about the death rates in Italy, the death rates here and the death rates all over the place. Looking at places like, for instance, I work in Denmark and the death rate there, Covid has been handled brilliantly apart from this recent outbreak issue. And thinking well, they've just got competent politicians and they've got a really good National Health Service. And then you get even more angry that if we're paying taxes, almost not at the same level as Denmark, but they do get other perks. Why don't we have a really good, well-funded NHS? So, obsessing over that kind of stuff for the last nine months really*. (SA02)

Perceived disinformation during the covid pandemic made some GPs concerned there would be reduced trust in medical professionals and potentially prejudice against healthcare professionals due to this.

> *At the moment, we're in a difficult environment because I think trust goes hand in hand with how society sees healthcare professionals and what the individual characteristics within a population are. So, for example, been a generalised reduction in trust in healthcare professionals, particularly primary care, during the current pandemic. So, I think there's just been a lot of misinformation that's been spread about vaccinations for example and the pandemic itself and the role which healthcare professionals have played within the pandemic and the approaches to management. Whether that be the reduced access to face-to-face appointments with GPs, being something they'll read in the media. Or often this right-wing extremism about spreading these lies about healthcare professionals being part of a widespread agenda to vaccinate people with harmful substances, for example, as part of a government agenda. So, I think interesting times as a generalised approach to trusting healthcare professionals*. (GP14)

SAs described prejudice in the context of systemic racism and how it impacted SAs in all aspects of life, including criminal behaviours which can impact health and cause distress.

> *There're a lot of issues in Britain, like racism, segregation. I think that's it. But the South Asian communities generally, they're already stigmatised a lot, from my own opinion, in Britain… You hear in the media all these issues. It's always a race relations issue, something to do with BME communities. It's always an issue. The area where I was brought up and grown up in, you see it day and night, drug dealing, people passing time, no work. So, all of this criminality, day in and out. I'm not saying it's restricted to one community, one group, but I'm saying in Britain it's a real problem.* (SA06)

Prejudice was felt on a personal level, particularly with experiences in childhood of SAs raised in the UK. The below example describes experiences of prejudice and traumas in childhood which caused distress, and provide a context for distress experienced at a later date by SAs with LTCs and faced with multiple forms of inequality.

> *I experienced a bit in schools when it was predominantly white. It was a racist school, where you go to school and it's predominantly white. There's only about ten, 15 Asians in the whole school. So, there was a lot of bullying, which some of the classes, you think you didn't want to do. Although, if you want to try a subject out like RE, you'd go in the class and you'd think bloody hell, I'm going to find all of the racist idiots in this class. So, before you even start the class, you just feel that your stress levels are going up because of what might happen in the class, or the stupid remarks that might be coming towards you. So, that in itself did bring your mood down for that day, because you know there's going to be an RE [Religious Education] lesson today. So, before you even go to school, you think oh, bloody hell. I don't want to be in that lesson today. What is actually going to happen in that lesson today? What are we going to be called today?* (SA07)

GPs described witnessing prejudice of SAs within the medical system.

As described earlier, some GPs described SAs as ‘acopic’. Conversely, another GP participant described how this term is used in a pejorative and unfair way by clinicians  due to not taking into account the social determinants of health and prejudices SAs may have faced.

> *Traditionally, when I first started, I was often advised that this group of people were termed acopic, i.e. difficult to cope with life. I can’t remember exactly who used that term, I’d never really heard it before until I arrived here. But that was the predominant feeling about them.* (GP05)

GPs described seeing prejudice from GPs towards SAs and how this would cause problems for development of rapport within a primary care consultation.

> *The problem was that often the junior doctors or younger GPs who were from other ethnic minorities or who had culturally a disdain for that population, they often spoke down to those patients. And therefore that rapport was never developed because the patients were often seen as either uneducated or lacking in education or lacking in awareness or lacking in experience or just poorly motivated.* (GP04)

Prejudice was described against the SA community during covid, such as venues being closed for Islamic festivals and opened for Christmas.

> *The mosques were closed for Ramadan was very upsetting. The fact that they announced the lockdown the night before Eid al-Fitr was extremely frustrating. And the fact that now, they’re pulling out all the stocks, and they couldn’t care less about any increase in the infection rate for Christmas, it’s infuriating. The fact that during the first lockdown where we couldn’t even go to the mosque for Jummuah, what can you say? My family, I actually shipped them off to Pakistan, just before the lockdown. They were there for four months, but I was quite close to thinking about just maybe taking a couple of months off work and going to Pakistan, just because the mosques there were open. At least I could do Friday prayer.* (SA02)

Contextualising distress as described above incudes distress around diagnosis of the LTC, adjusting to life with a LTC, social factors including the impact of the covid pandemic and prejudice. These directly influence conceptualisation, understanding, explanation and formulation of emotional distress.

## 6.4 Conceptualising distress

Distress was conceptualised in different ways by SAs and GPs, emphasising distress not depression, negotiating multiple identities and alternative paradigms of health.

### 6.4.1 Distress not depression

Emotional distress, whilst defined briefly in the interview topic guide, was a term that seemed unfamiliar to both SAs and GPs. One participant when asked about what he understood by emotional distress described it in opposite terms, as ‘*Zyaada Khushi’ [lots of happiness]’* indicating that he understood the term of emotion, but the linguistical use of distress was an abstract concept to him. The term was also generally unfamiliar to GPs, with one requesting a definition of emotional distress prior to talking about it.

> *Just to clarify, can I just check your definition of what you mean by emotional distress, does it tie in with what I was talking about? Or is that part of your research?* (GP04)

Although distress was a term unfamiliar to SAs interviewed, when it was explained in a way they understood, it was felt to be an experience universal to every human at some point in their life. A SA participant explained this.

> *If somebody has a fear or something, an anxiety, somebody’s going through a bad time in their life, if some experience has happened to them, that’s anxiety. That can lead a person to mental health issues temporarily. You see lots of people in the community going through that, whether it’s social, financial, domestic, or health, or whatever it is. And everybody goes through some distress in their life, and how they manage it.* (SA03)

Distress was understood by SAs and GPs to be a term to describe generally negative emotion.

> *Tension, distress, all these things, different name but it’s the same thing.* (SA13)

A SA participant elaborated further on distress by describing it in in terms of negative emotions one may experience.

> *I think all signs of being uncomfortable, being distressed, being on edge. A shock. I think all of these words are associated with distress and discomfort, yes.* (SA06)

Some GPs approached their understanding of emotional distress by differentiating it from mental illness. Mental illness was felt to be chronic, and distress more transient. Some GPs suggested that  mental illness as a biological condition as opposed to broader causes for emotional distress. GPs felt they had different symptoms.

> *So, mental illness is more of a chronic disease, with a problem with obviously certain chemical make-up in the brain, with separate symptoms. I think emotional distress can be a more transient feeling, which manifests with different types of symptoms.* (GP08)

GPs expressed concerns that distress could be medicalised with the negative impact on patients’ lives due to this overly biomedical approach.

> *The more we medicalise matters of emotional wellbeing, the more further away we get from a point of success for patients.* (GP02)

Whilst SAs and GPs described there was a clear difference between distress and mental illness, they felt that emotional distress could be considered a precursor to mental illness, and, which if left untreated, could lead to mental illness.

> *Emotional distress, I think, is a universal human experience, it's a normal human experience. And I think that clearly there are different levels. There's the day-to-day normal and then it becomes gradually more and more difficult to deal with, to survive. And eventually, at some point a person gets to their threshold where they think that it's appropriate to consult their doctor or their healthcare professional.* (GP03)

SAs echoed this difference of distress and depression, with depression being more severe.

> *I don't think they're far off. It's just about controlling, I suppose. But it depends on how severe it is. I don't know. Emotional distress could change to mental illness quite rapidly, and you could feel, I don't know, trapped. You can't do much, or you don't have much of a challenge in your life. Yes, that could be hard, yes, mentally.* (SA17)

There was concern regarding classification of emotional distress and of mental illness in a broader context. Over-diagnosis and management of mental health problems was a concern for both SAs and GPs. The very conceptualisation of mental illness was challenged by both sets of participants. This was described by a GP with several decades of experience in general practice who built up significant experience dealing with distress, reflecting upon the link of racism and mental health.

> *Well, I'm not a great believer in mental illness, the classification of emotional distress. I think it has a place, but I don't work using those classifications. It took me a long time to move away from that and it's much easier. I think there are many issues with diagnosing mental illness, not least the fact that it's over-represented in people of black heritage, along with custodial sentences and stop and search use of the Mental Health Act. So, I'm not a fan of mental health labels although I see they do have a place…* (GP03)

GPs perceived that SAs presented with distress but used language around physical illness to describe their distress, such as headaches, and it was their role in bringing out the distress but using familiar terms such as tension.

> *So, I can think of three or four gentlemen who would often present with headaches, with tension in their eyes. They wouldn't refer to the stress specifically or the word, stress. The most common term that they responded to and I use this in the language of the Asian elderly patients, is tension. So, tension is the equivalent word for stress. That's often used by the population that I'm referring to, so 65+, South Asian gentlemen, they would use the word tension to refer to stress in the family, stress in their finances, stress in the relationship or a recent bereavement. So, tension is that whole catchable term that refers to stress. So, often they wouldn't use that term themselves. It would have to be volunteered by myself to say is there a tension in the household, is there a tension in the finances? And then the information might start to be revealed a little bit.* (GP04)

Some SA male participants felt that there was an intrinsic link between physical and emotional wellbeing which could not be separated, with one impacting the other.

> *I think they do very much work together. I think if you're not active, if you're not using your hands, then I think that does affect your mental ability. I find that when I am working, if I managed to get a walk or a short bicycle ride in before I log on, I'm much better than if I've just crawled out of bed and dragged myself to the laptop. So, I find my mental ability is improved if I'm doing exercise. Then I think if I'm mentally calm and refreshed, let's say, and feeling okay, then I'm more likely to do some physical activity. So, I think it all goes together in a nice circle again, if you keep things nice. But then obviously, there is a vicious circle there. If you don't exercise, you start feeling bad, and if you're feeling bad, you don't exercise*. (SA02)

Perceptions of distress have been described above, in terms of being differentiated from depression, although some viewed that distress is left untreated may lead to depression. The conceptualisation of distress can also be seen in the negotiation of multiple identities which SA males described being associated with.

### 6.4.2 '*Asian men don't cry'*: Negotiating multiple identities

SAs described negotiating multiple identities, including being SA, their faith, and British culture, all amalgamated into their lives with balance.

> *I like the lifestyle. I love the culture. I love the way of life we live, which we keep, instilled in us by our parents, and we try and pass it on to our children. It's comfortable, providing you adapt the way you live in the system accordingly. You adapt with the English culture and your own, and you balance the two. Islam is important in one's life, so you follow the Islamic laws and commandments. Again, it's really easy because you've got the Islamic aspect, then you've got the Asian or Indian culture aspect, and then the English, so you try and balance all three, so there's a balance… Islam is very important in life, that's the first and foremost, that you follow the commandments of Allah Subhaanahoo Wa Ta'aalaa [Glory and praise to Him], which is an amalgamation of all the other laws and Quran and everything. That's number one. And your life is based around that. Number one.* (SA03)

Participants sometimes described culture and faith interchangeably, highlighting an intrinsic link between them, with faith being part of their culture and collective identity. Faith was perceived as a moral grounding that SAs felt accountable to show others their good character due to this.

> *Culture is important because, culture is what we're brought up in, which shows us our way of living your life with Islam in it, which is respecting people, looking after and caring for everybody in the family, and others, and elders. So, that's the two most important things. And then, again, English culture, you live with your colleagues and people, you try and demonstrate what a good person you are by having Islam in your life.* (SA03)

Culture was felt to be stronger and more preserved through socialisation between generations in SAs given more common multi-generational households, in particular amongst SAs from a low socioeconomic classes. This had the potential for such people to have stronger cultural aspects of lifestyle which may lead to distress.

> *I feel as though a lot of the poorer ethnic minorities that we see, certainly in the close vicinity of the practice, they tend to be multi-generational households with a lot of different health beliefs. And cultures which might influence what they believe their condition to be.* (GP08)

SAs described a feeling of duty and importance to pass on their identity and cultural values to future generations. This may influence later generations of SAs perceptions of mental health from a cultural perspective.

> *I love the culture. I love the way of life we live, which we keep, instilled in us by our parents, and we try and pass it on to our children.* (SA03)

Culture and identity need to be understood to appreciate the lens from which SAs with LTCs conceptualise distress. SAs described a *collective* identity, valuing their culture and different elements of culture, in particular the language and family values. A SA participant described the importance of SA culture in his life, which is common to a number of different SA communities with different religions and geographical locations. When asked if there was important to him about being South Asian, he described:

> *It's all very important to me. The heritage, the language, the customs… For instance, the customs we have. The way we have, I don't know what you call it in English, but purda [literally meaning veil and colloquially used to described different facilities for men and women] between men and women, even when we're talking amongst men. The etiquette, the respecting of elders and that kind of stuff. I think it brings a lot of niceties to life.* (SA02)

From a GP perspective, culture was felt to be intertwined within mental health, with its ideas, customs and social behaviours impacting perceptions, understanding and help-seeking behaviour for mental health problems.

> *I’ve always felt that psychiatry, mental health, along with everything else, it is culturally driven, as well as medically driven.* (GP01)

The implementation of managing culture and mental health is described further in chapter 7.

A part of SA culture regarding males was a concept of being breadwinners and not being allowed to show signs of weakness.

> *I think most men are tight-lipped anyway. In various cultures, whether it’s the Muslim culture or the black, African cultures or even the European white, Western culture, men are always seen to be the breadwinner, men are always expected to be the strong character. So, there’s so many pressures on them, and then it’s hard for them to show weakness by seeking help.* (SA10)

SA participants advised how SA males have an expectation not to share emotional situations such as distress with others.

> *Especially the Asian. They don’t share their feelings with anyone else.* (SA12)

GPs similarly described a cultural perception that men should not display sadness or sorry but instead anger and frustration were felt to be more culturally appropriate.

> *Asian men are conservative, they're reluctant to… There's a bravado approach as the I'm a man thing and I shouldn’t be crying, and I shouldn’t be… I think there is more of an ease to express anger and frustration rather than sadness and sorrow because those are seen as weak traits in men. So there's a cultural issue there.* (GP16)

A key element of SA culture was the job of the SA male to be a ‘breadwinner’. This heavily influenced the conceptualisation of emotional distress in the context of LTCs. In particular, a significant illness such as a heart attack caused significant distress if the man was unable to work afterwards, and fulfil what was expected to be one of their primary roles. This could cause distress in terms of anger and upset, and lead to depression.

> *I can think straight away of a 37-year-old Bangladeshi young man who unfortunately had a massive heart attack, extremely young patient, he… I've had these conversations with him about libido, I've had conversations about diet, about his ability to work. Extremely depressed now because he can't work, because Asian men have to work, they have to be the breadwinners of the house. His wife is essentially the breadwinner now and she has to run everything, he is severely debilitated since he's had that severe MI.* (GP16)

SAs and GPs felt that within SA culture, emotional health was viewed as less important than physical health.

> *I think in the Indian subcontinent and our culture, we just see physical as being the most important, not emotional. Emotional, you should be able to manage yourself.* (SA09)

A GP described similarly described how emotional health may come second for this group of patients.

> *I think a lot of people are still trying to get their heads round that mental health can be just as important as physical health, and sometimes dominates and they both influence each other… I don't think it's as prioritised perhaps in this group as physical health. I think, like you say, it maybe comes second line and let's deal with the physical first, and then we'll deal with the emotional aftermath later.* (GP09)

GPs suggested that SAs may value emotional health less than physical health because it cannot be seen in the same way that that physical illness can be seen.

> *I think physical health has always been valued more than emotional health, rather than on a par. And people don't see you can be very distressed inside and look*

> *completely normal. And people just don't see that. They don't see it as a disability. It's that stigma oh, yes, it's nothing. You're just a bit upset. So, it's minimising symptoms and maybe there's a cultural minimisation or just a lack of understanding, and lack of health awareness, and the impact that mental illness can cause someone, or long term health so physical symptoms, and obviously relationships with the rest of the family.* (GP11)

A strong communal identity was reported by some SAs, linking with their faith and culture so that they became distressed when considering worldwide suffering.

> *This culture and this generation, all the things we do, they think we're doing everything we're doing everything. Because there's zulm [oppression]. Zulm is very bad. Allah doesn't like it. They are causing the problems themselves, governments and country. I just cry, myself. They finished Syria, they finished Iraq, they finished Libya, all those things… You're killing people and making a better country for yourselves. That's wrong.* (SA04)

Negotiating multiple identities are described above, connecting aspects of SA heritage important to patients and their impact on the conceptualisation of distress. Heterogeneity in identity will be discussed next.

There were cultural differences between first generation SAs and second generation SAs whose culture was more intertwined with British culture. The difference in these was described as a source of tension and potentially surmounting to mental health problems within the community.

> *There's definitely a clash because the way the second generation of South Asians are being brought up in Britain is completely different. The way they want to live their lives, the way they integrate in British culture. Whereas the first generation, they came with the mentality, the South Asians, generally speaking from opinion, we've come into Britain for a better livelihood, a better sense of opportunity. So, I don't know whether now with the second generation that it's more relaxed, and they don't*

> *see the first generation had as many problems as the second generation did. But I think mental health is what suffered as a result. And I think now it's heavy in the South Asian community, that mental health is a real issue.* (SA06)

GPs also described this tension, seemingly from first generation SAs recollecting their SA country as it was prior to leaving, which had changed to the modern day, basing their understanding of the UK based on imperialist expectations, somewhat different to what second generation SAs experience. This brought about a tension between their cultural expectations of themselves and their families and practically the situation to which they lived. This led to stereotypical expectations that SA men should be expected not to display their emotion.

> *Their expectations of what a family should be, how one should conduct themselves in a foreign country, is forged, I think, from their experiences in their home countries in terms of what, fundamentally, the archetypal English, White, imperialistic man expects of them. And I think they find those shackles really difficult to shake... The generation that are second and third, that are born in this country, that don't have that direct connection to their home nations, their ancestral homes, they feel detached… And I think the tension around that is, ultimately, internalised. And I think it manifests itself in ways where you've fundamentally got people reverting to what's expected from them as being a good Asian man versus the actual realities of the current situation and what it demands of that individual. So, there's an expectation, for example, a bereavement, the Asian man shouldn't cry, they shouldn't wail, they shouldn't be allowed or permitted to express their emotion, because it's just not the done thing.* (GP02)

The heterogeneity of SAs was also described by GPs, the breadth of the term to cover people who have significant differences in their cultures.

> *I'm thinking about the younger person now who, perhaps is struggling with negotiating different generational and cultural terrain. On the one hand their parents' expectation is and other hand their peer expectations. And I suppose just*

> *being conscious of the fact, I mean, what is a South Asian man? I mean, do I picture a fat, 45-year-old person with diabetes and short trousers and a beard? Or do I picture a sophisticated, gay, businessman wearing clothes more stylish than I would ever imagine existed? They're both South Asian men, aren't they? But they're really different South Asian men and their differences are not about the colour of their skin, their differences are elsewhere.* (GP03)

Being a male SA GP led to GP02 being contacted when members of their community, including professionals, were experiencing emotional distress. This was viewed as a privilege given the level of trust one must have to open such conversations.

> *And what's really fascinating, which, as I'm just answering your question, I've thought about, is there are a significant amount of people within my social circles who are south Asian men who contact me for no other reason than just to share. And there's lots of professionals, there's lots of doctors within that group. And these are people that I don't socialise with actively, I don't have regular interactions with, but it's a privilege, because I think, fundamentally, I think they're sharing emotional distress in a way where, I suppose, it's relative independence.* (GP02)

Heterogeneity of SAs in their identity was elaborated on, in particular between SAs of different generations. Professional identity of GPs will be discussed below.

Professional identity

Professional identity was a source of tension for GPs. For a GP, abiding by their own culture and beliefs whilst serving SA patients with different and often devout religious beliefs, at times created awkwardness for the GP. GPs were keen to maintain a professional relationship without divulging their personal beliefs, and sometimes assumptions from patients in conflict with their own personal beliefs created a awkwardness. A SA GP with a Muslim name but who did not ascribe to the faith described palliative care discussions more difficult with SAs due to the expectation of being from the same religious group and being asked to pray for patients.

> *I don't openly say, look, I'm not a Muslim or anything like that. I don't challenge their perceptions of me like that. Because I think it's just difficult to explain my own views. So, I keep that out of the consultation. So, I think there is one of that. They see you as a kindred spirit, in a way, and they would like that. Though of course as I said, privately, my own religious beliefs don't tie in with what they actually believe in.*
> *I find it more difficult to talk about death and dying with this group of patients because of their religious beliefs and maybe because it might superimpose themselves on that. They're very religious and the simple things, like saying, you will pray for me, won't you, doctor, and things like that. I just smile to them and mumble something. So, there's that side of it.* (GP01)

The GP described further how religion is important to SAs and he felt his patients would not understand how he did not ascribe to the faith, creating an internal conflict when treating them where he felt that he had to partially hide his beliefs and go along with his patients belief systems.

> *So, I think that emotional distress. Because I think religion is very important to this group of patients. I would say, universally, I very rarely, I'm unusual as a person bought up as a Muslim but that doesn't follow that faith. So, I think religion is important to them and I think, sometimes, for them to understand this within the context of their beliefs in someone can be quite difficult.* (GP01)

This searching of SA patients to find 'kindred spirits' extended to GPs from different backgrounds. A Caucasian GP described being presumed to be Muslim particularly when his beard grew. Again, he described not wanting to open up dialogue about his own personal beliefs with patients.

> *I think sometimes some people, I don't know, perhaps when my beard grows a bit longer, would assume I was a Muslim. And sometimes I just don't want to get into that.* (GP03)

When a GP was of the same religious belief as their patient, as well as both being devout in their faith, there was still a tension described given the perception within general practice of being a neutral setting.

> *We have to remain apolitical and areligious within our consultations themselves, and it's a very fine balance. And that's another challenge for us. That, whereas this person might have very strong religious beliefs, and I personally might also have very strong religious beliefs. We've got to keep that out and keep it as neutral as possible.* (GP05)

The professional identity of GPs and tension involved maintaining these with SA patients has been described above, the patient advisory feedback on the themes follows.

### 6.4.3 Alternative paradigms of health

Alternative paradigms of health were described by the SA community. These included a greater trust in traditional forms of medicine more commonly used within SA countries. A SA participant described previously in his SA country using a traditional doctor (known as hakeem from the literal root word of wisdom), and lamenting of the lack of such figures in the UK and contrast of UK doctors:

> *In the old days, I remember, all villages, there was good Hakeems (traditional doctors) always helped you. And these days, the doctors say have this test and that test.* (SA11)

> *My patients do mention things like Hijaama, which is the cupping, to help get rid of the bad blood, and I know that's not prophetic medicine. So, I respect it, but I have to admit I don't know the science behind it and I've not had the time to study it. But what I tend to say to those patients is, if you're comfortable with it and it's not going to cause you harm, then do that.* (GP10)

Other paradigms of health included concepts of black magic, which first-generation SAs described experiencing, and second-generation SAs described their families diagnosed them with and asked them to go to a SA country for treatment of what they felt was distress.

> *I believe that, that sihr [magic] and jaddu [ghosts] is happening. Yes, definitely. Yes, yes, oh definitely. I had a very very stressful event in the past, you know, people, they say, nazar [evil eye], they call evil, can happen, this and that, yes it happened…Well, one time it happened in the town I grew up. In Pakistan, they have lots of people who, if they grew up there, they know black magic and they do things and these things happens. When you grow up there, even your friends, become your enemy. No one listens to you. Whatever you do is due to a bad habit.* (SA01)

A SA participant described distress after a marital-break-up being put down to black magic and his family encouraging him to get treated in his own country.

> *So, I think for about a year or two, when I became very unwell, that's what the discussion was in the family and the community, that someone had done black magic, which wasn't the case. It was mental ill health. I was suffering from distress over the fact that my relationship didn't turn out to be as it should have been. So, I think that's what it was. But a lot of the community, the first-generation community of South Asians, they have that opinion, a lot of them, that it's black magic. We need to take you to a religious leader. We need to give you this Taweez, this ribbon for you to wear. So, that's really it. There is still that going on, because mental ill health is largely misunderstood in the South Asian community. I think that's my opinion, but I don't know if it's correct.* (SA06)

A participant who suffered from mental illness questioned if his illness was due to being possessed by a supernatural being, whilst considering other causes.

> *I believe in black magic, I believe in Jinn [supernatural beings], I believe in Hasad [envy that affects others], I believe in the evil eye. Me, personally, sometimes I do think, am I possessed? Is this what causes my illness? But there's no conclusive proof*

> *about that. But at the same time, what I believe is that not every case of mental health issues or mental health challenges, not every case of them is related to these spiritual causes. Because I also believe that it could be genetics. It could be trauma. It could be trauma. It could be a chemical imbalance in your brain. A variety of different causes it could be, as well as the spiritual causes that we just mentioned earlier.* (SA10)

Black magic was described not only as a source of emotional distress, but also as a possible cause of LTCs.

> *It's funny because when we first both got diagnosed, there was that thought in my family. Because it wasn't anybody in the family that got diabetes, it was me and my sister, the two that went to Bangladesh and came back. So, there was a thought of either somebody's done black magic or somebody gave Nazar [evil eye], because nobody in my family has ever had in the background. The entire family, nobody ever had diabetes. Is it just a coincidence that me and that sister that went to Bangladesh got it? How come nobody else got it?* (SA08)

Whilst black magic was described as a phenomenon, SAs felt the cure for it was in regular spiritual practices.

> *Nazar [evil eye] is a fact, and black magic. It's true. Bad people can cause these problems. But if you do good practice, do religious practices, read the Holy Quran, and pray five times a day, that doesn't affect you.* (SA08)

Concepts of black magic were rarely picked up on by GPs.

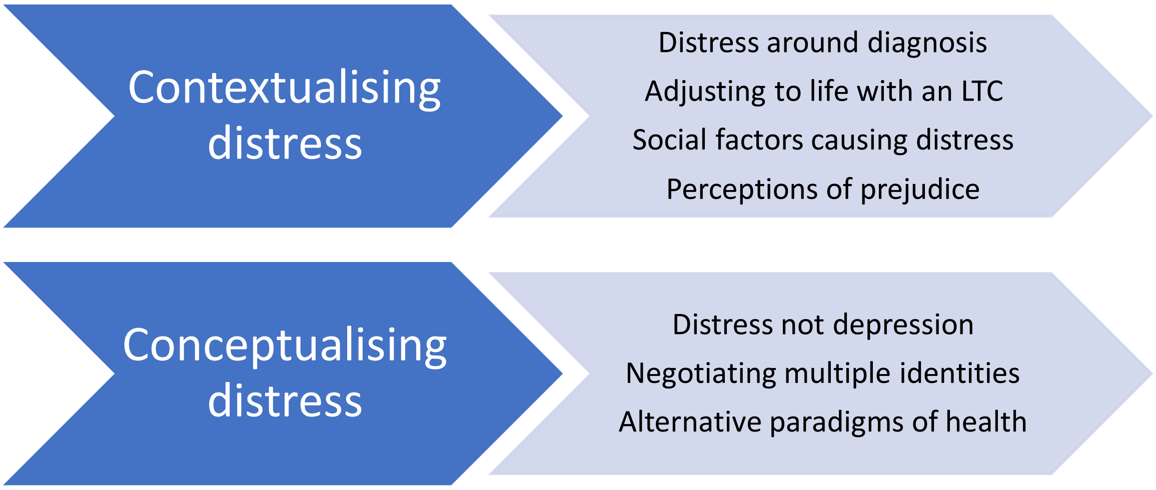
> *In the 20 years, I've probably had that about two or three times. Tends to be more with those at the severe end of mental illness. The ones who are psychotic and suffering with bipolar disorder and those sorts, at the severe end. Those patients are well known to the metal health services. They've had counselling and support, and continue to do so. I don't really get involved in that, that patient [unclear] as much.*

> *They don’t come to us needing it. But I suppose, in 20 years, having that two or three times is not very common.* (GP05)

## 6.5 Overall themes

The themes from this chapter are summarised below in Figure 8.

Figure 8 Summary of overall themes:



## 6.6 Patient advisory group involvement

Raw data extracts and provisional themes were discussed with the PAG, as described in 5.4. The group validated the themes, describing themselves and family members experiencing similar situations. The themes were evolved and developed based on PAG feedback. Members emphasised the value of culture and its effects on health. The group described the concept of being ‘betrayed by the body’ as part of mismatched health beliefs and a misconception of being healthy. They talked about poor health based on lifestyle choices, which may not have been understood or realised by some SA participants. They related to family problems as a main cause of distress within the SA community. The group suggested that the initial theme of ‘identity’ instead into consideration of multiple identities which developed to negotiating multiple identities that SAs may be balancing, as well as other levels of heterogeneity based on different differences in first/second/third generation immigrants and their exposure to SA and British culture, religiosity and educational levels. This negotiation of multiple identities were described to be subjective and highly personal, which would affect how distress was understood by SA males.

Members of the PAG suggested that an interesting area to explore would be assessing the level of religiosity and spirituality in SAs and how that impacted their viewpoints but adding in quantitative assessment in future projects.

An initial concept of ‘world politics’ as a cause of distress was felt to be potentially insensitive to aspects of human suffering. The PAG group helped in thinking about causes of distress from a perspective of social determinants and categorising them. They described an expected cause of distress being legal problems, such as court cases, which were felt to be more common in SAs but were not present within the data. Legal problems were therefore included as a prompt in later interviews, but participants did not mention legal problems as a specific cause of distress.

Members of the PAG were pleased that distress experienced during the covid pandemic was included in the analysis as they felt that this was a major contextual factor to the research and had a significant impact on the SA community. Members also concurred with SA participants around ‘conspiracy theories’ during the pandemic, such as one member describing a message about face masks having insects in them being circulated via WhatsApp. They displayed interest in which media and television participants use, which would affect their perspectives. It was felt that exploring this during future interviews would detract from main aim of my study, so would not be done, although it could be considered in future studies. The impact of the covid pandemic was discussed as an extension of the social determinants of distress. This was important to analysis as initially the impact of the covid pandemic was presented as a separate theme, but with discussion and input the findings were later changed to have the impact of covid pandemic weaved throughout the themes.

## 6.7 Reflexivity

I wrote a reflexivity diary throughout the PhD, ensuring to think and write reflexively after every interview. I appreciated becoming part of the interviewee's story, intertwined with questions, following up on cues, and taking notes. As a practicing GP, I had to make a clear change of style when conducting the research interviews, and reminded myself before each interview that I was doing a research interview and not clinical consultation, with each having different objectives and styles of interview. When GPs spoke of work pressures and difficulties during the pandemic, I related to the challenges they faced. I reflected upon this and made extra efforts to be neutral during interviews. When SAs spoke of different pressures in their lives, many resonated within mine. I reminded myself before interviews of my role as a researcher, and not as a doctor. The importance of this played out in different ways. For example, I was asked medical advice during interviews, which I politely declined. My approach to interviews had to be different to my approach to consultations in general practice, more exploratory and less focused and directed. However, I appreciated that all participants were aware of my role as GP as well as researcher and the influence of this in interviews. GPs may have been more open in discussions. One GP spoke at length of a quality improvement project he was doing, encouraging me to take on the same project in my practice, and I gently steered the conversation back to the focus of the interview. SAs may have felt a power imbalance of being interviewed by a GP and I tried to mitigate that by trying to act a as researcher and not responding as a clinician within interviews. When I was asked about clinical topics by SA participants, I reminded them of my role as a researcher during the interviews and encouraged them to speak to their GP for further support.

I found myself working to build trust with SA participants in particular. For example, one participant early on in the consultation mentioned he had never suffered from distress, and later on in the consultation described suicidality when his marriage broke up. I ensured safety by referring to my risk protocol as described in 5.3 (Ethical considerations). This made me appreciate the sensitivity of interviews, and the careful navigation required to allow participants to speak.

Some SA participants had limited English language and required careful thought and re-phrasing of questions if they were not initially understood. Some words from SA languages were often mentioned, which do not have exact linguistic equivalents in English. I had to be careful with my speech, learning from my first interview after upsetting a SA interviewee. He described how problems in Kashmir and Palestine were upsetting him, and I replied '*so world politics is something that upsets you*?' He took offence at this, saying '*it is not world politics*.' I appreciated that one's sense of community and relational understanding of others is different in different people, and to be aware when communicating not to come across as insensitive and to use participant words rather than my interpretation of them. This made me reflect that whilst the UK may be 'home' for myself, other people's consideration of 'home' or linking with other countries, in particular SA countries, may be much stronger.

I found my interview technique improving after the first few interviews, with discussion within my supervisory team and feedback from transcripts both in terms of content and style of questioning. Initially I stuck rigidly in structure to the topic guides, as a good clinician may ensure structure in taking patient history, but with feedback from my supervisors the structure loosened to become more of a conversation, exploring relevant cues whilst diving through the interviewee narrative.

## 6.8 Chapter summary

This first findings chapter of the qualitative study introduced the participant characteristics and then presented the findings in relation to the context of distress of SA men with LTCs. This included contextualising distress, in particular distress around the diagnosis of a LTC, challenges adjusting to life with a LTC, social factors as a cause of distress, and perceptions of prejudice from both SA and GP perspectives. Conceptualising distress included perceptions of distress different to depression, negotiating multiple identities, intersections of social factors contributing to distress, and alternative paradigms of health such as black magic. The involvement of the patient advisory group was presented such as how specific themes developed with their input. Reflexivity was discussed from the perspective of an interviewer who shares a number of characteristics with the study participants. The following chapter 7 will focus on consulting with distress. Based on the two findings chapters

6 and 7, the 3Cs for co-navigating emotional distress in SA men with LTCs is discussed in chapter 8.

# Chapter 7: Consulting with distress

## 7.1 Introduction

In chapter 6 I described the context and conceptualisation of distress of SA men with LTCs. The following chapter describes findings relating to consulting with distress from the perspective of SA men with LTCs seeing the GP when distressed, and the perspectives of GPs consulting patients experiencing distress. The chapter is titled consulting *with* distress, as it incorporates the views of SAs who may consult with the symptoms of distress, as well as GPs who consult SAs with distress. Consulting *for* or consulting *about* distress do not incorporate the presence of distress as part of the consultation which may or not be directly brought up by the patient, or asked about by the GP.

GPs described how SAs with LTCs would have multiple contacts with primary care, and that these could be used as an opportunity to engage and open up discussions about emotional wellbeing. These multiple contacts were felt to be an excuse for patients to see the GP, with GPs describing their skills in facilitating patients to open up about their emotional wellbeing. Conversely, the challenging cohort were felt to be those who do not have any regular contact with primary care and therefore may present in crisis.

> *The interesting thing is those who have chronic disease problems are more likely to present because they come in with the excuse about talking about their pain, or their health, or their blood pressure and things, and then it moves on to other things. I think the hard to capture group are those who've never really come to the doctor and those with those problems, because they tend to present in crisis. I think those with chronic diseases, a lot of their diseases are the factor for them to have mental health problems. But because they have that condition, it's an excuse for them to engage with the doctor. You hope that the doctor would explore their mental health.* (GP10)

In this chapter I will describe the multiple barriers perceived by SAs and GPs which limited the effectiveness of such opportunities. These include consulting with distress, specifically around trust, co-navigating care, relationship-based care, a whole person approach, culturally sensitive care, community engagement and professional development within general practice.

## 7.1 Trust

SA males described a mistrust of GPs, and GPs interviewed were aware of this. This related to perspectives that GPs would over-medicalise distress and offer treatment options which reflected this – such as medication. SAs and GPs described how this may make SAs with LTCs hesitant to seek medical help for emotional distress and present late when they did seek help, often presenting due to family pressures. They described trust in faith, family and self-management.

### 7.1.1 Mistrust of GPs

SAs described a mistrust of GPs. They felt they were of limited use in managing their distress, or the appropriate term they used such as tension. Reasons given for this mistrust related to perceiving that the role of GPs was limited to prescribing, a lack of time, perceptions of GPs being more interested in ensuing their targets were hit to make payments rather than serving patients, and lack of access to appointments as described below.

> *They [GPs] don't know nothing. They're useless, they are, anyway. Because they do nothing. GPs, they don't know. They just make money. All they want, money. They just give that prescription. That's it. Every month. And that's all. Once in a blue moon, they call you to have a sugar level test or blood test. But on the other hand, whenever you ask the timings for them, say alright, I would like to come, they don't have a time to check you. And then, they keep delaying your appointment, delaying or something. Because what time they give you, they don't suit you, suits me… GPs are useless. GPs do not do much.* (SA12)

Conversely, GPs perceived SAs as being medication-orientated and seeking a diagnosis and medication when presenting for distress, such as the response when a GP was asked what patients expect in terms of management of treatment. This highlighted a clear mismatch between clinicians expectations of what the patients wanted and patients expectations of what clinicians could offer.

> *Usually a diagnosis, that's a big one. Usually medication, they are the top two… I think they want a label. And a fair few don't have depression, they have adjustment disorder, they're just going through a really, really difficult period, whatever that is. And they're finding it hard to adjust through that. And it's transient because once that's sorted then they move on and carry on, except for those who genuinely do have depression. But they want a label, I don't know why, maybe that makes it easier for them to explain at home that this is my behaviour because I have depression, for example. And medication because, for them, it's not their fault. Doctors have created this narrative that if you give somebody a pill that's the answer to everything.* (GP06)

GPs described frustration and sorrow that others such as allied health professionals were trusted for healthcare advice and management but not GPs. Reasons for this were suggested, such as the perception of GPs being in a rush, minimise patient issues and not understand the patients due to different backgrounds.

> *I do feel they sometimes even have more trust in nurses. I don't feel they have trust in GPs. Again, I think some of it is because they feel that we're in a rush, they feel that we can't do anything to help anyway, so why tell them? They feel that they're not going to take this seriously, that this is a big issue, and that we won't understand anyway because our life is completely different than theirs.* (GP17)

Frustration of GPs was further present when they perceived SAs to trust complementary therapy practitioners more than them, when GPs did not respect or value the knowledge and skills of these practitioners.

> *You've got a lot of quacks out there as well. You have all these complementary medicine type practitioners, if you want to call them that, for lack of a better word. I've seen osteopaths and things like that. People go to see them because they're not happy with the explanation they're given by their GP. It's quite sad, really, that they*

> *seem to go down that avenue, to be honest. It's not evidence-based. And trying to explain that to them can be... You're fighting a losing battle sometimes, because they just don't want to listen.* (GP12)

Even when there was no awareness of the reason for the lack of trust of SAs in in GPs, GPs experienced this sentiment. GPs reported encountering a sense of mistrust from SAs, with the perception that SAs believed they were not making genuine efforts to assist them.

> *Yes. I don't know why. There seems to be some element of distrust like, you're not trying to help me.* (GP12)

Mistrust due to perceived discrimination

The previous chapter described perceptions of prejudice. Experiences of discrimination within the health service was reported by SA males to deter them from further seeking help for emotional distress.

> *I went with my mum to see a white doctor. And she was wearing her niqab [face veil], right? And he was making faces. He was behaving rudely. And when you experience that, it's very hard for you to trust them. It's very hard for you to put your faith in someone at the end, who behaved like that towards you.* (SA10)

Several GPs described their own experiences of racism within the NHS, which was felt was systemically racist towards both patients and staff.

> *And I think, unfortunately, the NHS, this is one of my other big bugbears, is an institutionally racist organisation. It's racist to the patients with all the barriers, and all the prejudices, and all the system failures, and then it's racist to those who work in the service as well.* (GP10)

GPs described how racism had impacted SAs, and evolved over time to be more subtle as opposed to overt racism.

> *The elder generation had significantly overt experiences of interpersonal racism, structural racism, and institutional racism. And if we look to the generation now, actually, the racism, for me, certainly, as a person with lived experience, I don't think the racism has ever gone away. I just think it's become more insidious, though the interpersonal racism, whilst you still get examples of people being called out in the street and so forth, certainly, as a professional, you have a situation where the racial tendencies of an interaction is more unconscious, is more established, in a way.* (GP02)

### Mistrust due to colonial history

There was a described mistrust of British culture due to the colonial history. A SA participant described conspiracy theories circulating within his community around healthcare due to British and Pakistani military links and Pakistan's military rule. When asked if he felt whether these are more common in SA communities, he described:

> *Yes, I do. Because I read other stuff, not just the media stuff, I read books on Middle East and Southeast Asia history and stuff, I think that is almost, I want to say a valid situation. Because we have been ruled in Southeast Asia by, let's say, dictators or very authoritarian people. In Pakistan, we've been ruled by a military leader for I think, well over half our history. And then when we see these military people who have ruled Pakistan for a great deal of their history, and we find that that they are trained at Sandringham and they've gone to elite colleges over here. Then there is, let's say, relationships between the Pakistani military and the British military, even though they're slightly and maybe quite innocuous connecting, I think that's a feeding ground for these conspiracies amongst Southeast Asian people. Definitely Pakistani people. So, I wouldn't say that we are more susceptible to them, but I think the situation our country has been in, Pakistan has been in, it means that it's very hard to completely discard them as nonsense for quite a lot of people, myself included.* (SA02)

Similarly, SA GPs picked up on historical issues which led to a mistrust of GPs and healthcare, such as leading to lower uptake of covid vaccinations.

> *And we were looking at this actually about in relation to the covid vaccines in that there's a certain mistrust about it and why wasn't the vaccination taken up as much along the BAME community, African and BAME community. So there's a historical distrust with institutions. Historically we have done things that haven't been right that created a mistrust amongst people.* (GP16)

Mistrust due to overmedicalisation of distress

The previous chapter described a mismatch between care offered and care wanted. Overmedicalisation of distress was a perceived barrier to SAs presenting to their GP. SAs felt that GPs were uninterested in finding out causes of disease and their cures, but rather on prescribing medication, making SAs less likely to seek help from GPs. Conversely, GPs felt that SAs sought help from GPs to get medication. The differing understanding of health and approaches to the management of healthcare conditions without a shared understanding led to a reticence from SAs of seeking help from their GP from the perspective of SAs and GPs. This was felt by SAs to be because of the biological approach as opposed to searching for a cure of illness.

> *I don't think that GPs are much help anyway. I don't think even doctors are much help. Doctors, they don't find the root cause of any illness, they just give you medication after medication.* (SA03).

A number of GPs described a strong biological viewpoint perceiving their role to prescribe medication for SAs presenting with emotional distress and believing they want medication, in contrast to SA descriptions of reasons for consulting. When asked what SAs want from a consultation when presentating with emotional distress, a GP replied:

> *I think generally, they just want some form of medication, just to make them feel better.* (GP08)

SA participants described a mistrust in overmedicalised paradigms of health whereby they felt GPs in the UK prescribe medication as the first step for any symptom, which had side effects. They indicated different cultural understandings of health and wellbeing in SA countries.

> *Well, the things is when you go on medicine, you will stick with it, and then you need more and more. Especially in English medicine, there's benefits, but there's always going to be side effects with it. So if you take that, there's another tablet, take that.* (SA01)

A GP similarly described how overmedicalisation of distress led to perceived inappropriate prescriptions of antidepressants.

> *They [SAs] often get medicalised very quickly. So, they're put on antidepressants and stuff rather than addressing the deeper social issues that come with it.* (GP07)

SAs described being prescribed medication when distressed without their health beliefs being taken into account and not taking them. Some SAs described not taking the medication due to side effects. In this instance, talking therapies were perceived by SAs to be of most benefit.

> *There was a background about ten years ago. I was off work with stress and I went to one of these cognitive behavioural therapists. I found, again, it's just a case of talking and having somebody listen to you was much more beneficial than any tablets that the doctor prescribed. The doctor prescribed tablets and to be honest, I didn't take the tablets. I didn't want to be a person who would then fluctuate between different types of moods… That's always been a worry for me, taking tablets and then becoming reliant on them. But also, I've heard some horrible side effects about some of the mood brightening tablets.* (SA02)

GPs perceived that SA males were resistant to labels of mental health diagnoses. If SA attended due to their families arranging the appointment, and were acutely distressed, they would not agree with or accept a diagnostic label of mental illness such as depression and hence concordance with their GP-led management plans was poor.

> *And if mental illness was suggested they would often say no, I'm not depressed, no I don't have a mental illness, even if the explanation was to go down the route of anxiety or a reference to anxiety. Even those patients who are acutely so distressed that there were other family members around them who were having to support them with their distress. They would be very, very reluctant to be classed as someone who was suffering with an acute mental health issue… Again, I think it goes back to both stigma and a belief that mental illness is a sign of weakness of the self… The management of these patients is far more difficult because the acceptance is poor. So, they are unwilling to be diagnosed as having a mental health problem or a stress reaction, etc. So, because of the lack of diagnostic acceptance it's harder until that barrier has broken and the patient has accepted the reality of the situation to proceed with treatment.* (GP04)

Overmedicalisation of distress was also described by some GPs, with specific reference to trainees and less experienced GPs. One GP described himself having resistance to perceived over-biological perspective of mental health. He explained evidence-based reasons behind this of an exaggeration of the efficacy of medication for mental health. Furthermore, he questioned the very paradigm of mental health within UK practice.

> *If you look at the trainees, I supervise trainees and they are more willing to prescribe an antidepressant. And I think that reflects their training, actually. Because if you look at the psychiatric model of treatment, the British psychiatric model, it is very, I think I'm not unfair in saying that it's a very medical model. And I know this because I used to work at (names hospital), and I've seen that extreme end of psychiatry and I've always had an interest in that. I think British psychiatry is very dominated by the medical model and does treat heavily, and I think invariably they are training the generation of doctors like that, about the antidepressants, about that. And I see it in*

> *medical students. So, I think it's a generational thing. But then, I'm also unusual because I do read about these things, and I have an interest. I will have a toss-up with a trainee or a medical student about the value of giving antidepressants a lot and how the research evidence is very poor and, ergo, is there a case. Now, I'm not saying I never prescribe. But definitely because of that attitude and belief, which is driven by my own knowledge and my own study, that I am far more reluctant to prescribe, yes, for that reason.* (GP01)

Mistrust due to stigma

Related to presenting with more severe symptoms and/or in crisis, SA males described a 'community stigma' which might deter people from their background from seeking help when experiencing emotional distress. A reason for this was embarrassment that they were suffering from distress. It was suggested that SA males may then present with more severe symptoms and/or in crisis, leading to GPs assessing the need for medication. When asked about how stress and tension are perceived within the community, a SA participant replied:

> *The community just want to brush it under the carpet. They don't even want to address it. It's something that is taboo at the moment. Nobody really wants to talk about it. They wouldn't necessarily ask for help because not necessarily the psychiatrists but what are they called? The psychologists right?... People don't access it even through medically let alone their own friends and family that they are with because they are too embarrassed to talk about it basically. So, people don't talk about it, it never gets addressed and it just gets worse. As a result, there are so many people both male and females are on these what do you call it? The citalopram tablets, anti-anxiety whatever. All your family are on them. So many people I know.* (SA05)

When seeking help, SA males made a distinction between seeking help for emotional problems, from family and friends, to physical problems, from GPs. When asked if he seeks help differently for emotional and physical problems, a SA participant replied

> *Emotionally, yes, because you'd probably speak to your family or friends. Whereas physical conditions, you go to the doctor or hospital.* (SA07)

Mistrust due to health beliefs *'from two angles'*

GPs described poor concordance with GP-led management plans (which had limited negotiation of the management plans with patients) which can be attributed to variations in health attitudes and diverse cultural interpretations of health. This affected health literacy in particular with regards to UK understandings of health. For example, a GP described the challenges in explaining the need for mental health medications to be taken for minimum periods of time, with some SAs expecting immediate treatment to solve the problem.

> *And I think the other challenge is medication concordance. Many times, I've given them medicines, and then I see them for review. And they don't seem to understand that it's a longer-term process, at least six months of antidepressant or more if you've got the issues, but they don't seem to understand that. But it's not something that is just relating to mental health because obviously, with diabetes, hypertension, this same culture of short-term treatments… Many times, when people are feeling down, they're just like, give me an injection to make me feel better, so not tired, and not down, and things. So, I think that stems from South Asia. I don't want to stereotype, but I have heard of anecdotes of getting injections, from my patients, when they went to Pakistan or Bangladesh. And they don't know what they were injected with, and they want something similar here. Vitamins is a very common request as well, that they have. So, their health beliefs and my health beliefs is a challenge, especially when I'm trying to use Western interventions to tackle these issues.* (GP10)

Due to differences in health beliefs and other reasons, missed appointments were very common, leading to patients being lost to follow-up.

> *There's lots of DNAs [did not attend], or they don't even attend the triage appointment, either. And they get lost to follow up and things.* (GP10)

There was a feeling amongst GPs that a cause of the differences in health beliefs was related to the level of education of SAs as well as previous engagement with healthcare. If both were limited, GPs felt that concordance to management plans was limited.

> *I recall that it was a difference of educational level as well as awareness of health beliefs that was brought up through families. So, it was also a social demographic. For example, where families have been brought up in an educated system or where they have access to healthcare from a young age, they were able to understand the reasons for taking medication and the accordance rates with medication was much higher. For example, in families where access to healthcare was poorer or where the family didn't have much engagement with healthcare services, when medication was provided to them they were very reluctant to take it or took it on an ad hoc self-directed basis. Even if they were provided advice and guidance on how to take it, even if they started developing side-effects to diabetes, for example. Or developing complications of their diabetes, they would still be reluctant to follow treatment plans as they were given.* (GP04)

Differences in health beliefs and a lack of information were felt by GPs to cause emotional distress in the context of a LTC as SAs were less aware of treatment options available to them (such as self-help resources, talking therapies and medication), and therefore more pessimistic and likely to get distressed if their initial treatment did not work well.

> *I think certainly, I would say that the emotional distress is more evident in the demographic that you mentioned [SA men with LTCs]. I think they feel as though… I guess because they don't have a full understanding of what's happening. And say, if a treatment doesn't work, I think they feel as though nothing is going to work and they tend to become more emotionally distressed because of that lack of understanding.* (GP08)

A lack of awareness, including how to manage health, was felt by GPs to impact physical health problems as well as emotional health in particular within the context of social stressors.

> *I think that on top of that are the social stresses they have around them, like issues to do with their general health. And not being aware of their own health issues in terms of improving things like control over their diet, or lifestyle.* (GP07)

Differences in health beliefs were felt by GPs to cause increased emotional distress related to LTCs as SAs would not understand the complications of LTCs or how to manage them. This was described as a lack of *emotional stability*, limiting the ability of SAs to manage emotions when experiencing problems in the lives.

> *Yes, certainly the manifestations of those conditions say whether it's chest pain or diabetes, if it's a nerve problem, there's a complication of it, they don't tend… They feel more distressed by the symptoms. Even though I try and explain to them the reasons behind it, I feel as though their understanding or lack of understanding might prevent them from having emotional stability, really, to be able to manage and take control of the problem themselves.* (GP08)

Some GPs described how they felt the differences in health beliefs that impacted management was a problem of GPs rather than SAs, due to a lack of knowledge of SA culture and health and engagement with their patients' health beliefs. Due to this lack of knowledge on the part of GPs, they were unable to deliver appropriate advice to SAs which would be relevant to them within their culture.

> *So, health literacy from two angles. Number one, we are illiterate as a community as healthcare professionals, we're actually quite illiterate when it comes to looking after the health needs of our BAME community, of the Asian community. If you ask a lot of GPs, colleagues out there, practice nurses out there, what is a portion, what is a portion of rice, they'll struggle. If you ask them what is a portion of curry, they'll struggle. If you ask them what is a portion of halwa, they'll struggle. So we are illiterate in delivering messages, you see. If you deliver it in the right way, I think the literacy level among the Asian chap compared to the Caucasian chap is not going to be that different.* (GP16)

Variations in health beliefs were felt to be in part a healthcare problem with a lack of health literature in languages other than English, creating a barrier to supporting understanding among SAs about health.

> *I'm very aware when I want some patient information leaflets if they're not English first language it's trying to access appropriate materials for people. And I guess that's maybe not so much health literacy, in terms of being able to understand and comprehend written language, it's more the language barrier that creates that problem.* (GP08)

As well as lack of engagement with SA health beliefs and culturally appropriate advice, mistrust of GPs was felt by GPs and SAs to increase during the covid pandemic due to increased barriers to consulting during this time.

Mistrust affecting presentation of distress

Due to the mistrust as described above, SAs described not contacting the GP when suffering from emotional distress.

> *I won't go for emotional health or mental health issues, I wouldn't really talk to anyone about it. I'd just keep it to myself.* (SA09)

GPs described that when they did present, due to delayed presenting, they were more likely to present in crisis.

> *I think the hard to capture group are those who've never really come to the doctor and those with those problems, because they tend to present in crisis. I've had that, where I had a psychosis or they're suicidal, because it's got to such a stage that the family are phoning up and asking for an appointment and a conversation with a patient. It was at quite an extreme level.* (GP10)

As well as presenting with more severe symptoms and/or in crisis, GPs described that when SAs did see a GP when experiencing distress, they used terms to describe and emphasise somatic symptoms as opposed to emotional distress. This made the skilled GP able to recognise the symptoms may be reflective of underlying distress and move the consultation forwards in this direction.

> *They'll often present with nothing else except, oh, yes, they can't sleep, or their concentration is very poor, and they lack energy. And that's usually simple presentations of psychosocial presentation rather than like, oh, yes, I'm depressed. They won't phrase it like that. They won't say I'm depressed… So, because depression is labelled as being, in terms of language wise, they might phrase it in terms of being mentally crazy. So, they won't phrase it in terms of like that. It'll often be, oh, yes, I just don't have any energy. I can't sleep, Doctor, nothing really interests me, or I'm sleeping too much. And I don't enjoy things as much. They might phrase it like that. Or they're getting irritable or everything else. But they won't say I think I'm depressed. I think I've tried this, and I've tried that and people have said this to me. And I get really dark thoughts. They won't phrase it like that. They won't explain their thought process there much. It'll be more physical presentation of symptoms, which tick the box really. But they're not… And you have to be sharp to listen to that stuff.* (GP07)

GPs described  the practice of 'defensive medicine' where GPs felt their first and foremost job may be to rule out physical causes to protect themselves from being subject to claims of litigation was a barrier to providing appropriate care if SAs did present with emotional problems described in somatic terms.

> *And you will get the patients with health anxiety, where they've looked at the worst-case scenario. And then they're coming in to you going, right, I need this, this and this. And I suppose our role it's turning into very much a defensive type of role, because the patient's being treated like a consumer almost. I think in these days we're practicing a lot of defensive medicine, as opposed to actually what the patient will actually require.* (GP11)

However, GPs described sometimes when SAs presented with physical health symptoms, GPs were able to unpick that the cause of this was that SAs were experiencing distress.

*When you get into the conversation you'll realise that their HbA1c is going up significantly. Their foot care is very poor. And then there's an element of self- neglect that's coming into it, with elements of it. And often when you explore it, it's often due to a high level of stress, maybe difficult housing arrangements. The list is often quite big with regards to this. But it's a usually a mixture of social stresses causing a degree of anxiety and depression.* (GP07)

<u>Mistrust exacerbated by the covid pandemic</u>

SAs described reduced access to primary care during the pandemic, with telephone consultations which were found to be more difficult to speak than in-person. SAs described telephone consultations to be more difficult to speak even when they were strong and fluent in English, possibly related to English being a second language and the loss of body language during telephone consultations and cultural expectations of seeing the GP in person, as well as practical differences in not having a set appointment time but being expected to answer the phone at any point.

> *But now, during this Covid situation, for the last year, I haven't been for a check-up. The surgery has been a lot less accessible. It's all phone interviews, and it's just been very difficult to speak to a doctor at times.* (SA02)

Whereas one may book time out of work for an in-person GP appointment, phone consultations were not necessarily at a specific or set time that SAs were able to book off work. This led to challenges of phone consultations and not being able to answer the phone when in work.

> *Yes, not being seen, they want to call first. I had some issues with my hair, my head. They said, oh, we'll call you back, and they call you at a really silly time, when you're working, you can't always pick up, and it's really stressful. So, even now, symptoms*

> *are coming, so I didn't go to the GP, because I've got this thing that it's just going to take so long. It's not easy, fast, effective. It's calling them, then they call you back, you see if they've got another appointment. If not, then you have to wait, and they'll call you back, and if you miss it, that's it. It's just so long, that's what puts me off from even going to the GP with it.* (SA09)

From a GP perspective, changes in access due to the pandemic led to SAs and the general population presenting less to general practice due to a number of reasons, including fear of contracting covid, perceptions of healthcare being closed along with many other sectors closing, not wanting to use healthcare services due to appreciating how stretched they were, and negative experiences of healthcare during the pandemic where they did not feel listened to and dismissed or directed elsewhere. These all potentially made it more difficult for SAs experiencing distress to access primary care.

> *I think the long-term conditions it follows a general trend of what's happened to the rest of the population. That is that primary care and secondary care have become unavailable to people for a number of reasons. One is fear of contracting coronavirus. The second is the perception that health services have been closed. The third is the fear of contracting coronavirus in healthcare settings. The fourth is that they feel a social responsibility not to inundate the healthcare services at the moment. The fifth is a feeling of the general issue around access to healthcare, that when they've tried to contact healthcare services that their issue has not been listened to or that they've been redirected elsewhere.* (GP04)

Changes to access were felt by GPs to reduce holistic care, with a loss of the cues picked up with in-person appointments that included seeing the patient in front of them, body language, more open communication. In particular, changes to access were felt to systemically disadvantage people with lower levels of digital literacy.

> *Lack of contact with GPs, and reliance on telephone and video appointments led to a lot of things missed. If you want to disadvantage people in terms of having holistic appointments, the best way is to just keep everything on video and telephone,*

> *because it requires a certain level of literacy and everything, and text savviness to engage with services through that process. Those systems that were meant to protect them have also led to them suffering in other ways.* (GP07)

The covid pandemic was perceived by GPs and SAs to have a negative impact on care of people with LTCs, due to pressure within both primary and secondary care and delays throughout the system. This could potentially be a source of distress.

> *In the day-to-day managing, doing blood tests and trying to manage the day-to-day side of things, but then trying to get an appointment in secondary care or something like that, the delays have been shocking. So yes, it has, in that sense. I think we've really struggled here. It's just put a lot of pressure on primary care, while at the same time secondary care has really been struggling. I think the priority has been covid, so therefore, yes, it probably has had an impact.* (GP12)

As well as problems of access faced by the general population during the pandemic, GPs highlighted the language barrier and digital literacy as significantly impeding SAs in seeking help for distress during the pandemic, with practices moving to book appointments via online systems and no in-person bookings.

> *I think that was more out of fear of obviously, one, coming out and contracting something. I think secondly, was probably an access problematic with how the way GP operated. I think, for one, they weren't sure how to access the services from the GP now that things have changed to a more digitalised form also. If there is any form of language barrier, that's going to be an obstruction as well, for them to seek help.* (GP08)

When SAs did seek medical attention during the pandemic, their symptoms were typically ascribed by GPs to significant physical illness that compelled them to seek care. Covid was felt to exacerbate previous behaviours, whereby emotional distress was prioritised less and they were not perceived by GPs to present with these problems.

> *I think people have dealt with their distress themselves during the pandemic. I think very few people have come forward to discuss their distress during the pandemic. They've kept it very much to physical health issues rather than to emotional of mental health issues.* (GP04)

Fear was expressed by both GPs and SAs about the impact of covid on people's health long-term. A GP described his concerns around both the physical and mental health impact for the future for SAs as well as the general population.

> *And just like all the other healthcare issues that have been left, from my perspective, there will be an impact on the healthcare services in a few months, years' time once the covid pandemic starts to ease. These distressful states will have caused long-term either mental health or physical health deterioration that will present to services at a later stage.* (GP04)

A mistrust in GPs has been described, often stemming from a perception that GPs would overmedicalise their symptoms. Broader mistrust due to discrimination and British colonial history was discussed. These led to SAs seeking medical attention only when their symptoms became severe or they were in crisis. Mistrust was perceived to be exacerbated during the covid pandemic. The following section describes areas SA have trust in.

### 7.1.2 '*The religion is your life*:' Trust in faith

The most prominent belief that SA males with LTCs described was a trust in faith.

> *The religion is your life.* (SA01)

Faith was regarded as a protective factor for distress by providing a means of understanding why distress occurs and the trust in the wisdom of a higher being. It was felt by a number of SAs to be the first point of support to get them through distressing times, providing positivity and hope.

> *Right, so what is important is my religion, okay? Then, obviously, being from a Pakistani culture and tradition, cuisine, language are important. Yes, that's [religion] actually very important to me because I am a practising Muslim. When I would be around any issues regarding myself personally or my family or friends it's basically my belief that sees me through these challenges, issues and calamities that may befall us… So, specifically the belief is that when things happen, when tragedies happen and we can't really come to terms with it, then my belief is that this is in Allah's wisdom. There is a better plan beyond what we are experiencing at the moment. That's where the positivity comes out of all of this thing. So, that makes me a lot more positive as an individual.* (SA05)

Faith was felt to support SAs to endure challenging circumstances within their lives.

> *Faith is number one on my list. It's not something I've mentioned earlier, but having faith in Allah, doing my prayers and reciting duas [prayers], invocations, supplications. All these things can combine, and they can be really beneficial. They have been beneficial for me. Because I've through some harsh times, but my faith in Allah has helped me get through it. So, faith is definitely a factor.* (SA10)

Faith linked with a belief of divine destiny. SAs described they felt they should take all the means to look after their health, yet not to worry about the future as it already written by God. This belief in divine decree was reported to provide solace.

> *Sometimes I try and keep myself looking at the positive side of things. Because there's nothing much you can do. If something happens, it's going to happen. It's all written down. So, I try to keep myself thinking like that... In religion, the time of our passing is written. When it's our time, it's our time. There's nothing much we can do about it. Obviously, I'll try to do everything to keep myself healthy. But it's no point worrying too much about when you're going to pass away because nobody knows.* (SA02)

All illness, disease and death were felt to come from the higher being and could be taken away by the higher being with their divine decree.

> *When you've got to go, you've got to go. It's not something you can help by worrying or getting stressed. Don't worry. All things are from God. All good things and bad things are from Allah, from God.* (SA08)

SAs described a protective factor for health being the belief in taking practical measures to improve their health while also placing trust in a higher power. These two were felt to work and-in-hand to reduce emotional distress and concerns and fear about future health problems.

> *There are a couple of things. One is I have to put the effort in, right to do the best I can to look after my body which was what I was doing with exercise, sport and a healthy diet. Secondly, I have put my trust in Allah and those together helped me get through the issues.* (SA05)

Positive faith was felt to be protective through practical actions such as prayer, which acted as a preventative to distress, irrespective of religion. Reasons for this included giving the mind a different focus to the issues they were facing.

> *Prayer's very helpful. That's what I'm saying. If everyone was doing five times prayer, then five times a day, he'd never have any depression, I believe. It's not only for the prayer. Mostly, I'm talking the faith. Because if I see English people around me, the one who goes to church, and one who regularly goes to church or with the community, the faith, or set on a faith programme, they don't have any depression. No, I've never seen anyone who has depression when they are doing some faith activities... The faith gives you lots of hopes, lots of courage to deal with the problems, I believe. Because it diverts your mind. It diverts your mind from one place to another, where you're not thinking about your issues.* (SA12)

SAs described speaking to others to hear their difficulties, in a form of downward social comparison, to make their own problems seem smaller.

> *You're talking about some other people. You're listening about some other people. Because when we go out, and listen to other people's problems, they have more big problem than us. And at that time, people say thanks to God. Yes, you have a littler problem than him.* (SA12)

Faith was perceived by SAs and GPs to help people to cope with and manage distress, not just from a theological perspective on facing challenges in life, but also via the communities and centres that were built around faith. Going to faith venues was felt to be a means of peace and emotional positivity.

> *Obviously, you feel more peaceful when you go to the mosque, it feels nice, you feel good about yourself when you are going to the mosque and praying and things like this.* (SA09)

Faith was felt to act in a way as a protective factor from becoming distressed and maintaining wellbeing by its structure of going out to faith centre regularly and the benefits associated with that, such as spiritual uplift and being connected with the community.

> *I don't think there is much in South Asian community, compared to other English people all around you. I don't think so, there is much depression. Unless they are not going to mosque, they don't pray, or something. Any person like that, yes, then he has. But if you do some work or go five times a day, at the masjid [mosque] I mean, so I would say he doesn't have any depression, distress. The person who doesn't do this, keeps staying at home, yes, they have this.* (SA12)

Lack of faith or going against faith was felt to result in negative outcomes and possible distress.

> *We are Muslims, and we should do the good things that our religion says. Religion is always guiding society in good areas. But if you are not doing what you are supposed to do, then things, of course, go bad. Bad things result.* (SA08)

One participant described how not praying and being away from his faith brought up negative emotions and guilt. Hence both practicing of faith was felt to reduce distress, and not practicing faith led to negative emotions which could be precursors of distress.

> *Sometimes, if I'm not praying as I should be, I'm not practising my faith as I should be, I do get a negative feeling, yes, sometimes guilt.* (SA09)

Some SAs and GPs felt that faith beliefs made SAs rely solely on faith and family for seeking support and not healthcare services when experiencing distress. When asked what a SA participant does when he becomes stressed, he replied

> *I just share with family, or do more prayer and rely on my Allah. It's best to be patient, pray to Allah, and rely on him.* (SA08)

SAs described the treatment of emotional distress purely from a faith-based paradigm, that turning to God is the source of cure for distress. Specific elements of worship were described by SAs, such as supplicating to God (Dua), five daily ritual prayers and the remembrance of God (Dhikr).

> *Turn to Allah… Get close to Allah. Ultimately, he's the healer of all illnesses and sicknesses. So, with faith in Allah, with Adhkaar [rememberence of God], with praying Namaz [prayer], with Duas [supplications], Allah will make it easy for you. Whatever hardship, whatever you're going through in life, whatever test you're going through, without Allah's help, nothing's going to work…* (SA03)

One participant described not turning to other forms of help for emotional distress which were not within his paradigms of illness and cure and only turning to God. He related prayers to be a means of contentment and peace, and had the mentality of dealing with any struggles in live with patience to be rewarded by God. When asked if stressed how he would seek help, and who from, he replied,

> *No, I wouldn't... I just turn to Allah. I don't go anywhere else… Contentment, peace. Contentment in your life, in your heart. Peace, that you know that you've got Barakah [blessing]. Peace of mind, you have. Day-to-day, doing your daily duties, it gives you that assurance that you've been blessed, you've been given a test from Allah. And any tests or trials you get, it's a test from Allah, and you take Sabr [patientce] and deal with it… Who gives you this disease? Repent to him.* (SA03)

GPs described not asking patients about faith and its interplay with distress. Although they would not ask about this, some GPs appreciated faith as a support mechanism.

> *I think faith is a powerful tool, and it can help a lot of people. And maybe that's sometimes what people tend to depend on, to help themselves when they're feeling distressed in that situation. Maybe their faith is a strong factor. A lot of people, the family is. So, I suppose, with Asians, particularly with Muslim people, they use their faith quite a lot, maybe speaking at the mosque and things like that. Probably that's an avenue for them, as well, I'd expect.* (GP12)

Trust if faith was described as the greatest source of support for SAs managing their emotional distress. The next section describes another main area of trust for SA men, trust in family.

### 7.1.3 Trust in family

The strength and depth of family and community support was a source of pride for SAs, who viewed it as one of the most beneficial aspects within SA culture. SAs turned to family and members of the community for support when distressed, and felt this support was unwavering, which led to a sense of belonging and identity.

> *The family support mechanism. With the South Asian community, depending on whatever, the community don't have a lack of understanding, or whatever their stance is on issues, they'll always pull together. So, whatever the hard times are, the community sticks together, and I think that's our pride in the South Asian community.*

> *The sense of belonging, the sense of community cohesion is valued to members. That's why I feel proud living in the South Asian community and being brought up in that community. Otherwise, some communities you hear, there's no sense of belonging, no sense of self-identity.* (SA06)

For some, family was the only support they would be comfortable reaching out to. SAs participant described seeking help for emotional distress primarily from family.

> *Do I seek help [for emotional distress]? Only within my household. Yes, I have got a couple of good friends that I talk to. Even then I wouldn't discuss it with them either. I will discuss it with the family so my wife and my daughters. Maybe my brother and sister and that will be about it.* (SA05)

GPs and SAs described SA men presenting to the GP for distress both because their family arranged the appointment, and also presenting with their families in the GP surgery. Within consultations, family members would sometimes take the lead in consultations.

> *So my son, he always say, when the medicine come, he put it here, he say, this is morning, morning, this is evening. He keep it separate for me. And that's like those, he say, any problem for the doctor, he give the letter, signed it from me, to the doctor. He put there his number as well. He say, my Dad some words, I have worry. And he talk to them then, and then they explain me.* (SA11)

Family was described as a main source of trust for SAs , and a means of facilitating and encouraging seeking help from general practice when appropriate. The next section describes trust in self-management.

### 7.1.4 Trust in self-management

SAs described a number of ways of self-managing emotional distress and valued this.

> *Because emotional problems, I've learnt that it's self-help you have to seek, your own help, in order for you to get better.* (SA06)

A number of tools were described by some SA males  to self-manage emotional distress, such as exercise, reading, writing, artwork and positive thinking.

> *Some emotional distress could lead you to anxiety, panic attacks, and all that. They're very common. So, bringing in exercises, I've done a few of them, so they have a few pointers how to breathe, how to certain exercises in certain ways. And when you do go through them, just to practice the exercises, so you could breathe better in certain situations that you're not very comfortable in… Just long walks as well. It might sound stupid, but on a good day, going out for a long walk, preferably where there's green, a lot of nature, and a lot of light. Walking around, having something to do. You're seeing certain things that you don't regularly see, there's always a massive difference that helps your emotional distress. That's how I see it.* (SA17)

A mistrust in GPs has been described, often stemming from a perception that GPs would overmedicalise their symptoms. This led to SAs seeking medical attention only when their symptoms became severe or they were in crisis. Health beliefs was described from two angles, regarding both GP and SA perspectives. Mistrust of GPs was also described as due to discrimination faced, as well as changes during the covid pandemic impacting access to consult with distress. SAs and GPs instead described trust in faith, family and self-management. The next section describes co-navigating care as a potential solution to improving trust within consultations.

## 7.2 Co-navigating care

Whilst SAs and GPs described a mistrust of GPs, they described a trust greatest in faith, and then family. They trusted in their own self-management. Understanding and co-navigating care, i.e. appreciating that GPs and patients both have a set of health beliefs which need to mutually respected and addressed to form shared management plans, was described as a way forward to improving care.

Without a shared understanding of the patient, within their culture and context, SAs did not feel GPs would be able to support them when experiencing emotional distress.

> *I just feel like with talking to a GP, it's going to be so long, and they probably won't know what's going on, because there's so much cultural baggage that comes with it sometimes, it's just so hard to explain, to be honest. I fear that they probably truly won't understand it properly. (*SA09)

The next section describes how SAs and GPs envisaged productive consulting, from a perspective of relationship-based care. Whilst many challenges were discussed by both SAs and GPs, positive experiences were described as well as suggestions for how care can be improved. These included relationship-based care, a whole-person approach, culturally appropriate services and community engagement.

### 7.2.1 '*You need stability*;' Relationship-based care

Both SA and GP participants described the importance of a continuity of care. This was described as a key factor to building trust.

A SA participant described how seeing the same GP led to a *professional bond,* trusting a known figure who they could turn to.

> *I've been involved in psychology sessions for a number of years, and it's not something that happens overnight, the professional trust, the professional bond between patient and service-provider. It's not something that happens overnight. It takes time and effort, and it takes patience to build that relationship. Like my psychologist. Initially, for about two months, we didn't discuss anything to do with mental health. It was all about, oh, she had experiences about writing. Tell me about your books and your writing, your reading. So, it took a long time before the trust was built. For a GP to do the same thing, it's not something that happens overnight. You don't just suddenly start offloading to your GP, without any kind of trust-building*

> *time… It’s very important. You need stability. You need a stable figure, who you can turn to whenever you want to, whenever you can. But it’s very important to have stability.* (SA10)

Not being able to see the same GP, a common challenge for patients, was reported to make SAs less likely to seek support.

> *My doctors keep changing regularly. Because it's quite a big practice, you don't have that one GP where you constantly see the same GP, so he knows a lot more about you and the build up a rapport where you can just go and talk to him about anything or he knows you a little bit. That's very hard to find nowadays, because every time you go to the GP, there's a different GP there. When you go to the practice, it’s not the same GP that you used to speak to years before.* (SA07)

Relationships could be established throughout different points in illness and at a time of crisis, managing their emotions and facilitating a relationship where SAs felt they were able to open up.

> *And with him I remember clearly, because it was such a sudden [heart attack]… Because there was no need for him to come and see me, I hardly ever saw him before then. And the first time I really got to know him was this massive MI [myocardial infarction i.e. heart attack]. So I had to build up that rapport with him very quickly and I clearly remember it was difficult for me to have conversations like that with him. He was shy, he was angry, he was upset. And he said very little initially compared to how we are now.* (GP16)

Providing proactive care and scheduled follow-up as part of relationship-based care was felt to build up trust by demonstrating to patients that they were cared for.

> *A good GP is probably someone who listens to them first, understands or asks them what type of help they need, what is out there to help them, and a good GP is probably someone who actually arranges follow-ups themselves. That says, I’m going*

> *to call you, think about this, and who is persistent in following them up regularly. I don't think you can be a good GP on the first visit, but I think a good GP for them is someone who they eventually feel they do care if I'm doing this or if I'm not doing this, and they're following me up regularly. I think that will start to develop some trust as well.* (GP17)

A GP described how trust was built up with a SA male who was experiencing emotional distress. The trust was based on a relationship that had been established over a period of two decades, during which the patient's father had received medical treatment from the GP. This relationship of trust was developed further during the patient's teenage years when he also presented to his GP.

> *I get a lot of anxiety-related symptoms from a lot of my patients. I have one man who's Bengali and he's actually, again, I know his family very well. So, I consult his father who died and then I looked after his mother, and he has a lot of mental health problems in the sense that he gets quite agitated at times. He lashes out at times. He has to control his anger. He's told me a lot about what's happened to him as a child… Because if I had, in the same situation that I've looked after his family, that person. So, I think that's the context, really. The fact that I know the family circumstances, the fact that I have seen, I've been there and known them for a long time. He's been consulting for 20 years. He's in his mid-40s now.* (GP01)

Giving patients time was felt to be integral to developing the doctor-patient relationship, as one GP described that clinicians should treat patients as well as one would want their own family to be treated.

> *So, try and understand where they come from. Give them time and the space to let them explain themselves. So, imagine they're your father, that's what I'd say. There's nothing unusual about them. They're just a man with a family, just like your father has and treat them like you would your father to be treated.* (GP01)

Bringing in patients for multiple appointments was used as a tool to develop relationship-based care when appropriate, appreciating the opportunity for gaining trust could be easily lost.

> *Your ten minutes are incredibly valuable and if in those ten minutes you can't deal with the issue, invite the patient back for a follow-up appointment. But don't ignore it, don't just pretend it's not there, don't brush it under the carpet because it might be the last conversation you have with this patient before they lose trust with your services.* (GP04)

Developing trust

SAs and GPs described a sense of being able to relate to each other as a key factor in developing a good relationship. Whilst this was not limited to race or religion, having a SA GP with a similar cultural background led to some patients being more at ease and trusting of their GP.

> *I'm the only Asian, ethnic, however, you want to say it, doctor at the practice. So, I pretty much see everybody. They do hover towards me. In fact, one of my patients he said I'm so lucky because you're the only brown-faced doctor he'd had for a long time and it's just really nice seeing someone who I think I can connect to, just by your face.* (GP06)

A number of SAs and GPs described how they thought a SA GP would be more helpful and supportive in managing their distress due to having more cultural awareness.

> *My old doctor, he is an Indian. The same culture. Same thinking. They can help you more, I would say. They sometime, they help. They're quite helpful, you know… They from same sort of background. They live here, but they knew our culture. They knew our thing. With the doctor which, they didn't know anything about your things, you don't, they can help you. Oh, I can give you medicine. I can give you this. Sometime you don't really need some medicine, these things, you know.* (SA16)

To the surprise of a participant, a non-SA GP was described as being able to understand and help him.

> *To be honest with you, I was seen by a GP once who was from the South Asian community, and I have been seen by another GP who isn't from the South Asian community. But surprisingly, I was in shock, that how can someone from this background, and who's not from my background, the GP, have so much knowledge and awareness? That's where was in shock myself, that race has no issue, what race the GP is. It's about their education, about how they've been taught, and what type of education they've upheld. That's when I was in shock. Because I was seen by a GP who wasn't from the South Asian community, but his level of understanding and how he could relate, how he was very quick at identifying issues and everything, I was surprised.* (SA06)

A participant conversely described not wanting to see SA GPs due to their perceived being judgemental and not willing to use words from SA languages to make the patient comfortable, and preferring to see non-SA GP who he felt treated SAs better than SA GPs.

> *Asian (GPs), they are more worst. Because they don't want to see their own patient… They don't treat you right. They think oh, yes, I know him, he's just bloody making excuses. Even, they don't want to bother to say good words in your terms, to say oh, please yaar [my friend]. Because some of the GPs I've seen, they just say oh, to your bloody face oh, please don't make excuse… You're a GP as well, aren't you? You diagnose Asian before they enter, if they lie or not… You diagnose him before you check him or before you see anything, before you see anything, or before he say anything, isn't it? The English people, they are quite good with the other foreigners.* (SA12)

Part of developing relationship-based care was described by GPs as appreciating the barriers SAs have overcome in getting to the consultation, and showing this appreciation within the consultation.

> *So, when they do present it's often, from a personal perspective, I would often be very aware of this being a highly privileged situation for me to be in for them to be presenting in this manner. And therefore the discussion would be one of sincere respect and of real diligence and understanding the underlying need of that patient, without wanting to cross the boundaries where they wouldn't want to discuss those matters.* (GP04)

Key elements of relationship-based care included giving quality time and confidentiality.

> *Just have the time, give them the space, make it known that they're there and you can come to the GP to talk to us about that, and it's going to be confidential and things like that. Because I think that's quite important, knowing that it's going to be confidential.* (SA09)

Giving good explanations was also described as important by SAs, with a good explanation described as taking away most of the illness.

> *The GP, he will make it good for me if I go to my GP and sooner I go in and the way he will explain me something, the way he will talk to me, it will take at least 70%, I would say, of my illness away.* (SA13)

SAs described qualities of a good GP to include a passion to help people and good communication skills and medical knowledge.

> *A good GP is a GP who's very good at listening, who's assertive, who has the ability to relate to people, has a medical background, and the strongest key is, who's passionate about healthcare and the wellbeing of the citizens.* (SA06)

Listening skills were felt to include an appreciation of the patient-expert who was suffering with the illness.

> *Sometimes, some things the GP doesn't know. The person who is a patient knows better than the GPs. If I got a disease, I have to tell you, but that disease, I know a disease in my body.* (SA14)

SA males described a preference for seeing male GPs, and for females to see females, which they felt would lead to better outcomes.

> *A female sees the female, that's good. If male sees the male, they can diagnose better.* (SA12)

This was experienced by a female Caucasian GP who felt that SA male patients tended to choose to see a male GP as opposed to a SA GP.

> *I've certainly found more so, on gender than probably on ethnic background that consult with me. I do tend to see male patients, but I do tend to find that male patients of non-white backgrounds tend to go to speak to one of my colleagues who is a male GP of Asian background, and they don't tend to come me as commonly. I think it depends what they're presenting with or if it's more of a chronic disease review that perhaps might come to me. But for more personal or more intimate things I think they would go to my colleague as preference.* (GP09)

GPs described different experiences of building trust and how SAs could trust GPs more. One example was older GPs, who were felt to be more knowledgeable and experienced.

> *They perceive I may be more experienced, that I'm more understanding, I've seen more. There is this, well, it's a reverse agism. I'll have comments and they'll say to me, I like seeing you because you're experienced.* (GP01)

A key for good care was for GPs to be aware of their own biases, which all individuals may have, and by being aware of them they could manage their biases.

> *You might only have one chance to get it right with them, because they attend so rarely. And I think it comes down to the basics of any GP work and primary care work. It's just listening. Our job is to listen. And it's not to go in with our own biases, cognitive biases, or assumptions, driving things.* (GP07)

By avoiding biases and not generalising these patients as 'heart-sink' it would lead to GPs trying to develop and shared understanding and give the patients time.

> *If there was one piece of advice I'd give is don't see these patients as, in using your word, as heart-sink. Don't see these patients as wasting your time. Spend time with them, understand them, give them time.* (GP16)

Empathy was also described as a key ingredient for GPs.

> *I think a lot of it is just listening and understanding. And even in my patients who aren't South Asian, and, as I said, I don't speak the language… But when I've spoken to them through their family members or spoken to them directly when they've been in the surgery with family members, I think they can often see the empathy physically as well.* (GP18)

GPs also described seeing patients, and just by seeing them it gave them the therapeutic support to carry on.

> *In South Asian males, specifically, what they relate to is that they are, in essence, talking about emotional distress. And I do nothing for them, medically, in the traditional sense. I don't prescribe them anything. Fundamentally, what I'm doing is I'm giving them time. I'm giving them time in a relatively safe space where they, I think, they've come to appreciate that they are sharing because they feel hurt. Then it sort of sets them to be able to at least carry on a bit longer.* (GP02)

Challenges to relationship-based care

Whilst GPs valued relationship-based care, it was felt to be more difficult in within general practice which was felt to be challenging with GPs overworked and practices underfunded, and more GPs choosing to work part-time.

> *Yes, I think with continuity, obviously you'll get to engage with that patient and they'll probably, all the things they will after a couple of times trust you and start telling you more. Continuity is something we've always tried to do in our practice, but it becomes very difficult as most people work part-time.* (GP17)

Relationship-based care was felt to be impeded by challenges within general practice, such as time and workload challenges. Furthermore they described a lack of recognition for their work, which was only appreciated during the pandemic.

> *We saw some glimmers of this through covid, which was almost alien to lots of people, that people being called, so when I was at NHS, a person was being called hero. And that, for me, on one end, it was a damning indictment of where we've got to in the sense that somebody who naturally does a role within health and social care, regardless of what that task is, I'm a public servant, first and foremost, and for some reason, it took a pandemic for people to appreciate that.* (GP02)

The importance of relationship-based care, facilitators for developing trust in GPs and challenges to relationship-based care are described above. The next section discussed a whole-person approach.

### 7.2.2 '*Whole-person approach'*

A whole-person approach was described as a key element by both SAs with LTCs and GPs. GPs tried to manage patients holistically, asking themselves about the symptoms SAs presented with, and if the symptomatology described required further investigations from a physical health perspective or was primarily an emotional issue which needed to be addressed in its appropriate means. This caused a tension for the GP who described not have a dualistic understanding of a split between the body and the mind, and also hinted about over-medicalising and over-investigating when other barriers were present such as limited patient English.

> *When someone opens their mouth and starts talking, in my mind I'm wondering from the word off, my mind is thinking to what extent is this primarily an emotional issue? And to what extent am I wanting to think about medicalising this and thinking about it as a physical. I'm struggling a bit to answer that question because I don't have a mind, body split equally. I don't know is the answer. I just think that when someone says they've got pain in their chest I'm thinking from the beginning is this a marker of emotional distress or is this a marker of ischemic heart disease, or is it a marker of both really? And I suppose if I can't communicate very well with the person it probably ends up that the doctor shapes it and plays the safe option, which isn't necessarily the best one. And assumes it might be ischemic heart disease and either admits them or sends them for cardiological investigation unnecessarily.* (GP03)

GPs described how the system of healthcare in the UK led to an unnatural and unhelpful physical-mental split, in contrast to other models of health whereby doctors holistically treat patients.

> *Through the years I've been a GP, certainly in this [SA] community, I think where I've ended up is that the more we medicalise matters of emotional wellbeing, the more further away we get from a point of success for patients. I think some of the things we've spoken about earlier is that we've got this immensely artificial divide between a statutory body that delivers, fundamentally, physical health and a statutory body that, fundamentally, delivers mental health. If we go to those sort of orientalist places, the word for doctor is all-encompassing. It covers the whole breadth of wellbeing. There isn't this artificial divide. And nor should that divide exist based on where that care is received.* (GP02)

Fragmentation of care between primary and secondary services was further felt by some GPs to provide limited care as opposed to a whole-person approach.

> *So, there's a massive, it's not even a threshold anymore, as you know, it's a flowing river between primary and secondary care, what's termed in this country as primary and secondary care. And the management people talk about vertical integration and horizontal integration… I think the whole-person approach, if we're talking about an American term, the Americans talk about integrative medicine. They don't talk about integrated medicine, because I think integrated is the end point of what a service can become. And it's just long-term plan talks about integrated care systems. I don't think you can achieve integrated care systems until you have integrative therapeutic interventions.* (GP02)

Family-based management of emotional distress

One way of developing a whole-person approach was to manage SAs according to their cultural expectation of attending with families and being treated in a family-based approach. This was particularly relevant with regards to emotional distress where it was felt SAs tended not to present alone, and families were integral to care.

> *99% of the time another family member would consult me, the wife, the children, and inform about the stress in the household taking place. And it would be extremely unlikely for that individual, for the first generation, over 65, South Asian gentlemen to inform me directly themselves that there was a stressor in their household. But it would be someone else in 99% of cases who had already given me the information in confidence when they come to consult me about something else, knowing that I was the GP of their father or of their husband, and then they would explain that stressor to me. And when I'd be discussing it with the individual then they would reveal that information to me. 99% of the time that would happen. It would be in an extremely rare situation where the individual themselves would explain their own stress to me outright.* (GP04)

GPs described how they took the approach of a family-based approach, led by the patient's wishes, but treating the patient in the context of their family to improve care.

> *Going back to your question about how do they manage their long-term conditions. Using proxy access. They've got their children or grandchildren to help them to order repeat prescriptions, to read what the doctor or nurse has written. If I say to a patient, I want you to have a blood test in a week's time and come back in a month's time to check your blood pressure reading, it's the children and grandchildren who read that. And then try and make sure that their parent or grandparent gets the care they need. It's not perfect, but my God that's a million times more than what I'm getting where I'm living. From my own GP surgery. So, then we've changed their behaviours and looked at how families can help out. That's also meant that the children and grandchildren who are a lot more aware of things like mental health are able to identify things amongst their parents and grandparents. Or maybe push them to approach us.* (GP05)

GPs described a whole-family approach helped with concordance as family members could offer support and discuss health beliefs and facilitate understanding of the patient of their illness.

> *The more involvement you can get from families and other support networks that an individual has, the more likely they are to be able to understand their condition but also be compliant with any advice and management you give them.* (GP14)

Primary care management of emotional distress

GPs described how they would use steps in management of emotional distress during the consultation, including observation, counselling, signposting and psychological therapies.

> *You've got the counselling end. You've got online resources. You've got medication. You give them those options. Sometimes it's a supportive chat, which you're, then, just monitoring them over a period of time and trying to get them through whatever*

> *it is that's going on, I suppose. Trying to signpost them to the anywhere else that might be able to help, in that sense. I can't think of anything else other than that.* (GP12)

GPs felt that referring to counselling and support were helpful in particular for mild to moderate levels of emotional distress.

> *I've not made many referrals for psychological treatment, and I think, oddly enough, as a GP I've always felt strongly that as GPs that we should be dealing with a lot of to moderate psychological distress. I'm not one for saying then just refer them. So, part of what I believe in, is that I offer counselling myself. In a way, I offer them a cognitive behavioural therapy, modified type thinking, which I might do over a series of consultations. So, I think I've always believed that. So, I would argue that I give some of that treatment, anyway, rather than just refer them. So, that reflects my consulting style and what I like to do.* (GP01)

Within the consultation, signposting played an important role including considering social prescribing which was felt to be a useful support system.

> *Well, I sometimes find that I'll ask a social prescriber at the practice is there anything like this that you know of in the locality? Is there a group where this person might feel at home that you know about? Is there an organisation? I don't pretend to be able to store in my mind these things. I mean, clearly, there might be some specific groups for people say, with diabetes or there might be some specific programmes for people, cardiac or respiratory rehab. Or just slightly different things really. I wasn't really meaning those, I was really thinking about ongoing groups where people who are distressed or struggling with something can facilitate, to a certain extent, their own support, their own sharing.* (GP03)

Signposting was felt to work better with emotional distress if the services were in-house within general practice.

> *We had a mental health nurse at the practice which was very useful because when you mention a referral they don't want to go anywhere else. But if you explain to them it's at the same practice, a lot of people are more willing to say, okay fine, we'll come here, it's around the corner. So mental health nurse, just all the support in one place.* (GP17)

SAs also valued social prescribing and how it could benefit SAs suffering from emotional distress.

> *A GP, it's their job to basically prescribe you on the certain medication and find out what's going on. But with emotional distress, I'm not too sure. Rather than… I don't know. Maybe just say referring you to a gym or something like that. I know that sounds stupid, but that's something that just works for a lot of people. Just joining a gym. Doing cardio, swimming, stuff like that just to curb your emotional distress, and just to get onto the road of progress, really*. (SA17)

From a GP perspective, personalised management plans based upon their health beliefs were felt to be important.

> *I think always try and be reassuring and open and encouraging for people to come forward. And be reassuring when patients are discussing any type of distress with you and then obviously try and contextualise the management plan according to that individual's cultural and individual health beliefs.* (GP14)

GPs described how a one-size-fits-all approach to management plans was unhelpful.

> *And then the second bit is that if you don't try to give a cookie-cutter approach, you don't have like a one-size-fits-all advice. It's very much about getting to understand their own personalised needs.* (GP04)

Considering the wider social determinants of distress was also described as important.

> *Just take the time to explore cues, both verbal and visual cues that might indicate emotional distress. And just enquire a little bit more as to why they might be feeling such a way? What external factors, both at home and socio-economic that might be influencing how they're feeling. And how might that impact on their health-seeking behaviour and lifestyle modification and treatment compliance, really.* (GP08)

Some GPs described actively trying to manage the social determinants during consultations, feeling that this approach was the only approach to help SAs experiencing distress.

> *What do they want? Often, it's not improve their mental illness, because they don't recognise it as such. They just don't want to feel bad. They want to feel better. They want to feel healthy. They want to get back to how it was before. That can be really challenging because as we know, improving outcomes has almost nothing to do with solving their medical problems. That's about the socioeconomics talking. Which we can't just magically change. We know that. We know that getting a job is normally the most important thing of all, especially for mental illness. At a time when a lot of them don't have jobs, that's really very challenging. My success is really quite limited in terms of what I can do. All I can do is try to improve their health as best as possible so that they are available for being able to go for jobs… It's going to be challenging around what difference can we really make for them.* (GP05)

The GP described in details how he tried to manage the social determinants within the consultation by upskilling patients with digital literacy, for example teaching them how to order repeat prescriptions online as a step to further digital literacy. In this case, he felt supporting patients to get a job was equally as important as prescribing medication.

> *A lot of my work is looking more broadly at how we can improve the job prospects for this group of people. But even recognising that getting a job is really important, it's an important part our role, and they might not see it as such and think my job is just to prescribe antidepressants and things. But that's what I'm trying to do, is look at how we can get them back into work. One of the things that will help there is upskilling their IT skills. Which again comes back to as long as they continue to say, I*

> *don't know how to use the internet, they're not going to go on to the websites to be able to find jobs. I know in terms of future skills, that's really important. Which is why it's been wonderful to see that you can take this group of people and upskill them. It might be that the reason they do that is so that they can order repeat prescriptions. Or perhaps look at what the doctor has written for them. But actually, by them being able to do that, they can then start to imagine that they could come online to look for jobs and to do the kinds of things that most of the rest of the country takes for granted.* (GP05)

With the qualities of whole-person care in place, occasions were described when the GP became a 'pill' and means of treatment through a therapeutic relationship.

> *There was a South Asian man from, I think, a Sikh background who had a very traumatic experience with losing some family members, and he was under a lot of stress. I think he did have some medicine, but I didn't do much for him apart from I gave him regular follow up and just listened to him talking about his worries and concerns. And it was a good two years of regular follow up with him, and now he doesn't come. Because the last time I saw him was a success story in the sense that he said he was back on track with his life. And it was just more that doctor as a pill. So, listen, signpost, guide, give him a bit of your opinion, but most of it is listening to him talk about how horrible his life has become because he's lost family members.* (GP10)

A whole-person approach has been described above, including management steps to allow for it to take place. The following section will discuss culturally sensitive care.

### 7.2.3 Culturally sensitive care

To facilitate a whole-person approach, it was felt that culturally sensitive care was needed, providing healthcare that respects and considers people's cultural beliefs and backgrounds. This will be described further below.

Current approaches to managing emotional distress were felt to be inadequate due to a lack of culturally sensitive care appreciating patients and their backgrounds.

> *I think we have a situation, for example, where lots of these people, the outcome of any initial assessment is likely to be some form of talking therapy, if I can put it as broadly as that. Now, we know, and we have evidence, let's take cognitive behavioural therapy, CBT. We know that CBT aligned to the holistic approach for that individual is more likely to be successful than CBT that you click on a button, that's delivered online. And the evidence is there. And I'm sure experts have done the various literature reviews... And that goes back to what I mean by cultural competence, where you are absolutely looking at the whole person and what they bring to that moment in time. And not just a product that needs retrofitting, if I can put it so crassly…* (GP02)

Without culturally sensitive care, it was felt by SAs and GPs that GP consultations were potentially useless because the management plans would not fit within the SA paradigms of health and SAs would not concord with them.

> *Being able to identify with that group and understand them, and having appreciation of their wants and needs is really helpful… If you can't connect with people, if you're not culturally competent, and I've done talks on this cultural competency issue, you might as well waste your time. It's like prescribing someone Prozac [brand name for the commonly used antidepressant fluoxetine], who just bins it as soon as they walk out the door. You might be thinking you're doing well, and yes you've written beautiful notes in your record that the powers that be can look at, but actually you've made absolutely zero difference to the community of people that you serve. (*GP05)

Culturally sensitive care was described to incorporate culture and beliefs as well as the wider determinants of health.

> *What does a good GP look like for them? I think just a holistic approach. Someone who is inquisitive, looks at them not just on what their HbA1c is, but based on their*

> *culture, their background, what difficulties they may be experiencing. Why they're finding it very difficult to control their blood sugars, for example. Just really what kind of, as we talked about this, the wider social determinants of health, just being aware of those things and tailoring advice and treatment to that patient's situation.* (GP18)

Just by learning a few words of a language it was felt to build rapport with regards to culturally sensitive care.

> *I think if you know even 5% or even a little bit, or even if you spoke a sentence of their language, if you learnt a little like that, that just eases them off. If you can say one or two words in Bengali, it makes them smile and I think it does develop that, okay, they know something about me. They know a couple of words. To know a little bit more about every country would be good and it would be like an icebreaker as well, that okay, yes, you come from that city, I'm aware of it. It's a capital, isn't it? Simple things like that would make them think, okay, they know something.* (GP17)

As well as a level of cultural awareness, cultural humility was described where a GP had the curiosity and courage to ask about SA culture which related to health.

> *It's this curiosity, but in a way that's not judgemental. So, you're not saying you're an expert of that culture, but just try and understand the backdrop of where that person's come from, and respect, and don't dismiss people. I think that's where you could… The emotional distress could turn into mental illness.* (GP10)

SA participants described two aspects of cultural competency, both health professionals learning about different cultures and faith, and faith and community leaders learning about emotional distress and its management within medical paradigms of illness. It was more than a google search was needed, but health professionals to read a journal article on faith and mental health for example, and faith and community leaders to read a journal article around mental health for example.

> *So, basically, it's not just a one-way street. The psychologist, psychiatrist, doctor, whatever, has to learn about Islam. For me, it's not even based on googling it. If you really want to know your client, if you really want to engage with them and earn their trust, then it's ideal to learn… there are very, very basic things that they can do, like read a journal article about Islam and mental illness or whatever. And learn more about Jinn [spirits], black magic, and evil eye and all these… Hasad [envy that affects others] and jealousy and all these kinds of things. But equally, more spiritual leaders, like imams and community leaders, it's important that they also learn about the other potential causes of mental illness like trauma, chemical imbalance and genetics, so that through them the community heart is really changed, through faith and religion.* (SA10)

The SA participant further explained the importance of learning about faith and mental health because of the nature of present-day psychiatry which is taught from a God-less paradigm, and at times used as a political tool such as to subjugate black slaves. This is different to the paradigms of mental health of SAs whose basis includes a higher power.

> *Honestly, psychology is seen as quite Godless. It's quite Godless. And psychiatry as well. In psychiatry, they had this idea that black people were inferior to whites, or black people were less developed than the white people. So, that was part of psychiatry for a number of years and that's what justified the slave trade.* (SA10)

Cultural competence was discussed on an organisational level, and the need for organisations to be more culturally competent as they control the systemic factors and what is and isn't invested in.

> *It's not just for individuals, but it's for organisations as well. We've got a lot of growing up to do at the moment. Organisations need to transform themselves to becoming more culturally competent. But in terms of how do we do that? Well, organisations set… In fact, it's not organisations. Boards, more than organisations, set the culture of the NHS itself… The board determines what the key conformance indicators are. It determines where the money is spent, it determines who we employ,*

> *it determines what buildings we have, it sets the direction of travel and what they want to achieve and how they want to achieve that. So, incredibly important... This is what you need to do to not just raise awareness, but to change the direction of travel that the organisation, where it spends its money, where it [unclear] staff. How it uses its buildings…* (GP05)

A core component of making organisations culturally competent was described by GPs to make healthcare leadership more representative of the patients they serve, which was felt to be not currently the case. Without this, it was felt that organisations would not be able appropriately serve the patients they should be there for.

> *If the people on the board are representative of those they serve, the patients themselves, or those in the front line, the me's and you's who are actually seeing the patients. Then we are more likely to have that conversation with the board member to say, look, these are the problems we are facing on the front line… Lots of evidence, not just from here in the UK, but also abroad, not just within healthcare but with other organisations, the moment the board is representative of the people it serves and the front line, then that organisation becomes a lot more effective. Sadly, at the moment, within Greater Manchester, our boards are not reflective of the people we serve and it's not reflective of the frontline staff. Consequently, the kind of decisions that they're making, they just don't fit the needs of the people... And they are often the ones who set the policies and determine where the funds are spent and all that sort of things. That's where I'm seeing the points of weakness and why there are funds available but they're not being channelled in the right places to support this kind of work.* (GP05)

The GP further described how to make healthcare leadership more representative of the population served by investing in upskilling and developing senior leadership of healthcare organisations to be reflective of the communities they serve.

> *Part of that then, means that these are the very same people that we need to upskill. So that they can then one, hold boards to account, and two, choose to become board*

> *members themselves so that they can then help other people by themselves. In the long term, that's definitely what we need to do.* (GP05)

Due to a lack of culturally sensitive care, charitable organisations were relied upon to deliver care, which was felt to be a sign of the NHS not delivering the quality of care that it should.

> *So it ends up being heroic people. Why is it that I'm having to refer my patients to Diversity Matters North West? Why can I not directly refer them into the mental health service knowing full well that the mental health service is fully equipped for this population of people? That itself just says a lot about where the NHS is at the moment. The gap between where it is and where it needs to be.* (GP05)

Culturally sensitive care is described above. As well as this, SAs and GPs described the need for culturally adapted services.

### 7.2.4 Culturally adapted services

GPs and SAs described a need for specific services for SA men with LTCs manage emotional distress.

> *I definitely agree with one thing, that we should have more services for Southeast Asian men to cope with emotional problems associated with diabetes or heart disease. There are some people who suffer terribly with diabetes.* (SA02)

Culturally adapted services were felt to be needed by both GPs and SAs. GPs described a lack of services which acted as a barrier to care, as well as communication skills, time constraints and complex needs.

> *I think the key there is the communication skills that are involved in people who've got complex needs. And obviously time is a big factor for GPs with ten-minute consultations. The lack of services that are tailored for people with mental health issues basically.* (GP07)

Similarly, SAs described a need for culturally adapted services.

*So, for instance, I definitely agree with one thing, that we should have more services for Southeast Asian men to cope with emotional problems associated with diabetes or heart disease.* (SA02)

SAs described they would utilise services for emotional distress when acceptable to their paradigms of faith and health.

> *I think anything like that would be good, obviously for people who can't do those sorts of stuff like CBT, and mindfulness and don't feel comfortable doing stuff, like some of the new age therapy. So, yes, if there was a community-based or spiritually-based or whatever, definitely… So, for some of these people who do have severe problems with diabetes, if they did have a place where they could be understood, and there was some spiritual aspect of that and there was some community-based aspect of that, that would be very good.* (SA02)

GPs also described from their experience and perspective the need for culturally adapted services to support patients.

> *And I think, when we talk about restarting services. They need to be culturally competent. They need to be culturally astute. And they absolutely need to be culturally appropriate.* (GP02)

SAs and GPs felt that these services would be best placed within the community, with a key role for faith leaders and primary care working together.

> *And I think to try normalise this conversation within this community that we're referring to, we have to start across the generations and we have to start early. This needs to be, when somebody is troubled and they're going to see their Imam [faith leader] for what may be, for all intents and purposes, culturally competent talking*

> *therapy, because, often, that's what it becomes, the construct behind it needs to be that, actually, you can't detach this, I'm not going to medicalise this for you. This is you, living your life, and, therefore, it has to be relevant to the life that you lead. And so, if there was a hosting place, it needs to be pre-primary care. It certainly needs to be in a place where it touches society at multiple points, so it finds you, rather than you needing to find it.* (GP02)

Culturally adapted services were generally not found within the NHS. When asked about culturally and faith-based services, a GP spoke about the availability of such services privately. When asked if these services should remain private, or accessible via the NHS, he explained feeling it should be available on the NHS due to NHS serving the needs for all populations in the UK.

> *I'll give you an example, there was a lady, and she was having conventional therapy, and she really found herself, and she wanted to start practicing, praying, and stuff like that. There's actually an organisation that has a list of Muslim psychotherapists in the country and some of them offer specific Islamic counselling. There's a course that you can go on to deliver what's known as Islamic counselling. I think if the patient wants it, why not? Unfortunately, it's a private entity and it's not a part of the NHS. [IV Do you think these kinds of things should be on the NHS?] GP06 Yes, I do because I'm a big believer in the principles of the NHS, that healthcare should be free for everybody. And it's not right that just because one person can afford it they have a breakthrough. And if they can't they're stuck with what they've got and it doesn't work for them. So, I think it should be available and should be funded because there's such a diverse community in England, it should be there.* (GP06)

*'Emotionally, they may speak better in their own language*:' Linguistically adapted services

Language was brought up a key ingredient in culturally adapted services, in particular given the challenges of speaking about emotional distress in a second language that English may be for some SAs.

> *I think sometimes they don't want to have psychological treatment because they feel that the language won't be understood, as well, though they speak very good English. In order to give psychiatric counselling, sometimes, you need to have quite a nuanced understanding. I've always felt that psychiatry, mental health, along with everything else, it is culturally driven, as well as medically driven. So, that is a gap, yes.* (GP01)

Even if SAs spoke English well, it was felt that services should be available in SA languages so they could express themselves fully.

> *I do think there's a gap in service. Because I think sometimes it's easier to consult in your own language. I think that's a gap, really… So, the point is, I think, that even though your language and you can converse in English, one-to-one with someone, there are still, I think some people, especially when they are, because many of them, like [Name] for example, he speaks really good English. But emotionally, they may speak better in their own language. Do you know what I mean?* (GP01)

GPs described struggling otherwise with managing distress when language presented a barrier, as described below when a GP was asked about the barriers to managing emotional distress in SA males with LTCs.

> *Certainly, like I said, sometimes it can be language, if it's someone that's not a native speaker. The other thing is a lack of understanding of some of the cultural norms and religious influences that impact the lifestyle or health beliefs, certainly, of this patient demographic.* (GP08)

Language barriers were felt to be a problem with frustration using interpreters due to what was lost in translation.

> *So, I think that there's no doubt whatsoever that South Asian men who've come to see me who don't speak English that's good enough to converse without an interpreter, or freely, have a bad deal from the beginning. Because I'm frustrated, they're probably frustrated, the interpreter's probably frustrated. And the whole*

> *meaning of what is diabetes, what is cholesterol, what is a coronary artery, what is circulation, what is pain. It's just very difficult to explain them. And very difficult to know if the person understands… Where I would say something, they would say something and then we'd just wait for the patient to say something, you know what I mean? But it just doesn't happen like that. It's the, well I've been talking to a patient in the waiting room before we came in and I can tell you what the problems are. That's a classic, isn't it? Or interpreter you seem to be saying more than I could possibly. I just asked a simple question, but you've been talking for 30 seconds. She's saying, well he's not understanding, so I'm having to put it a different way. But I don't want you to do that, interpreter. I just want you to say what I said and see what he says. What do you mean? Or sometimes it's like, so I'm just checking that what you said was you've had a sharp pain on the left side of your chest. And the interpreter says, yes that's what he said. It's just impossible.* (GP03)

The importance of language appropriate-services was described by SAs, even if they spoke English to a good level.

> *Language, yes. It does help them if you speak the same lingo. You feel comfortable talking to the person and understand. Most of our people in my age don't speak proper English like myself. Look, lots of words I can't speak, but it does make hell of a difference if they're in the same community.* (SA13)

### Faith leaders as a source of support for distress

As well as GPs reaching out to the community, a SA participant also suggested faith leaders talk about faith and mental health, given the rich tradition with his faith and historical management of mental health.

> *I think they can play a vital role in changing attitudes in speaking up about these issues in Khutbas [Friday sermon], on Friday Khutba, starting courses for people about Islam and mental health. Some of the earliest psychiatric wards, right? They were established in Baghdad in Iraq, in 705 AD, long before the Mental Health Act, long*

> *before lobotomies and all these kind of things. And then there were people like Abu al-Razi. I don’t know if you’ve heard of him.* (SA10)

SAs described how faith leaders could be a greater means of support if given some training in how to manage emotional distress, balancing both a faith and medical perspective.

> *[IV So, for example, if the Imam was given training in basic medical management and counselling type things, do you think that would work as well?] SA09 Yes, definitely. If the Imam had qualifications or a little bit of basic training, able to know what depression looks like, or what stress looks like, or understand that not just the religious side of it, but understanding the mood swings and things like this, then yes, definitely.* (SA09)

Faith leaders as a source of support for emotional distress was described positively by a SA participant.

> *The Imams that I know locally, they are very good. They are very busy providing these services. People do go to them on a personal, individual level to get advice over all sorts of matters from divorce after being married for 50 years, their kids, their daughter or their son, their teenagers leaving Islam to so many other issues. So, there are a couple of people I know locally who do this but I don’t think they are enough. I think you are right, there should be more of these services that need to be made available.* (SA05)

Supporting faith leaders to develop expertise in managing emotional distress was suggested as an area of improvement.

> *Muslim clerics, leaders in the community, they should take that part and just be trained. If someone professional trained them, and they should implement these things in session in the masjids [mosques] or in centres.* (SA17)

There was a concern that if not appropriately trained, faith leaders could have a negative impact supporting SAs with emotional distress.

> *I'm sure there are other Imams and religious leaders from other denominations who may not be as appropriate to doing that kind of work, just because of their superstitious beliefs or lack of awareness of mental ill health. They might use this as an avenue to provide some support for the community, but actually might be doing more harm than good.* (GP04)

Some GPs described care needs to be greater than culturally competent interventions for different groups, but instead how the NHS could be receptive to people of different cultures.

> *But the interventions surely must be not just a specific one for that particular group, but for the generality of how we carry on practice and that's the issue, I think.* (GP01)

Culturally adapted services are described above, including linguistically adapted services as well as utilising faith leaders. Community engagement will be described below.

### 7.2.4 Community engagement

GPs and SAs alike described the need to for engaging with the SA community as a means of supporting SAs with emotional distress and creating awareness of services and building trust, as well as suggestions for how to do so. Reaching out to communities, and getting community input, was felt to be essential to developing trust within the community.

> *I think reach out to community centres like mosques, places of worship, and raise awareness of the services. And have more consultation within the community people, and understand some of the issues. Unless the community don't feel comfortable or don't feel ready to talk, then it's always going to be a barrier. So, I think that's where the issue lies, I think the barrier. How can you create discussion in the first place in the community? I think places of worship. Healthcare centres, like GP practices, obtaining consultation. And then, opinion from members of the community, and offering them*

> *reassurance and guidance that this is what the point is, and a full consultation is being carried out.* (SA06)

SA participants described how communities and faith centres should prioritise issues such as emotional distress and provide a space for these.

> *For the community, I don't think there's anywhere that you could turn to and go to in confidence. There're masjids or madrasas in every city and town. Where are the Islamic centres to help people with everyday issues? That's the most important thing. That is most needed here in this country, more than anything else.* (SA03)

GPs described culturally and faith-adapted services, based in religious venues in the community, as a key aspect of community engagement. A SA GP described the community work he was doing for SA Muslims suffering from emotional distress.

> *At the backend of last year we talked about getting doctors and psychologists involved, so I'm part of the brothers and sisters who do the wellbeing. There's an organisation in [Name] called [Name]. Google them, a very nice bunch of people, they're hoping to have a masjid [mosque] soon. So, the wellbeing service that we do on a Sunday, clearly, everybody said I found it very hard to go to my doctor and talk about these things, I'd much rather talk to a Muslim. Men, women, young, old. And the sisters wanted to speak to sisters and the brothers wanted to speak to brothers, even though it was just normal stuff. So, the plan is with [Name] is it stayed online throughout COVID, and rightly so, but Dr [Name], who is heading [Name], as soon as the masjid is built there will be a designed room for this, but in the meantime he's managed to secure a place. I think it's an [Name], actually, which will be like a clinical room. And it will be worked from on a Sunday in our free time, giving our time for the sake of Allah to people who need it. And I think there's a definite, definite role for this in our masaajid [mosques].* (GP06)

On a practical level, GPs were approached within faith centres to discuss distress with other members of the congregation, making them feel a need for services within these locations.

> *It may be an avenue to develop mental health services in local mosques... As someone who attends the mosque, I've noticed that many people do come to me and discuss those kinds of issues with me. They'll ask what can we do about this situation or how can we try and address this. And I think that gives people an avenue to be able to discuss their emotional distress.* (GP05)

When SA GPs were not actively involved in community initiatives as above, they were still approached as a means of support from faith centres because of being known within the community as GPs.

> *As someone who attends the mosque, I've noticed that many people do come to me and discuss those kinds of issues with me. They'll ask what can we do about this situation or how can we try and address this. And I think that gives people an avenue to be able to discuss their emotional distress.* (GP04)

GPs described how co-production of interventions based in the community was key.

> *The simplest approach is going out to those areas where they congregate the most. You have to stop leaving healthcare in the GP surgery. And we also need to stop addressing it of making GPs the only solution for every problem. I will say that the targeted areas should be community centres, mosques, temples. We should improve training and standardising of them, we need to reach out to self-employed groups which from an employment point of view vulnerable. But also we need to reach out to them so we can find out, look, how do we help you. And I would say the biggest thing that should drive all of this is co-production. We need to co-produce our approach to this with the communities, rather than against the communities. And I feel like, yes, and I feel that's probably one of the things in the end if we don't work with the communities, and we don't involve them in the process. And if we don't work to raise the standards for the support areas for these vulnerable groups, ultimately all we're doing is basically pushing water uphill. It's just going to fail again and again.* (GP07)

A positive example of this was described regarding the covid vaccination program, with vaccine uptake dramatically rising after GPs from ethnic backgrounds delivered healthcare messages within communities and in their languages.

> *I think the vaccine uptake initially was very, very slow, there was a lot of hesitancy, there was a lot of nervousness around accepting the vaccine in particular. But there were loads of hard work done in my primary care network in particular. Where doctors of the same ethnic origin would go and speak in community groups, and things like that, to try and encourage vaccine uptake. And actually that's been really successful. So we've actually done really well once that information has managed to get out to patients of different ethnic backgrounds. I'm really proud of that, because that's a real strength of the local community.* (GP13)

Community outreach was felt to be more important than an individual-based approach, due to being more impactful on the community.

> *Engage with them first and educate them so they feel more empowered about it. So, I think you can't get enough awareness in your local mosques. Because when we've done it in a mosque after a prayer, people tend to just stick around for five, ten minutes after if you give a brief overview of what to look out for. So, our depression talk gave an overview of common symptoms and said, if you're having poor sleep, you think this could be a depression, this is not something to be embarrassed about, but we can help you, and then we'd just talk about medications and things. And I think the more that the GPs go out there, into these communities, to address that… I think, if you raise the community awareness, then it will hopefully seep into the patient as well. I think, on an individual basis, it's almost impossible. That's going to be hard because we're so busy...* (GP10)

Part of community engagement was felt to be supporting members of disadvantaged communities to get involved in healthcare and minority healthcare.

> *And this comes back to my other area of interest, which is widening participation, which is to role model those from these disadvantaged communities to start thinking about ethnic minority health and giving back. So that, when they get into positions of influence themselves, they can give back, nurture people to start thinking that the purpose of our career isn't for self-glory, but it's about making a difference to those communities we've come from. (GP10)*

SA participants described the need to nurture SA GPs and researchers to help support the community as a means of developing authentic culturally appropriate services for SAs with LTCs experiencing distress.

> *This is just my personal opinion, but I find sometimes that researchers are almost asking questions that they want answers in a particular way. So, one person might be asking a question, and they prefer to hear this answer. So, sometimes, the follow up questions are maybe not nudging but slightly swaying the conversation towards them. I think if a person is not from a Southeast Asian background and is asking about what is best for the Southeast Asians, I think a person from not that background would be driving the narrative in a way that's suitable for them but not necessarily suitable for the South East Asians... So, I guess, more of this, where we have doctors or researchers from a South East or a similar background, asking questions and listening to them. And then acting upon that.* (SA02)

Finally, GPs described how community engagement is not an extra of the NHS, but should be an integral part of the NHS, given the diverse UK population, given the diversity of the population and the role of the NHS to serve all.

> *I think the NHS is for the people. It belongs to the people, and that's everybody. The typical British person is no longer White English middle class, but it includes these people as well. And we have a duty to look after them just as we do for everybody else.* (GP05)

The above section describes co-navigating care, including relationship-based care, a whole-person approach, culturally sensitive care, culturally adapted services and community engagement. The next section describes potential areas of professional development.

## 7.3 Professional development

GPs and SAs described potential areas of professional development to improve the care of SAs with LTCs experiencing emotional distress.

### 7.3.1 '*Unlearning'* fragmented models of health

A challenge that GPs described was the need to un-learn purely biological model of health when delivering care for emotional distress in community general practice. GPs described how it would take multiple consultations to realise an issue was related to mental health due to initially presuming a physical health problem.

> *There are so many instances, I guess. Even with myself where you're seeing patients who have multiple different physical symptoms, and as a doctor you're wired to try to find an organic cause. And that's with the patient's best interest in mind and you're trying to rule out any significant pathology with any serious complications. So, sometimes you're focussed heavily on that and it may not be until one, two, three, maybe four consultations afterwards. Where you've examined that patient, you've listened to them and you've investigated them until you come to realise that actually a lot of this is down to the patient's mental health.* (GP18)

Another GP described the need to unlearn a secondary care approach to be able to deal with distress in primary care, highlighting a lack of training.

> *One of the hardest things that I had to come to terms with when I first landed in general practice as an independent practitioner was the woefully inadequate training that I'd had. And, interestingly, it's not that I didn't have, so I had six months of psychiatry training, but, actually, the psychiatry that I was taught, and the psychiatry*

> *that I learned, and the psychiatry that I delivered, again, was woefully inadequate. It was it that was woefully inadequate, not the exposure that I'd had, because, actually, I'd had more exposure to real mental illness and emotional distress in A&E than in the general practice placements that I had. If anything, I'd describe the six months psychiatry placement that I had as a manifestation of how mental health services should not be delivered. And I'm sure that was coloured by the placement that I had, but I spent my first year on general practice unlearning what I'd learned. And that is an incredibly difficult task. And I think if we go right back to that first year medical student, and I'm sure this is right across the training disciplines, when I'm learning to take a medical history, the expected convention is not conducive to emotional enquiry in any shape or form.* (GP02)

Unlearning fragmented models of health from knowledge and experience inappropriate to dealing with distress in primary care is described above. A second area of professional development described was ethnic minority health.

### 7.3.2 Ethnic minority health

GPs described a need for professional development in understanding marginalised groups and why their health outcomes are worse, and how they can be improved.

> *So, I would say this, so in ST3 I thought very strongly that I wanted to give the ST3 group an opportunity to think about why certain groups of people tended to be marginalised, okay? So, we had a couple of workshops around that which I commissioned from an organisation that I'd been to their workshops, I was impressed. So, I would say the key thing is understanding that certain groups of people in our society are marginalised and being aware of that. And being aware of one's own assumptions. I think that's the training I would suggest.* (GP03)

GPs felt there was a need to increase awareness of emotional distress in SAs, including the reduced presentation to general practice and use of services. By increasing awareness, it was felt that this could help GPs pick up on cues and manage SAs appropriately.

> *But I think the clinician themselves being aware that there are higher rates of emotional distress in this group of patients and there’s less use of mental health resources from this cohort of patients, will help the clinician to be aware that maybe we need to probe a bit more into this patient’s presentations.* (GP18)

Minority health was felt to be an area requiring professional development, in particular from a health inequalities perspective incorporating the social determinants of health. This was suggested to be a speciality within itself, needing to be incorporated throughout training from medical school to speciality exams.

> *I think there needs to be a speciality of ethnic minority health, and it’s something I’ve been harping on about. And into the medical undergraduate programme, I’ve sneaked it in. I’ve sneaked it into a population health in year five, a module called ethnic minority health. And I think we need to educate at all levels. I think the Royal College of GPs, as a trainer, doesn’t give an adequate nod to the issues of ethnic minorities. They have an ethics section for the capability, which looks at respect for people from different backgrounds or accommodating for the languages, but it doesn’t really tackle the social determines health, which is some of the health inequalities that institutional racism creates. So, I think there needs to be a massive overhaul.* (GP10)

GPs described the need for training cultural competency, and cultural humility, focusing on one’s own humility towards other cultures and an inquisitive nature to find out more about patient cultures and how they impact health, needing to be incorporated from the beginning of the medical curriculum.

> *And I think to be honest in terms of culture I think we probably do need more training around it in terms of healthcare professionals. I don’t feel I know anywhere enough about other cultures. And what I have learnt has been through my own reading, and through speaking to individuals, and through asking questions, and being inquisitive. And I do think that we need perhaps to think a bit more about how to approach*

> *different cultural backgrounds when we're trying to talk about management of long-term and acute conditions. And I think I know a little bit about how to deal in terms of death with South Asian gentlemen and women, but that's because I've had to learn as I've gone along. And I think that would be really helpful perhaps to have a bit more of that in my training just so that you can be a bit more culturally sensitive and more culturally aware... I remember in my first year of medical school having I think one lecture on race, and racial discrimination, and things like that. And you were given very broad, sweeping statements about different religions, different backgrounds to try and illustrate some differences. But I think it needs to run throughout. We live in a multicultural society now and we have patients that come from all over the world that come and live in the UK.* (GP09)

GPs described how they felt medical education in its current format does not adequately deal with health of people from ethnic minorities, with a focus on white British people's health.

> *And sometimes I feel like we don't have the resources to adequately treat them [people from ethnic minorities], things like when you look at a dermatology textbook and the vast majority of the images on there are of a white skin. Well as soon as you then see a patient that has non-white skin, measles looks different in African-American skin and in Asian skin, it just does and if you've not seen that before how are you meant to treat that? So I think there's this almost inherent bias in teaching that is towards white males, most of the research in the UK has been done on white men historically. And I know it's getting more diverse, but I think we've got a long way to go in terms of trying to be able to teach more culturally sensitively I guess. And I think it should more all through medical school and throughout training, and beyond if I'm honest.* (GP09)

An avenue of GPs developing more effective community-based approaches to healthcare was suggested to include within GP training time spent in faith and community centres delivering health messages, building upon the significant amount of work that was done and lessons learnt during the covid pandemic.

> *For instance, we talked about the importance of mosques. And actually, religious institutions more generally, churches and synagogues etc. Gurdwaras. At the moment it's not really a requirement for GP trainees to spend any time, never mind trying to deliver care in those places. But how exciting would it be if it was a requirement for trainees to spend some time in such places trying to deliver that kind of care. The opportunity for people to ask questions about diabetes, about healthy living, lifestyle. At the moment the obvious one is, of course, vaccinations, and we've seen pop-up clinics in mosques and churches. Well, how about formalising them? That's just been an informal thing at the moment. But maybe we can learn from that, start to think about the fact that healthcare can be delivered in all sense of settings and it doesn't have to be within the GP surgery.* (GP05)

A concern from GPs was a lack of investment in ethnic minority health, which would not change until there were concerted efforts to engage with healthcare leadership and those in a position of deciding funding.

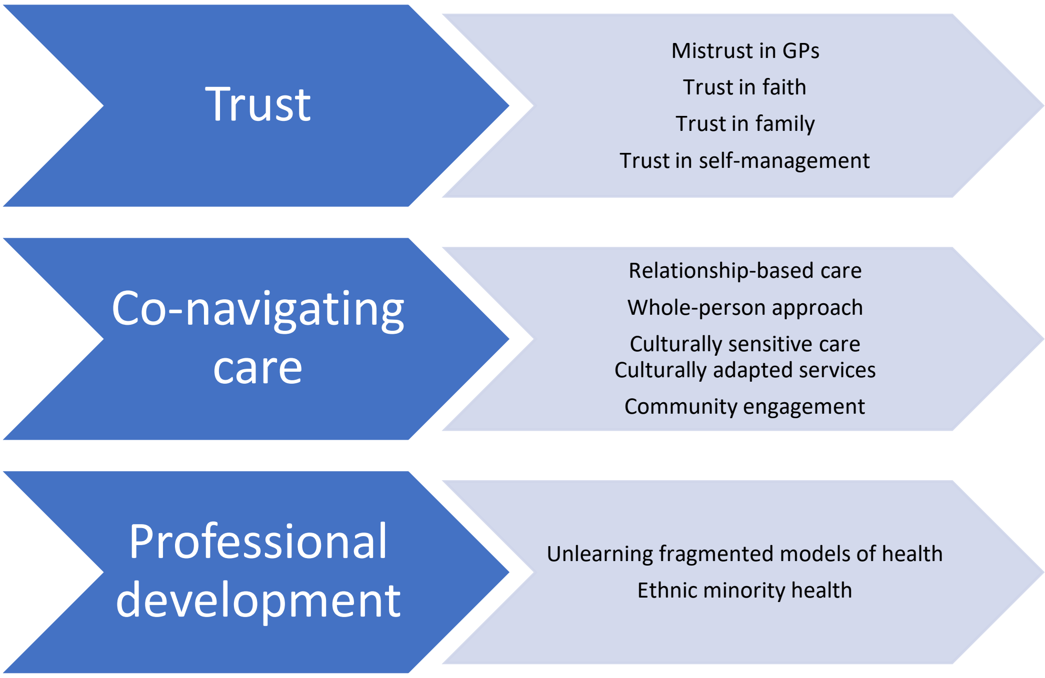
> *If money could be invested into ethnic minority health, which is an area that I'm passionate about… There's not enough funding that's being put into ethnic minority health, and it's a very neglected area. And the only way you're going to get that is if you have people in positions of influence who are in those rooms where the funding discussions are made, as well as engagement from community leaders. So, we always say that is the bottom up, top down approach to meet halfway.* (GP10)

Professional development was described in two main areas, unlearning fragmented models of health and ethnic minority health. The summary of overall themes is below.

## 7.4 Overall themes

The themes from this chapter are summarised below in Figure 9.

Figure 9 Summary of overall themes:



## 7.5 Patient advisory group feedback

As with the themes from chapter 6, raw data and provisional themes were discussed with the PAG. The group validated the themes, describing themselves experiencing similar situations. The themes were evolved and developed based on PAG feedback. An example of this is how the theme of co-navigating care was initially described as navigating health beliefs. However the PAG felt that this theme indicated that SAs health beliefs were barriers or hazards that had to be overcome during a consultation, as a driver has to navigate around any hazards in the road. This was felt to be inappropriate as health beliefs rather than being a hazard, were felt as part of any person's identity and a term to indicate the working together of a patient and their GP given the health beliefs of both was felt to be more appropriate. Hence the term co-navigating care was used. The group also suggested the sub-themes of trust in faith, trust in family and a mistrust of GPs.

The PAG also felt that family influence is the most important element with regards to managing distress, and that SAs would base further help-seeking behaviour dependent on what family would advise. The PAG described a mistrust of GPs and mainstream healthcare in detail, describing negative experiences they themselves encountered with healthcare services. They described conspiracy theories commonly discussed amongst the community and suggested increased misinformation during the covid pandemic may have exacerbated trust issues. They described an expectation of using traditional health practitioners as well as spiritual practitioners when seeking help.

The group suggested a holistic approach to healthcare being integration of medical and spiritual services, such as a GP being able to refer to a faith leader or spiritual therapy service if a SA wanted spiritual help for their emotional distress. They also discussed the challenges faced by faith leaders and their workloads and the expectation of the community for them to fulfil multiple duties, with a lack of awareness of their role and remit. The group discussed how services incorporating religion are needed, such as adapting mindfulness to Islamic practices, yet such services would need regulation. They described how sometimes it was felt within the community that if someone was suffering from distress, people in the community would advise that they need to pray more. The PAG also felt training around different cultures and their impact on health should be part of the undergraduate medical curriculum. They also felt that cultural capital was important, specifically the need to normalise contact with GPs via culturally related events and community events in which GPs reach out to communities in their communities.

They felt concordance in particular with faith and its role and relationship with healthcare. They described a concern of the social determinants of distress being perceived as overly materialistic, and felt faith and culture play an important role.

## 7.6 Reflexivity

From a reflexivity perspective, I was acutely aware of my own beliefs. In particular, based on my understanding of poorer outcomes for SAs, I felt that a different approach to healthcare, specifically with regards to managing emotional distress, was needed. However, I was not clear as to what approach this was. When talking to participants, I ensured to ask questions in a non-leading way, to allow for participant opinions to come out rather than blurring them with my perspective, such as regarding the role of family in managing distress.

During the time of undertaking the research, two clinical incidents happened which made me reflect upon the research and feel that it was very valuable and needed. During a clinical day whilst I was the on-call GP, a South Asian male with a LTC presented as an emergency due to being suicidal. When he saw me, he described how he felt that God had put me there for a reason, as he felt a GP without an understanding of his background, faith and culture would not be able to help him as they would not have understood him and he may have otherwise committed suicide. This made me reflect, the need is not for SAs to be seen by SA GPs, but how can people from different communities and backgrounds feel that the GP seeing them will be willing to listen to them and try to understand them based upon their health understanding? This impacted by thinking and questioning of interviewees as well as the development of themes when trying to understand what SA participants wanted in their GP, which was not necessarily for their GP to be SA.

A second encounter was within the SA community. A SA male who I knew from the community opened up to me about distress he faced after divorce, in particular as he was denied access to his child. He described at this point he was at a point of almost considering suicide, and saw his GP to request a sick note as he was unable to work. He described how the GP prescribed an antidepressant over the phone but he never took it due to differing health beliefs. When he spoke to his GP for a review, the GP gave a prescription of an increased dose of the antidepressant (that he never took), which he did not take. It again made me feel in clinical practice that part of patient-centred care is to understand health beliefs. Again, I made sure not to blur interviews with my perspective, but find out from participants what they understood of the problems and solutions.

When interviewing and analysing data I ensured to be aware of my background as a GP and as a SA and to let the data speak as opposed to speak on behalf of the data. The reflexivity diary that I kept ensured I was aware of my own emotions and thoughts during interviewing and data analysis and was able to understand how my emotions may influence the research process, and account for it. For example, during one interview a SA participant stated that

GPs have no training in dealing with mental health. My immediate reaction was to say that actually GPs have a significant amount of training with regards to mental health and it is one of our main presentations within primary care. However, I had to resist this feeling and did not state my immediate thoughts as a GP in defence of GPs, as I realised that my role as a researcher was not to 'correct' participants, but to explore their understandings. This resonated throughout a number of SA interviews where the medical community was criticised and I felt an unease in not defending the medical community or providing an alternative paradigm, however I ensured to resist these feeling and not do this. I also reflected on data that I was not comfortable with (specifically criticisms of the medical community) to be fair to the data and not let my personal feelings blur it.

Understanding myself as part of the research process was important. At times, when listening to SAs describe the stresses of being the sole breadwinner in multi-generational households and how illness and having a LTC impacted them, it made myself feel anxious realising I was in the same position except that my health was not impacting work. At other times, I realised I had left my culture behind. I asked open questions about black magic after suggestions from the PAG as they expected this to be important. This was not something I had considered, and I felt embarrassed to an extent feeling that I had forgotten about very common aspects of SA culture due to looking at the research more from a researcher lens. I critically reflected upon my own perception of faith, which is a guiding part of my life, and I ensured not to influence participants when exploring faith and health by asking open questions and allowing them to speak as much or as little as they wanted on the topic.

During some GP interviews there were a number of interruptions, such as an unexpected urgent ambulance phone call that the GP had to take. In these instances, the GP muted their microphone and recording was stopped and then the interview continued once the emergency was dealt with. This at times impacted rapport and the flow of the interviews.
I also found that sometimes the SA GPs would speak not only as a member of the GP community, but they also spoke as members of the SA community, intertwining SA cultural beliefs, and experiences of themselves and their families and friends. For example, a number of SA GPs spoke about discrimination experienced within the interviews.

During data collection, I presented initial findings in conferences and received feedback and suggestions for data analysis as well as further areas to improve. These were very helpful from a research perspective. From a personal perspective, I found the experiences extremely validating as after my presentations there would be multiple questions and discussion. I also won an award for a presentation as the best three-minute thesis in Keele university. These experiences solidified my feelings that the research is important work, and not just something I feel important.

## 7.7 Chapter summary

This chapter described consulting with distress from the perspective of SA men with LTCs and GPs, specifically around a mistrust of GPs, trust in faith, family and self-management. Co-navigating care included relationship-based care, a whole-person approach, culturally sensitive care, culturally adapted services and community engagement. Professional development included unlearning fragmented models of health and ethnic minority health. The influence of the PAG has been described as well as reflexivity. The following chapter discusses the findings in light of the current literature as well as its clinical and research implications.

# Chapter 8 Discussion

## 8.1 Introduction

Chapter 7 described the findings from the qualitative study with regards to help-seeking behaviour for men of SA origin with LTCs and GP perspectives. This is the final chapter which begins with a summary of the findings of the systematic review and qualitative study. This is followed by a comparison of my findings with the existing literature, a summary of PPIE, the contribution to knowledge, strengths and limitations of the study, reflexivity, implications for research, practice, education and training, future research direction and finally the chapter summary.

## 8.2 Summary of findings discussed with existing literature

The overall aim of the research were two-fold:

- How do males of SA origin with LTCs understand, experience and seek help for emotional distress?
- What are the perspectives and experiences of General Practitioners (GPs) working in practices with a high density of SAs?

This study included the first systematic review on emotional distress in SAs with LTCs and the qualitative work was the first to explore understanding, experiences and help-seeking behaviour of SA males with LTCs experiencing emotional distress, as well as GP experiences and perspectives. The research has made several contributions to existing knowledge around emotional distress in SAs with LTCs and more broadly emotional distress, working with underserved communities, and working with PAGs from underserved communities. It will be further described below.

The systematic review found that people of SAs origin with LTCs describe emotional distress using non-medical terminology such as tension, even when describing suicidality. A complex relationship between emotional and physical problems was described. Experiences included multiple forms of inequality, distress at diagnosis of the LTC, cultural factors and gender differences. The review found that clinicians can be viewed as an irrelevant means of support, and even a negative influence, when distressed. Conversely, help-seeking was found in self-management, support from family and friends, and faith. It built upon research around emotional distress and mental health problems in people with LTCs, as well as emotional distress and mental health problems in people of SA origin. The findings of the systematic review informed the qualitative study.

The qualitative study built upon the systematic review findings, giving a deeper understanding of contextualising distress including distress around diagnosis of the LTC, adjusting to life with a LTC, intersections of social factors contributing to distress, and perceptions of prejudice. Conceptualising distress highlighted distress as a separate entity to depression, negotiating multiple identities and alternative paradigms of health. Consulting with distress included mistrust in GPs, trust in faith, family and self-management. Co-navigating care was an approach to consulting, developing relationship-based care, a whole-person approach, culturally sensitive care, culturally adapted services and community engagement. Areas of upskilling included unlearning fragmented models of health and ethnic minority health.

New contributions to knowledge in light of existing literature included the application of the social determinants of distress as a novice area within the realms of research, and the application of an intersectionality lens to develop equity both at the macro and micro level of healthcare. A consideration of de-medicalising distress as well as understanding the negotiation of multiple identities including those of clinicians was considered. A new conceptualisation of distress is hoped to provide direction for the recognition and management of emotional distress which, when managed appropriately and differently to depression, has the potential lead to improved outcomes for distress as well as preventing mental health problems such as depression. Co-navigating care, building cultural health capital and cultural safety are all applicable to providing ways of treatment delivery in diverse populations to potentially improve outcomes. A new model has been proposed below in Figure 10 3Cs for co-navigating emotional distress in SA men with LTCs; the figure amalgamates analyses from the systematic review and qualitative study in light of the existing literature.

Figure 10 3Cs for co-navigating emotional distress in SA men with LTCs.

The key findings are discussed in light of existing literature within three main areas, contextualising distress, conceptualising distress and consulting with distress.

### 8.2.2 Contextualising distress

A discussion of the findings around contextualising distress in light of existing literature follows, specifically around the social determinants of distress and an intersectionality lens.

#### *8.2.2.1 Social determinants of distress*

It is widely understood that health is not based purely on an individual’s genes, biology and lifestyle choices, but heavily influenced by the social determinants of health, the non-medical factors that influence health, including the circumstances a person is born, brought up, lives, works, and ages in, as well as economic, political, developmental and social factors (World Health Organisation, No date.b). My research found that both SAs and GPs described how the social determinants impacted their lives, including ethnicity, having a LTC, being SA, financial pressures and prejudice faced. The social determinants of health can be more important than healthcare systems themselves and lifestyle choices, accounting for 30-55% of health outcomes (Booske et al. 2010). The social determinants of mental health have been increasingly recognised since the World Health Organisation 2014 themed paper which focused on the social determinants specific to mental health (Allen et al. 2014). The paper described how mental health and many common mental health disorders are significantly shaped by people’s social, economic and physical environments, and mental health inequality can be reduced by reducing these social inequalities via universal yet proportionate action to level the social gradient (Allen et al. 2014). It was based on a life-course approach. A clear link was described between common mental disorders and poverty. This was echoed within my research whereby both GPs and SAs emphasised how financial and work pressures caused distress. The WHO paper also emphasised the importance of primary care in supporting mental health care (Ibid). A 2018 review of the research around the social determinants of mental health and future direction described the reciprocal impact of mental health and the social determinants, whereby someone with mental health problems impacts the social determinants (Alegría et al. 2018). A rapid review of 37 systematic reviews found the social determinants of mental health to be conflict, violence and maltreatment, life events and experiences, racism and discrimination, culture and migration, social interaction and support, structural policies and inequality, financial factors, employment factors, housing and living conditions, and demographic factors (Huggard et al. 2023). All of these are potentially relevant to SAs and other communities experiencing the social determinant of mental health.

The social determinants of distress have been much less considered than the social determinants of mental health, with the very little research focusing on the social determinants of distress in minority communities (Nguyen, Goel 2015, Markwick et al. 2015). GPs and SAs clearly described how the social determinants impact specifically on distress. A qualitative systematic review exploring barriers and facilitators to GP-patient communication for emotional concerns of 342 GPs and 720 patients found a tension between understanding emotional concerns as a medical condition or arising from social factors, with patients hesitant to seek help from GPs due to the perceived lack of support they could offer (Parker et al. 2020). In my study SAs described not seeking help from GPs due to their perceived inability to help, and one GP described trying to tackle the social determinants in a small way by developing digital literacy of patients by teaching them how to order prescriptions and access results online. Research has shown a link between the social determinants and distress, in particular poverty and neighbourhood safety (Myer et al. 2008, Nguyen, Goel 2015, Markwick et al. 2015). A 2021 Lancet commission on global mental health and sustainable development described a strong association between social factors and poor mental health (Patel et al. 2018). People from ethnic minority communities are more likely to suffer from socio-economic deprivation, related to a wider social context influenced by racism, including housing, employment and the criminal justice system (Robertson et al., 2021b). Prejudice was described in this study by SAs and GPs, from prejudice faced on an individual level to systemic prejudice. Treatment burden is increased in populations with lower levels of health literacy (Hounkpatin et al. 2022). Notably, participants in my study described a significant gap between health beliefs of SA men with LTCs and health beliefs of GPs. People from culturally and linguistically diverse patient populations in New Zealand have found to have additional difficulties yet a lack of healthcare information (McKinlay et al. 2015). Similarly, SAs and GPs described a lack of linguistically appropriate healthcare information. The social determinants of distress can be considered as equally as important and potentially more relevant to the social determinants of mental health given the resistance to medicalisation of distress as described in the systematic review as well as qualitative study.

The social determinants of diabetes have been considered, such as gender, ethnicity and poverty which all apply to this population (Prinjha et al. 2022); however, consideration of the social determinants of distress for people with LTCs has been less considered within the literature. This is related to ‘society as a patient’ whereby globalisation has led to increased individualism, materialism and social fragmentation whereby dominant cultures have subordinated ethnically diverse cultures and languages at an unprecedented speed globally (Gopalkrishnan 2018, Marsella 2011). SAs described a key challenge being changing relationships of families whereby a common source of distress was their children not maintaining their traditions but rather being more individualistic. Key policy to address inequality within the UK, the Levelling Up Paper (Her Majesty’s Government 2022) which was produced to tackle inequality, has been criticised specifically for not supporting groups with poorer health such as people from ethnic minorities and those with socioeconomic deprivation (Iacobucci 2022). Research has shown that it is difficult for patients with multimorbidity to prioritise health conditions (Skou et al. 2022, Morris et al. 2011). Both GPs and SAs described an inability of SAs to prioritise emotional wellbeing due to other priorities including their physical health as well as social factors. My research adds further insight to the challenge of ethnicity and socioeconomic deprivation. By providing a greater focus on the social determinants of distress, a greater impact to improve emotional wellbeing may be possible.

Prejudice and perceived racism were described as contributors to distress by both SAs and GPs, and related to a mistrust of SAs seeking help for distress. This can be understood within the context of societies whereby mental health has been historically used as a tool for oppression. An example of this in 18th Century USA is that of draeptomania, a diagnosis of psychiatric illness whereby a slave desired to run away (Bhugra et al., 2021). Some SA and GP participants in this study mentioned a mistrust of Eurocentric paradigms of modern psychiatry with its the roots related to the slave trade and de-humanising non-white people. Similary, psychiatrists described ‘delusional-anti-whiteness’ as a symptom of listening to Malcolm X (Metzl 2010). In the modern day, there is growing evidence that racism leads to mental illness and a barrier to seeking help (The Synergi Collaboration Centre 2018, Memon et al. 2016, Bignall et al., 2022). Discrimination has been linked with mental health problems, in particularly with more recent migrants (Hatch et al., 2016). SAs described experiencing racism and prejudice when seeking healthcare support, which made them less likely to seek help in the future. There is a growing body of research around race and mental health. The

Race Equality Foundation report about racial disparities in mental health highlighted several key findings, highlighted in five main areas (Bignall et al., 2022). The literature review highlights increased prevalence of mental illness in ethnic communities, in particular Pakistani men, reduced access to mental health services, inequalities and discrimination during assessment, treatment inequalities such as being more likely to be refused talking therapies and being more likely to be medicated, and discrimination during the recovery process (Ibid). The report suggests matching cultural, religious, linguistic and/or racial identity of clinicians and patients can improve treatment outcomes. Both SAs and GPs described the need for such services. It has been argued that the primary cause of health inequality is structural inequality, including systemic racism (Berger, Miller 2021). The NHS Race & Health Observatory rapid review of ethnic inequalities in healthcare similarly found barriers to seeking help for mental health problems related to mistrust of clinicians, fear of discrimination and lack of language-accessible services (Kapadia et al., 2022). Notably, a number of the GPs interviewed described racism they experienced within the medical profession. This resonates with a British Medical Association (BMA) survey of 2030 doctors and medical students, whereby 76% described experiences of racism at work within the last two years and 60% stated that racism had impacted their wellbeing (British Medical Association 2022). In terms of physical health, Nazroo and colleagues suggested the difference in mortality after infection of covid being primarily due to racism, which influenced social factors such as where people lived, types of jobs, household make-up and transport used (Nazroo, Bécares 2021). Specifically with primary care, people from ethnic minorities report poorer experiences of almost every aspect of general practice than White British counterparts; for example, people from ethnic minorities diagnosed with cancer were found to have seen their GP 7 times more than White British counterparts prior to referral to hospital (Chouhan, Nazroo 2020). The authors described health inequalities in a context of political rhetoric around cultural assimilation and anti-immigration (Ibid), which can be considered within the realm of the political determinants of health influencing the social determinants. Addressing racism and discrimination was one of recommendations of the Health Foundation's report explaining the wider determinants of health in the UK (L'Hôte et al., 2022), was described my participants both SAs and GPs, and needs to be prioritised within mental health research.

Prejudice and perceived racism impact how a patient's previous experiences determine their demand for services and help-seeking behaviour – this is an example of recursivity (Rogers et al., 1999). This is particularly important in SAs with LTCs who have multiple contacts with healthcare due to their LTCs. Perception of Institutional racism within healthcare services makes minority groups feel less welcome, may cause delay in help-seeking behaviour and make patients less concordant with healthcare and is related to the culture of institutions (Ibid). Institutional racism more broadly can affect all aspects of an individual's life, including housing, employment, poverty and the social determinants of distress (Ibid). As well as prejudice, mainstream bias whereby clinicians and healthcare systems are embedded within cultural constrictions that are not generalisable can lead to poor quality and inappropriate interventions for mental health problems as well as reduced uptake (Gopalkrishnan 2018). GPs described a lack of diversity in senior leadership of healthcare led to a lack of funding for appropriate services for the diverse populations served. A large meta-ethnography of ethnic inequalities in mental healthcare in the UK similarly referred to structural barriers due to monocultural and reductionist frameworks of mental healthcare, as well as experiences of racism (Bansal, Karlsen et al. 2022).

A question arises if the social determinants of distress should be treated within primary care, or if it is purely a public health issue? Whilst public health provides a great focus for treating the social determinants, many factors to address the social determinants, within primary care, as Sir Michael Marmot stated

> *'Health inequalities and the social determinants of health are not a footnote to the determinants of health. They are the main issue.'* (Marmot 2018, p1)

Marmot described two steps primary care should take to reducing the social determinants, developing a practice culture that values health equity, and developing a team-based approach to addressing the social determinants of health. These included cultural competence and community-based resources and reducing bias (Marmot 2018). These all equally apply to the social determinants of distress and primary care's potential role in reducing the social determinants of distress. GPs spoke about the need for cultural competence and SAs and GPs felt a greater need for community-based resources in my research. People diagnosed with anxiety or depression in more deprived areas have fewer mental health consultations yet more prescription medication and higher levels of unplanned secondary care use (Hodgson et al., 2020), and it has been suggested by The Health Foundation, a leading independent charity for health care for people in the UK, that resources should target such populations (Ibid). SAs with LTCs and GPs described deprivation and similarly may be suffering with little support from primary care until they present in crisis. As GP Andrew Moscrop and others ask, '*if social determinants of health are so important, shouldn't we ask patients about them?*' (Moscrop et al., 2020, p1)

#### *8.2.2.2 An intersectionality lens*

Intersectionality was a term initially described by female black academic Kimberlé Crenshaw to describe how the multiple social forces, social identities and ideological instruments influence power and intersect to create disadvantage (Crenshaw 2017). The approach can be used not only to understand inequalities, but to have a *transformative potential* to reduce inequalities (Overstreet et al. 2020). Whilst I did not consider intersectionality at the start of the study, during interviews participants described multiple layers of disadvantage. The systematic review and qualitative study illustrate how multiple social determinants of distress as well as other factors could build up to cause a context of distress. Ethnic minorities with LTCs can be considered from an intersectionality lens as a group with a greater need for services for emotional distress. Economic deprivation, being ethnic minority, having a LTC, prejudice faced, and other social determinants of distress may lead to intersectionality and disparity in distress suffered. Without an intersectionality perspective, reducing disadvantage to singular problems such as race, ignores the complexity of how biological, socioeconomic and racial factors influence health inequality (Metzl, Roberts 2014). An intersectionality lens has the potential to improve patient-clinician interactions by better understanding those who are disadvantaged in multiple ways by reflecting on the institutional and structural forces that lead to health disparities (Wilson et al., 2019). This may move the perspective of some GPs that SA men with LTCs are 'acopic' to understanding the reasons behind these and reflecting how they can be supported. An intersectionality perspective incorporates the intersection between individuals and institutions as well as the micro and macro facets of the politics of health (Gkiouleka et al., 2018, Evans 2019). It is deeper than socioeconomic factors taking into consideration how institutions incorporate social privilege and disadvantage (Ibid). For example, online consultations during the covid pandemic may have created deeper inequalities with populations from ethnic minorities where language barriers and other factors may have been challenging for patients to access general practice (Turner et al., 2022). The Health Foundation report *Tackling the inverse care law* describes how policies in general practice potentially exacerbate health inequality and how funding allocations and oversight need change to address inequalities (Fisher et al., 2022).

Structural approaches to intersectionality to reduce health inequality ask how systems of oppression vary and relate to each other on a macro level as well as how they shape the health of populations based on constellations of individual factors such as race, gender and socioeconomic status (Homan et al., 2021). SAs and GPs described layers of structural racism within healthcare. The 2021 *Ethnic Health Inequalities* paper by the NHS Race & Health Observatory and the King's Fund described the need for an intersectionality perspective to address the broader and overlapping causes and dimensions of health inequality (Robertson et al., 2021b). A number of participants in the study described a preference of SA men to see SA GPs, which is consistent with previous research (Memon et al., 2016, Kapadia et al., 2017) and can potentially improve care (Ali et al., 2017, Aggarwal, Pieh et al., 2016). It is not feasible that patients of different disadvantaged backgrounds will always be able to see a GP with the same or similar characteristics, however an intersectionality lens where the Clinician must reflect upon their position of power and privilege as well as their biases and how that will impact the consultation (Wilson et al., 2019). The clinician can then mitigate this differential position of power to support patients. Included within intersectionality is to consider historical oppression of groups. This is extremely poignant considering participants in the interviews described a mistrust of GPs, healthcare and institutions in general, due to historic crimes and colonial oppression. Intersectionality deals primarily with structural factors and has been argued to be a priority for academic medicine (Eckstrand et al., 2016), however intersectionality lens has tended to be adopted to specific issues, for example men's health (Griffith 2016). An intersectionality lens has not been explored within primary care from a broader perspective of addressing health inequality.

### 8.2.3 Conceptualising distress

Distress in this study can be conceptualised as universally experienced negative emotional state related to one's internal response to their life stressors, related to their coping strategies and support mechanisms, and can develop into a mental health problem if not managed appropriately or the life stressor does not resolve. A discussion of the findings around conceptualising distress in light of existing literature follows, specifically around de-medicalising distress and negotiating multiple identities.

#### *8.2.3.1 De-medicalising distress*

The perspectives of SAs and GPs in this study found distress to be considered as a distinct entity from depression and other mental health diagnoses. They also described a continuum whereby if distress were prolonged and severe it could cause depression. This is similar to other research; Distress has been defined as the manifestation of symptoms such as feeling down, worry, irritability and poor concentration under difficult life circumstances  (Terluin et al., 2006). Depression has been considered more as a dysfunction of emotional regulation, with additional symptoms such as anhedonia and thoughts of self-harm symptoms (Ibid). Research has shown that people who present to primary care can be differentiated to have distress or depression, based on symptomatology (Geraghty et al., 2015), and is consistent with this study. Men prefer to use non clinical terminology when engaging with mental health services, similar to the views of SA men in this study (Stein 2018). A previous study found that some GPs felt distress and depression were on a continuum, and distinction was not possible, whereas other GPs struggled to separately define the entities and others linked distress with the absence of biological symptoms (Geraghty et al., 2019). Differentiating distress from depression can aid appropriate diagnosis and hence appropriate management, as well as reducing inappropriate overdiagnosis and management of depression (Geraghty et al., 2015). SAs and GPs in this study felt that inappropriate overdiagnosis and management of depression occurred which made them less likely to seek help from the GP. Culture impacts health, for example in one study Caucasian people perceived white medication as sedative and African Americans perceived it as a stimulant, and vice versa for black medication (Bhugra, Ventriglio 2015). The influence of culture on the experience and expression of distress specifically has been known of and written about for decades, such as in the work of Laurence Kirmayer which challenges ethnocentric interpretations of mental health (Kirmayer 1989). In the seminal realist analysis by Pilgrim and Bentall on the medicalisation of misery, cultural tensions were noted with the term depression for example from Asian populations with sociologists describing no inherent conceptual superiority of the term depression to descriptions of unhappiness from other cultures (Pilgrim, Bentall 1999). This relates to SAs conceptualisations of distress and provides a platform for distress to hold the same weight within healthcare as depression and clinical diagnoses.

In my study SAs and GPs found a clear and strong distinction between distress and depression. A reason for this may be related to SA culture and reduced use of depression as a western-centric concept. GPs also described a similar distinction, which may be related to a large proportion of GPs being of SA origin, potentially sharing in some cultural viewpoints. SAs and GPs both described a concern of overdiagnosis of mental illness when distress was present. The impact of culture on the recognition, labelling and interpretation of distress has been appreciated for decades (Kirmayer 1989). The conceptualisation of depression itself has been challenged to be a potentially culture-bound syndrome of ‘western’ countries, lacking the validity of a discrete pathophysiological basis or utility as a guide to treatment (Dowrick 2013). The example of China was given whereby US-based pharmaceutical companies funded the translation of the DSM IV criteria which led to a large increase in the use of antidepressants (Ibid). In more recent years, where decolonisation frameworks have become increasingly used, the decolonisation of mental health is being considered  (Millner et al., 2021). Mental health practice are situated within systems of power and can be considered as tools of neo-colonialism, dominating over cultural values and beliefs (Ibid). Moving away from mental health diagnoses to terminology that SAs are more comfortable and familiar with is a potentially liberating whereby less medication-orientated models of health are given permission to be present not only in the minds of patients but also in the consultation setting. One may ask, is it time to decolonise distress?

#### *8.2.3.2 Negotiating multiple identities*

SA men with LTCs described negotiating multiple identities, pertaining in particular to their faith, British and SA culture, and masculinity. Faith and mental health have a rich history of interconnection. SAs turn to religion when suffering from mental health problems and religion has been found across a number of studies and patient groups to improve mental health and help in the prevention and management of depression (Papaleontiou-Louca 2021, Larson, Larson 2003, George et al., 2000, Bonelli et al., 2012). Of note, not only the individual belief has been found to be protective, such as a belief in a loving and forgiving God, but also the congregational factor and communities of worship developed within a number of religions (and potentially all of the main SA religions). There is a rich history of religious healing and mental health across diverse religions throughout different cultures (Dein 2020).

GPs in my study appreciated that faith is important to health, but said that they did not ask patients about their faith and its relationship to their health. SAs did not view their GPs as a point of support due to a lack of understanding of their faith and culture. The concept of black magic was an obvious example of this, whereby no studies in the systematic review picked up on this area, but when SAs were asked directly, some discussed this in details including belief they had black magic done on them, and seeking treatment for this in light of their distress. Culture can be considered a broader concept that encompasses race, religion, language and other shared factors. Cultural identity varies between groups more than between individuals, and can include beliefs, practices and values. Culture influences what is considered as a problem, how it is understood and what treatments are acceptable (Hernandez et al., 2009). A study in Southeast Asia in disaster zones described the influence of culture on disaster mental health, such as lacking of emotional expression, shame, power distance between the patient and therapist, collectivism and spirituality and religion (Hechanova, Waelde 2017). It is also understood that culture is a fluid concept that changes from place to place and generation to generation. In chapter 6 I report how first and second generation SAs with LTC lived and experienced culture in very different ways, with first-generation SAs perspectives on distress being more related to the culture of their country of origin, and second-generation SAs perspectives being more related to British culture.

Research around culture and distress has traditionally focused around different cultural presentations of distress, such as the expression of distress based on personal and cultural meaning and expression of that meaning (Nichter 1981). The Diagnostic and Statistical Manual of Mental Disorders (5th edition, 2013) describes cultural concepts of distress. However, distress can be considered not only individual suffering but social complaints and anxieties (Kaiser, Weaver 2019). In my study, SAs described a collective distress at times, related to collective experiences faced by SAs. It is important to understand the different *idioms of distress* which are socially and culturally mediated to recognise and support people with distress.

Whilst there is research around identity and health of patients, professional identity of clinicians and its impact on the clinician doctor relationship is less known with regards to its impact on managing distress. GPs in this study described at times a tension between their own culture and beliefs and their professional roles. Clinicians can unknowingly stereotype people and show hostility to those they perceive from being in an out-group  (Bhugra et al., 2021). A cultural gap and potential misunderstanding is not only present when people from diverse cultures are seen by clinicians different to them, but also when being seen by a clinician from the same culture and background, whereby the practitioner brings their own professional culture which can create a barrier to care (Satcher 2001, Gopalkrishnan 2018). Internationally, in higher income countries such as the United States, Canada and Australia, people from diverse ethnic population tend to present later than the general population for mental health problems and in crisis (Gopalkrishnan 2018). Reflecting more on professional identity, and incorporating faith and culture may provide a tool for inclusive care for people of different cultures.

### 8.2.4 Consulting with distress

A discussion of the findings around consulting with distress in light of existing literature follows, specifically around co-navigating care, cultural health capital and cultural safety.

#### *8.2.4.1 Co-navigating care*

Co-navigating care, a term developed in light of a PPIE meeting as described in chapter 7, refers to the reality whereby GPs and patients both have a set of health beliefs which need to mutually respected and addressed to form shared management plans. In this way, GPs can appreciate that they are part of the patient journey, and walk with the patient on that journey rather than directing the journey. This is a new term which can be considered as part of person-centred care, whereby the needs of an individual and their preferences guide the care that they receive (Health Foundation 2016). Person-centred care focuses on important guiding principles such as care being personalised, coordinated, enabling and that the person is treated with dignity compassion and respect (Ibid). In my study, participants engaged in self-management of distress which was consistent with their health beliefs, and was informed by their faith and culture. Without understanding, appreciating and providing a reflective lens upon clinicians own health beliefs as well as the cultural paradigms of healthcare systems, one may argue that person-centred care cannot be delivered. SAs described not seeing their GPs because they wouldn't understand emotional distress within their cultural context, and GPs felt that this group of patients had less trust than then general population. Focus groups exploring GPs perspectives of the management of what they described as emotional concerns found that diagnoses were collaboratively negotiated based on GP and patient health belief models (Parker et al., 2020). This can be understood in the light of my research which highlights not just management but diagnosis as a shared journey, i.e. co-navigated. The focus groups also described the importance of continuity (Ibid), which is an essential ingredient to co-navigating care. Research has shown that the culture and expectations of healthcare providers impacts consultants; they may see different perspectives as a hindrance to the care they wish to deliver or conversely as integral aspects to delivering good quality care. Otherwise, ethnocentric healthcare will be delivered, whereby clinicians and healthcare systems overvalue their own dominating healthcare culture leading to bias against those perceived to be from different cultures (Westermeyer et al., 1997). Of note, some researchers have written about how fatalism is linked with SA culture and beliefs (Osokpo, 2021). In my research, the belief in a higher being was conversely felt by SAs to push them to work on improving their health, whilst not worrying about the future which was not in their hands. They did seek help when distressed, but the limiting factor to engaging with healthcare services was that they trusted other avenues of support and had a mistrust of GPs.

Analysis of interview date suggested that SAs would consult clinicians with similar health beliefs, such as a senior GP who was felt to prescribe fewer antidepressants. Diversity of perspectives of GPs in understanding emotional distress has been found, for example with some GPs describing distress and depression as a continuum, others differentiating them, and other GPs describing uncertainty and difficulty in differentiation (Geraghty et al., 2019). It is not necessarily problematic for GPs to have divergency in health beliefs, and is natural part of the diversity of any society. A cross-sectional study of 382 participants in Pakistan found 44.9% of respondents attributed mental health problems being due to black magic and a higher proportion of 47.2% believed this caused physical health problems (Fawad et al., 2019). A study in Bangladesh of 321 participants given a questionnaire found similar beliefs of Jinn (supernatural beings) and black magic as causes of mental health problems (Mullick et al., 2013). Within the UK, a study in African and African Caribbean users and carers found Jinn and magic as proposed causes of mental health problems, of which some participants felt were only curable by faith healers, and felt they would not be understood or respected by services (Rabiee, Smith 2014). This may explain why such topics were absent from the systematic review but were described upon direct questioning in interviews. Different health beliefs and beliefs systems cannot be ignored when dealing with patients for optimal care and concordance. If this is not done, concordance will be an issue (Atal et al., 2019). Incorporating a patient’s bio-psycho-social-spiritual history can be helpful in understanding the context of health and illness to which a patient lives (Bogue 2019, Ang 2017, Gopalkrishnan 2018). By co-navigating care and reflecting upon the GP and patient health beliefs, patients of different backgrounds and health beliefs may be comfortable to GPs with different health beliefs, with the key condition that the GP is open about their own health beliefs and not ethnocentric in formulating their treatment. This approach takes person-centred care to a higher level than focusing purely on patient beliefs, and relates to candidacy, which can be considered as to how people’s eligibility to healthcare is determined between themselves and health services (Woods et al., 2005). The seven areas of candidacy can be reflected upon from a perspective of co-navigating care (Dixon-Woods et al., 2006); identification of candidacy, navigation, permeability of services, appearance at health services, adjudications, offers and resistance, operating conditions and the local production of candidacy can all be influenced when care-givers and services reflect upon the health beliefs underlying the care they offer and the health beliefs of the people they are serving. In this way, SAs may feel more eligible for healthcare, and GPs and other healthcare professionals may offer healthcare provision in a more acceptable approach (Garrett et al., 2012). As described in my study, to facilitate this, it may not be enough for GPs to signpost to appropriate services, but have a basic awareness and understanding of how culture and faith are intertwined with conceptualisations and help-seeking behaviour for emotional distress.

Person-centred care recognises the importance of families in some people's lives and treating accordingly, termed as person and family-centred care (Health Foundation 2016). The systematic review and interview findings emphasise the relationship between family and distress in SAs. Family is a central concept to SA culture; a major source of distress was when there were family problems, and a major source of support was from families, including families bringing patients who were distressed to the GP as well as families involved in the management and support of SAs with LTCs who experienced distress. Family cohesion has been found to improve resilience and potentially improve mental health in immigrant communities (Alegría et al., 2017). Family relationships have been perceived at times as a barrier to seeking help from health services (Karasz et al., 2019). The largest mental health survey in the world, the Wellcome Global Monitor of over 119,000 people in 113 countries, found in 2020 that 78% of people experiencing symptoms anxiety and depression would seek support from family and friends (The Wellcome Trust 2020). By co-navigating care regarding family involvement, GPs and SAs can work to understand and appreciate patient wishes and what works for them in terms of family involvement in health.

A facilitator to co-navigating care is relationship-based care (Royal College of General Practitioners 2021). Both SAs and GP described the benefits of relational continuity. The evidence base for relationship-based care is extremely strong; mortality is reduced (Gray et al., 2018), including a study specifically within primary care (Baker et al., 2020), concordance increases (Warren et al., 2015), emergency hospital use and admissions into hospital are decreased (Barker et al., 2017). In SAs where there may be mistrust of clinicians, with possible good reasons for this, relationship-based care and relational continuity can be a tool for facilitating this trust by co-navigating care on a relational basis. Conversely, continuity of care is lower in some SA communities, i.e. Bangladeshi and Pakistani communities, than the White population in the UK (Stafford et al., 2022). Whilst there are challenges in the delivery of relationship-based care, the RCGP prioritise relationship-based care in delivering healthcare that is '*fit for the future* (Royal College of General Practitioners 2022).'

The heart of the research deals with the challenge that SA men with LTCs do not consult when distressed or trust their GP when distressed; co-navigating care provides a potential solution to this.

#### *8.2.4.2 Cultural health capital*

Within the sphere of developing trust with SAs, participants described the need for engagement with communities and services to be not only culturally sensitive but engaged with and embedded within communities. This can be considered as building cultural health capital, 'the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviours, and interactional styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal health care relationships' (Shim 2010, p1). This concept is developed from cultural capital, which is different to other sorts of capital that every individual has such as economic, social, educational and political capital (Bourdieu 1984). This can be considered a part of health capital, an emerging concept which captures social and cultural dimensions of health (Schneider-Kamp 2021). Cultural capital derived three sources of cultural capital, objective sources such as books and arts, embodied sources such as language and institutionalised sources such as qualifications (Bourdieu 1984), as well as other sources by more recent protagonists (Bhugra et al., 2021). Cultural capital impacts wellbeing, and has been shown to be statistically significant in impact life satisfaction and happiness (Kim, Kim 2009). Cultural health capital can include for example not just knowledge of language and health literacy, but appreciation of the culture and attitude of people based on their cultural backgrounds to optimise health (Shim 2010) and can be an approach to consider systematic and macro-level or upstream factors as well as individual and downstream or micro-level factors such as individual encounters with healthcare professionals. SAs and GPs described in a sense the need to build cultural health capital, speaking about care moving to community and faith centres, culturally sensitive services, working with faith leaders etc.

The 2020 Commission for equality in Mental Health paper described how mental health is created in communities, and emphasised different aspects of communities need to come together, including business, charities, faith groups and others in civil society (Commission for Equality in Mental Health 2020). A recommendation of the Ethnic Health Inequalities and the NHS paper included increased investment and community engagement with minority ethnic groups to develop and deliver culturally competent services, and build trust within communities of services, all which can be considered as part of building cultural health capital (Robertson et al., 2021b). All of these were described by participants in my study. Within this is a need to support the development of authentic ethnic minority researchers, which was described by a SA participant. Of note, the NIHR's first year of diversity data for funding programs in 2020-2021 found that people from ethnic minorities are less likely to secure funding for a research program, 16.5% in comparison with 21.2% for white applicants and are also under-represented on funding committees (National Institute for Health and Care Research 2021). It is needed to address racism in research commissioning, academia, assessment of research excellence, dissemination, involving people from ethnic minority groups in leadership positions and participants in research and greater PPIE involvement (Powell et al., 2022).

A perspective of cultural health capital on a systematic level with SAs can include culturally and linguistically appropriate services (Whitaker et al., 2022), of which there is a growing evidence base such as reducing length of hospital stays for inpatients (Schiaffino et al., 2020). SAs and GPs described the need for culturally and linguistically-appropriate services. A review of meta-analyses of culturally adapted mental health interventions found that they are more effective than usual care (Rathod et al., 2018). Of note, the review found poor quality of meta-analyses and highlighted issues such as a lack of consideration of cultural issues (Ibid). Specifically for depression, a systematic review and meta-synthesis found a culturally adapted therapies are more effective than usual care (Anik et al., 2021). Within Canada, there has been a call to action to culturally adapt and improve access to evidence-based psychological interventions, as the authors describe how CBT is underpinned by Western value systems (Naeem et al., 2020). Muslims have been found to prefer religious teachings incorporated into therapy over standard approaches, although required more support than the authors anticipated (Mir et al., 2015). SAs in my study felt there needed to be faith-appropriate services, and clinicians and faith leaders learning from each other to support the community and understand the perspective of each other. Muslims have the lowest rates of recovery from psychological services from any faith, 3% in comparison with 8%, and services have been developed specifically to support the communities with improved outcomes (Mir et al., 2019). The place of services needs to be considered, locating then within community (Marsella, 2011). An example of this is mental health service partnerships in Black faith communities, which utilised churches in a community-led intervention to reduce stigma of mental illness (Codjoe et al., 2019). Within the SA community, the ICope is an example whereby culturally sensitive services were delivered in Begnali Sylheti, as well as Mindfulness recordings which were played in community centres (Khamlichi 2017). A systematic review and meta-ethnography of the experiences of SAs accessing mental health services found three main themes, of distance from services outside of their awareness and cultural norms, dilemmas of trust and threat to their cultural identities with a lack of collaborative care and cultural sensitivity (Prajapati, Liebling 2021). The authors describe cultural safety as a model for moving forwards, which will be explored further in the next section. Culturally adapted care within mental health provision has an increasingly prominent role in reducing health inequality in people from ethnic minorities, as part of embedding equity within services (Naz et al., 2019).

Cultural health capital could be cultivated on a systemic level by reverse-commissioning, whereby people from ethnic minorities are given the power to commission services needed for them (Memon, Taylor et al. 2016). GPs described a big problem of a lack of diversity in healthcare leadership. There is a growing evidence base for social prescribing (Drinkwater et al., 2019, Buck, Ewbank 2020, Husk et al., 2020) and the need to develop high quality research around social prescribing (Husk et al., 2019, Pescheny et al., 2020) and involving communities to improve health (Buck et al., 2021). A systematic review of social prescribing for migrants in the UK found improved self-esteem, confidence, empowerment, and social connectivity (Zhang et al., 2021), all potential facilitators to improve emotional distress. The authors describe the need to deal with the wider determinants of health, and tailored services according to language, culture, gender and delivery format (Ibid). However, the studies in the review are generally low quality evidence and hence the conclusions cannot be relied upon. A systematic review of non-pharmaceutical primary care interventions for mental health in deprived populations found improvement in wellbeing and mainly positive results for anxiety and depression (Tanner et al., 2023); notably the quality of studies included were weak. A lens of cultural health capital leads to social prescribing that SAs may want and find benefit from, such as liaison with faith leaders and spiritual therapy when patients want this, which is a need by people on a global level in different communities in treatment of mental health problems (Gureje et al., 2015). This has not been explored in a UK setting or systems and structures to facilitate this. Faith Action have provided case studies of faith-based organisations being utilised in health and social care (FaithAction, Not Known). The voluntary sector was found in a mixed methods study to have a distinctive and important role to play during mental health crisis (Newbigging et al., 2020); whilst this study focused on crisis events, the role of the voluntary sector has been shown to be helpful in other mental health settings such as older people with loneliness (Dayson et al., 2021). GPs and SAs in my study described how social isolation caused loneliness, with social isolation understood to be the lack of social connections and contacts which happened particularly during the pandemic, and loneliness being the feeling of being alone, irrespective of the amount of social contact. ‘Culture as treatment’ for mental health problems has been used in Canada to support indigenous communities who were taken away from their families and sent to residential schools to ‘kill the Indian and save the man’ (Gone 2013). Whilst this is treating an extreme situation, it leads a question if culture can be used as treatment in other contexts of mental health. On an individual level cultural health capital with SAs can include co-navigating care within the consultation, including taking into account both the clinician and patient’s cultural health capital to facilitate patient-centred care (Dubbin et al., 2013). Co-navigating care incorporates what Dubbin and colleagues describe as the patient and provider habitus (Ibid), a sort of cultural partnership which can both influence the consultation and possibility of patient-centred care to take place (Gopalkrishnan 2018).

Cultural health capital should not be considered as a tool solely in managing distress in SA men with LTCs, but can be used as a perspective of managing health in people from all backgrounds by taking into account their cultural perspectives and reducing health inequality (Dubbin et al., 2013, Madden 2015). This can be used to make facilities where services are based more appropriate and acceptable for people from different ethnic minorities, and has shown promise reducing health inequalities in Mexican Americans (Madden 2015). People from the majority population may also benefit from this lens, such as White British in the UK, by making services and systems and well as individual consultations more adaptive based on the patient's culture and needs. Cultural health capital moves a level above cultural competency frameworks whereby the goal is for individuals and systems to learn about different cultures, to developing cultural partnerships and recognising limitations of approaches focused solely on cultural competence (Gopalkrishnan 2018). These include cultural competency frameworks being a new form of racism by 'othering' non-white people and using absolutist and stereotypical views of culture, neglecting the nuances of changes of culture and historical and present forms of oppression (Pon 2009), and creating tick-boxes to achieve competency (Kumagai, Lypson 2009). Focusing on cultural health competencies can be reflective embedded ethnocentrism, perpetuate biases and fails to recognise the depth and breadth of systemic racism (Berger, Miller 2021). In this study there was heterogeneity amongst perspectives of first and second generation immigrants, which may not be understood within cultural competency frameworks. Cultural health capital encompasses a range of interventions from a long-term perspective. The risk of short-term engagement with communities, such as over £23 million invested in community champions to engage with underserved communities during the covid vaccination program, may make these communities as described by the author, becoming 'hard to reach' again (Mujong 2021). Practically, underserved communities may become 'harder to reach' with more trust eroded after short-term and short-sighted community engagement. Hence building cultural health capital encompasses long-term development, and can be considered as a key ingredient to developing cultural safety, which will be addressed in the next section.

#### *8.2.4.3 Cultural safety*

Cultural safety is a broader approach to addressing health inequalities of minority groups. The concept was first proposed in the 1990s in the background of New Zealand indigenous community health inequalities from a nursing perspective (Ramsden 2005), and has and is developing as a concept. It describes how healthcare professionals and organisations must examine themselves and the impact of their own culture on healthcare service and delivery (Curtis et al., 2019). It challenges clinicians and systems to reflect upon their own biases to deliver culturally safe care and promote equity. This definition is limited as its emphasis on one's own culture undervalues the different and diverse cultures that having some understanding of can lead to cultural safety. Cultural safety may facilitate a 'global cultural home' for the global village within which humanity now lives (Chen 2015). Cultural safety can incorporate levels of cultural humility, whereby the shift is from knowing the cultures of others to instead knowing one's own biases and assumptions (Fisher-Borne et al., 2015, Danso 2018). Included within this is training clinicians in cultural safety (Curtis et al., 2019), which may equalise power relationships and reduce ethno-centric care. Participants both SA and GPs described feeling culturally 'unsafe,' whereby SAs would not trust GPs and GPs found them challenging to manage. GP described how their professional identity at times conflicted with their beliefs. Interviews with healthcare professionals around found that they understand concepts of cultural awareness but not of systemic approaches such as cultural safety (Shepherd et al., 2019). This is an important consideration to medical education whereby clinicians need to understand systemic as well as individual factors related to health inequality. GPs in my study described a need for training throughout the medical curriculum around issues such as ethnic minority health. Faith is often described within literature from an ethno-centric perspective, with belief in destiny and divine decree interpreted by researchers as providing a negative perspective of resignation to fate (Webster et al., 2003); this study found that belief in divine decree acted as a solace and positive influence for participants to work on their health knowing there was a higher being supporting them. Developing cultural safety within general practice could be a tool for improving care of distress not just in SAs, but ethnic minorities and people of different and all cultures by self-reflection and analysis of the culture of systems and individuals within healthcare. This can be facilitated by a shift from viewing mental health problems and emotional distress as individual syndromes to systems which need further exploration, and focusing on supporting the individual (Fried 2022). Cultural safety is a tool for moving away from a biological reductionist approach to managing emotional distress and mental health problems to a systems-based approach.

Developing culturally safe primary care is in line with suggested actions from the literature and evidence review in racial disparities in mental health, whose approach was broader than focusing on single communities but looking at how to systematically create change to reduce health inequalities. These include how policy makers and commissioners should better commission of talking therapies according to local need, engage with minority communities to make sure they are culturally appropriate, provide better access to healing systems and therapies including complementary therapies, offer services in multiple languages and involve people from ethnic minorities more in patient and public involvement in the NHS (Bignall et al., 2022). The authors recommend that mental health services should work more with community sector and faith groups and consider the impact of racism and discrimination on mental health care (Ibid). They also recommend that practitioners have a better understanding of cultural and faith beliefs of people from ethnic minorities and how they impact mental health, develop and move towards more holistic approaches to health integrating mental and physical health, culture and belief, and use services non-stigmatising to people from ethnic minority communities such as ‘wellbeing’ rather than ‘mental health’ (Ibid). This is similar to findings from my study whereby participants preferred use of non-medical terminology. The review recommend that researchers work to address the inequity in mental health (Ibid). All of these are relevant to developing cultural safety within primary care.

## 8.3 Patient and public involvement and engagement

### 8.3.1 The role of patient advisory group

The central role of the patient advisory group has been described throughout the thesis. In chapter 1 I described how the patient advisory group was convened. In chapter 2 I highlighted the research landscape around ethnic minority groups within health research. In chapter 3 I described how the how the PAG refined the systematic review question, key terms and analysis, highlighted in the publication (Awan et al., 2022). In chapter 4 I highlighted the lack of as well as need for patient and public involvement and engagement from people from ethnic minorities. In chapter 5 I detailed the standards used when working with the patient advisory group and the main outcomes of each of the six meetings. In chapters 6 and 7 I explained how the PAG contributed to the analysis of the results of the qualitative study. In chapter 8 I describe explains key inputs from, and impact of, the PAG group, including co-creating an animation video summarising the key findings from the study, as in Table 8.

The role the PAG plays in my research was presented specifically in conferences including NAPCRG (North American Primary Care Research Group) 2022 Annual Meeting and SAPC (The Society for Academic Primary Care) North 2022 Conference as well as blogs for SAPC and the School for Primary Care Research (SPCR) where thoughts and ideas and working with a PAG from underserved areas was further developed and refined. At NAPCRG there were many patient partners at the conference, presenting and running co-workshops. In discussion, I was challenged as to why my PAG were not co-authors of my poster presentation about working with a PAG. My perspective shifted from PAG members being a patient advisory group, to being patient partners in research. This conceptual shift is something I plan on incorporating into future research by involving PAGs in publications and co-presenting at conferences, providing a space for the patient voice on an academic level as well as throughout the research. A framework for working with PAGs from underserved groups which I developed with the patient advisory group is presented in Table 9, based on Hiccmat, a word meaning wisdom in Arabic, Urdu and a number of other languages.

My journey with the PAG can be summarised in three lessons lived throughout the research:

- Ethnic minority groups are not ‘hard to reach’ but may be ’easy to ignore’
- Developing PPIE groups in underserved communities can be facilitated by engaging with existing networks
- PPIE groups are integral to research, even if researchers are from the same background

Table 8 PPIE input and impact

| Research area | PAG input and impact |
|---|---|
| Research question: | **Developed the research question and aims via a team approach** |
| Public facing documents: | **Adapted to be culturally appropriate, including wording and pictures** |
| Recruitment | **Targeted, e.g. shops, specific radio stations, community and faith centres** |
| Analysis: | **Challenging and re-working themes such as co-navigation; research gaps noted such as black magic and jinn** |
| Dissemination: | **Animation video co-created** |
| Future priorities: | **Next steps after this research discussed including a possible intervention study** |

Table 9 Hiccmat (wisdom): Working with PPIE groups from underserved communities.

| | |
|---|---|
| • **H**umility | Appreciate the PPIE group are experts by experience, even if the researcher(s) share the same characteristics |
| • **I**nformation sharing | Understand the best ways of sharing knowledge with the community served |
| • **C**ollaboration | Work together as a collaborative team in all aspects of the research, from advisers to partners |
| • **C**ommunity outreach | Go out to the community in their venues and on their terms to build the PPIE group |
| • **M**anage sensitivities | Appreciate reasons behind community mistrust if present; Manage cultural sensitivities |
| • **A**pplicability | Ensure the research is relevant to underserved communities |
| • **T**hriving research culture | Create an environment where authentic researchers and research is developed and supported |

### 8.3.2 In-person and virtual meetings

The first PAG meeting took place in-person in Keele university. Due to the covid-19 pandemic, all further meetings took place online, guided by resources such as from the NIHR and research webinars (for example https://www.youtube.com/watch?v=yEEFxVz_lrU). Online meetings were shorter and did not have the natural informal communication over breaks that in-person meetings have. Conversely, online meetings were easier for some participants to attend, as they did not have to travel to attend the meetings. Consideration was made to ensure online meetings included visual cues to keep the groups engaged and direct their focus towards the research, and at the same time facilitate full participation for a visually impaired and registered blind member of the PAG. Time was scheduled within the meetings to allow for informal discussion to replicate the team-working relationship that develops naturally in-person.

## 8.4 Reflexivity

Reflexivity has been described throughout the thesis. In chapter 1 I included an introduction of myself and my roles as a SA, clinician, community member and faith leader, as well as challenges of being a member of the research group of interest and how they were accommodated for. In chapter 3 I describe my embarrassment at realising I had left behind aspects of SA culture when acting as a researcher, for example not considering aspects of black magic and mental health. In chapter 4 I explained my epistemological and ontological viewpoints and how I kept a reflexive diary throughout the research. In chapter 5 I highlighted thoughts and feelings I experienced throughout the research, as well as considerations of how I may be perceived by others. In chapter 6 I described my emotions around interviews and some of the themes, relating to work challenges described by GPs, reminding myself not to overstep my role as a researcher when asked medical questions by SAs, and developing a style of interviewing very different to clinical history-taking. In chapter 7 I In chapter 7 I reflected upon how scenarios within the clinical and community settings influenced my thoughts about the research, and how at the same time I tried to let the data speak as opposed to speak on behalf of the data. In chapter 8 I highlighted clinical encounters which impacted my thinking during the interview-taking and analytical process and my approach to trying to be a voice to the data rather than putting my voice on the data.

Monthly supervision meetings with my supervisors, PAG meetings, as well as presenting at conferences and other clinical meetings in person and online, publications and social media opened the door to discussions and further refinement of ideas. For example, a large step change in direction was talking about the concept of SAs and GPs describing the need on an individual as well as service-level of healthcare to be appropriate for people of different cultural backgrounds. For example, I initially conceptualised this to be around cultural competency as a tool to make primary care more culturally sensitive. Within the multiple and nuanced layers of discussion, this developed into considering how primary care can contribute to reducing health inequality to people of all different backgrounds through a lens of cultural health capital and cultural safety. The data remained the same, but the level of analysis and interpretation increased exponentially with discussion of people from different backgrounds and perspectives.

My background of being a GP, researcher and South Asian male led to occasional conflicts. Prior to any interview, I made a clear role change in my mind, ‘I am a researcher today, not a clinician.’ I was acutely aware of my own understanding and reasoning for undertaking the research, a belief that SAs are underserved and have poorer outcomes, yet as GPs we are trying our best, so what is the problem and more importantly what are the solutions? I appreciate my own interest in health inequality and a keenness to contribute to a reduction in health inequality. Conflict occurred for example, when a SA participant stated that he would not go to a GP when distressed as GPs are not trained in mental health. I had to hold back my gut instinct, a reply to say actually GPs are trained extensively in mental health, and ask further open questions without challenging the participants. Participants often spoke negatively of GPs, which again I reminded myself that this was not a session of myself educating patients or defending GPs (nor providing therapy), but listening to and exploring different viewpoints in the creation of knowledge. Conversely, conflict occurred when I wore my clinician hat. During the research period, when I was working as the on-call GP, I saw a patient who was suicidal. He was a SA patient and immediately spoke of being reassured at seeing a SA GP, he described how he would have killed himself if it were not for myself. This made me appreciate the research I was doing more, but also kept me aware to add in my reflexivity diary and reflect upon the experience so that I could be honest to the research and express what participants were saying rather than my own experiences. I was conflicted as a SA male at times. My interview technique developed with training and support from my supervisors. Initially, some interviews were taken from a clinician- style interview in which they were systematic and the topic guides were more rigorously followed; later interviews were more flowing in which the interviews progressed according to what participants brought up, with the topic guides being covered yet not stringently to the order of areas of questions.

During the first lockdown, I found my productivity became significantly lower and a discussion with an academic mentor led him to suggest that I may be suffering from depression. I had not considered this but I did realise an increased level of anxiety in particular with clinical work related to the pandemic and took steps to improve my mental and physical health. Being a male of SA origin, living in a tri-generational household in which I am the only breadwinner in a family of 7 (8 including our cat), I found at times I lived through some of the experiences that people spoke of. At other times, I realised I had had left my SA origins behind at work. For example, when discussing the systematic review findings, the patient advisory group discussed cultural concepts such as a black magic and surprise at why these concepts were absent, and possible reasons for this. I realised that whilst as a SA I am very aware of such ideas, I had not linked them with my research whilst wearing my research hat.

Reflexivity is not only about the researcher and their own feelings and experiences, but also about their relationship with interview participants and perceived status and how this can affect the interview. I found GPs tended to be enthusiastic when speaking to ‘a fellow GP’ and a feeling of kindred spirit was displayed, with GP participants describing happiness as ‘helping a fellow GP out’ by taking part in interviews. This sense of comradery may have been accentuated by the covid-19 pandemic and challenging workloads that all healthcare staff faced, with GPs having a shared experience in this. GP interviews tended to last an hour and they were very willing to speak and discuss topics at length. For SA participants, I felt that my being SA was a key component in their minds when being interviewed. My name is a clearly SA name, and my attire of traditional clothing would have apparent in online interviews. Participant often used terms consistent within different SA languages. SAs were often openly critical of GPs, and described cultural issues such as black magic openly, which I felt was due again to a feeling of 'kindred spirits.'

Literature can discuss areas such as *insider* and *outsider* researchers and the benefits and challenges of these. An *insider* researcher shares common characteristics with the group they are studying, and an *outsider* researcher is considered a non-member of that group. *Insider* researchers must be more aware of their personal and cultural perceptions and not presuppose these onto participants  (Teh, Lek 2018). There may be a greater power imbalance with outsider researchers that needs to be reflected upon  (Grove 2017), especially when interviewing participants from underserved communities. Participants could be more willing to speak openly to *insider* researchers who share more cultural norms (Teh, Lek 2018), or conversely more willing to speak openly to *outsider* researchers whom they view as separate and less likely to have any issues of confidentiality or cross-over with. Whilst such concepts of *outsider* and *insider* are useful in relating a researcher to their participants and developing reflexivity, I believe that it can be oversimplistic. I regard myself to an extent an *insider* with each research participant, we share common grounds, be it the country we live in, race with SAs, profession with GPs, and more. I also consider myself an *outsider* with each research participant, we have uniquely different circumstances and upbringing and see the world in different ways, and this should also be considered. Issues of being an insider and outsider at the same time have been described when a researcher has *intra-community outsiderness*, whereby they may share some qualities which include and exclude them from being part of the community (Ademolu 2023). I found this particularly when interviewing SAs, when we shared some similar backgrounds, but my level of education, and limited travel to South Asia, may have given me a level of *intra-community outsiderness.* My multiple roles and identities cross the assumed boundaries of different roles within research. I kept a reflexivity diary throughout the research to reflect upon my own experiences and feelings, which is further described in chapter 5 methods.

My thinking around emotional distress in SAs with LTCs has evolved and developed immensely since conducting this research, and provided a vision for improving wellbeing not just in SAs with LTCs but people of different backgrounds that I hope to spend the rest of my career working for.

Conversely, I found it incredibly challenging finishing writing up my thesis whilst working full-time as a GP to support my family, with long hours and work pressures as well as being present as a family and community member, which made me appreciate more the need for delineated research time and the need to secure fellowships to facilitate myself to do this work. I conclude my reflexivity section with increased humility and awareness of my ignorance on field of emotional distress, expressing the statement of Al Shaafi, a scholar who lived over a thousand years ago, to whom I have a living chain of teachers, *whenever I have increased in knowledge, it is through increased awareness of my ignorance.*

## 8.5 Strengths and limitations

A strength of this study was the unique contribution to knowledge as already described in the previous section 8.5, from a perspective of answering the research question as well as working with a PAG from underserved communities. A second strength the ethnically appropriate PAG of SA males who acted as patient partners throughout the research. Community sampling took place whereby community voices of people from the SA community who may not otherwise be heard. Having an *'insider researcher'* may have facilitated SAs to be more open to talk about issues around culture and mental health such as black magic, which were included in the topic guide after discussion with the PAG. An iterative topic guide allowed for further refinement and development of analysis as the research took place. The creation of an animation video summarising the key messages from the research, in conjunction with the PAG, provided a platform for dissemination for people who may be neglected by other forms of dissemination. Presenting the findings at multiple conferences as well as online discussions allowed for further development and crystallisation of the research.

Some limitations of the research should be noted. Chapter 3 systematic review describes limitations of comparing experiences of SAs within and outside SA countries. Qualitative interviews took place during the covid-19 pandemic and hence all interviews, and most PAG meetings were online. The dynamics of virtual and in-person interviews are different with word-dense transcriptions in-person, and virtual meetings being potentially more accessible for people as well as having similar interview lengths, subjective interview ratings and substantive coding in comparison with virtual interviews (Johnson et al., 2021). In a time of pandemic and post-covid, virtual interviews are more common and often preferred by research participants due to the ease of accessibility (de Villiers et al., 2022). Secondly, the demographics of interview participants should be noted, which had a diverse range of SAs from different countries, although the majority of participants were of Muslim faith and one participant was of Hindu faith. Thirdly, interviews were all undertaken in English due to a lack of funding for interpreters, which may have limited the population. Fourthly, the majority of GPs interviewed were multilingual SAs with two GP stating they were of White British ethnicity, possibly as recruitment was from practices with higher proportions of SAs, and SA GPs may be more experienced and interested in the management of distress in SAs. This provided rich data around their experiences. The ratio of male:female GPs was 7:2 which again may be explained by SA men preferring to see male GPs. Qualitative research is interested in perspectives, so these notable demographics did not necessarily detract from the research but should be considered in conjunction with the results. Of note, a number of professionals in primary care see people with emotional distress. Whist research has shown that case-finding for depression in people with diabetes and heart disease by practice nurses has been found to be of limited value with questions biased towards negative answers and practice nurses not feeling equipped to deal with the answers (Maxwell et al., 2013); interviewing those involved in mental health in primary care including practice nurses with their evolved roles, physician associates, mental health practitioners and other professionals can add further insights.

## 8.6 Outputs and dissemination

Outputs and dissemination activities were prioritised from the start of the research, in conjunction with the PAG, for both academic and public audiences.

The systematic review and qualitative study were presented at a number of national and international conferences, including oral presentations and posters. Presentations also included clinical audiences such as at Primary Care Networks and Clinical Commissioning

Group meetings as well as sharing the research on radio via BBC Lancashire and Indus. I won an award for 1st place at in Keele University Three Minute Thesis 2022. My systematic review has been published as well as a BJGP YouTube video (https://www.youtube.com/watch?v=yiH_xzf8Who) and a BJGP live podcast and video (Awan 2020a). Publications for the qualitative study in conjunction with working with the PAG are being drafted. Blogs were written for National Institute for Health and Care Research School for Primary Care Research around setting up a culturally sensitive patient advisory group (Awan 2020b) and the Society for Academic Primary Care on Facilitating lay involvement of people from underserved groups in Mental Health research (Awan 2021).

An animation video (https://youtu.be/pSuTAf_JU1I) was created with the PAG which has been shared in community groups, added to undergraduate medical curriculum at the University of Central Lancashire and shared across a number of health, research and other channels such as the National Forum for Health and Wellbeing. An example of feedback received to the animation video, with permission, is shared below from a member of the SA community to exemplify some of the feedback received.

> '*I just wanted to respond to the animation – its brilliant and reminded me a lot of how my dad struggled with accessing support, probably due to the stigma attached and his pride but he eventually did and it was beneficial. I lost my dad in 2016 and I've always had a high regard for medical staff who made him feel valued. I will definitely be circulating this amongst my friends network*.'

Outputs resulting from the PhD are listed in appendix 16. The following section discusses strengths and limitations of the study, followed by implications for SAs, clinical practice, other sectors, policy and training. 8.8 Future research is based on the outputs and dissemination undertaken.

## 8.7 Implications

The research has several implications, which will be discussed in terms of implications for SA men with LTCs, implications for clinical practice, implications for training, policy implications and implications for other sectors.

### 8.7.1 Implications for SA males with LTCs

The purpose of this research was to serve and potentially improve care for men of SA origin with LTCs dealing with emotional distress and several key implications are noted. SA men with LTCs should be made aware of the symptoms of emotional distress, which they may be experiencing but not be aware that it is something they are suffering from, it is not a sign of weakness to seek help, and that support is available. In particular, they should be informed of the potential support that can be received in primary care when suffering from emotional distress, and that their voices will be heard not just in terms of their biological symptoms but from a bio-psycho-social-spiritual perspective considering the social determinants of their distress, intersectionality and living with a LTC. Engagement is needed to allow for SA men with LTCs to trust clinicians within primary care, and to support them to speak to professionals without feeling that they have to hide aspects of their life of impacts of emotional distress and help-seeking. They should be informed that they can present with families when distressed and their beliefs about treatment will be respected, included and adhered to.

### 8.7.2 Implications for clinical practice

Several implications apply to clinical practice. Firstly, GPs when seeing SAs with LTCs and people from ethnic minority communities with emotional distress must be open to ethno-diverse models of health and wellbeing. GPs need to be able to listen to patients so that they feel not only heard but listened to, and their beliefs validated. GPs do not need to agree with the beliefs of their patients, but facilitate patients to feel that they are able to share their conceptualisations of distress. This should be holistic and include asking about faith and culture and how these are impacting or being used as coping strategies for distress. Materials such as leaflets should be available in different languages to accommodate those whose first language is not English, and utilise terminology appropriate for the populations, such as not medicalising distress. If this is not done, SAs may be encouraged to visit their GP when distressed but find little benefit.

A second implication for clinical practice is for GPs and other clinicians to critically reflect upon their own diverse health beliefs and how that impacts on consultations. This may include reflecting upon their own sense of professional identity, similarities or differences to the patient in front of them, and analysing unconscious biases that they, as every individual, may hold. Co-navigating care can be used to conceptualise their own and their patients' diverse health beliefs and preferred treatments to facilitate truly shared management plans that patients will be willing to adhere. The 3Cs for co-navigating emotional distress in SA men with LTCs can be used in consultations in clinical practice by GPs reflecting upon the components and asking how they impact the patient in front of them; this has the potential not increase time of consultations, but potentially decrease the burden by getting to root issues and providing care which can improve quality of life.

A third implication is for GPs and primary care clinicians to provide a platform whereby the voice of families is listened to and families feel comfortable to contact practices for support for relatives suffering from emotional distress, within limits of confidentiality. Systems in primary care should incorporate cultural safety and recognise this, as well as being responsive to the needs of different communities via culturally sensitive care and linking with culturally sensitive services that are available and which patients can be referred to. Flexibility should be provided for patients whose first language is not English; this should not be limited just to interpreters, but written information and services facilitating the preferred language and online booking systems for appointments to facilitate this.

A fourth implication for clinical practice it to develop cultural health capital. Practices should consider reaching out to community and faith centres and delivering events in partnership such as around health education and inclusive of mental health and wellbeing, and support the delivery of healthcare within communities. Social prescribing should include networking with and referring to appropriate community groups, resources, and people, such as faith leaders when appropriate. There should be a focus on recruiting and retaining members of practice patient advisory groups who are given a platform to input and direct services to care which develop cultural health capital and cultural safety.

### 8.7.3 Implications for training

Implications for training can be understood in terms of training in primary care for the different team members who may see people presenting with emotional distress, such as GPs, nurse practitioners, physician associates, mental health practitioners. A second approach is focusing on the trajectory of the development of GPs and doctors in general, from a perspective of training. This begins in undergraduate medical school and continues throughout post-graduate training and continuous professional development. The implications for training apply equally to both perspectives, i.e. training within primary care teams, and training across professional development of GPs.

A greater focus is needed on professional identity and how one’s one beliefs influences the consultation with their patients, in particular from ethno-centric perspectives when treating people from different backgrounds. Co-navigating care can be taught as a model for working with people from different ethnic backgrounds. For example, within GP training, sessions could run around what to do before, during and after seeing a patient from a different ethnic background or community. These may focus around presumptions that people can make, and how clinicians should reflect upon their own prejudices and biases, including their health beliefs and understandings of wellbeing and sources of wellbeing, and how these impact the consultation. Such training should also reflect upon cultural humility and anti-racism. Training in co-navigating care is equally applicable to people in non-clinical roles who serve people and their health, such as social workers, receptionists of healthcare centres including General Practices and within secondary care, support workers and managers of voluntary and other organisations.

Teaching in reducing ethnic minority health inequalities should be included as part of wider teaching around health inequality. This should be taught from the first year of medical school, throughout training for any speciality, and should include potential solutions and actions that can be taken to reduce health inequality, such as building cultural health capital. The social determinants of distress should be studied as well as biological and psychological factors related to distress and how it can be viewed as different to depression. Training should also consider cultural safety and how clinicians can work individually and within systems and organisations to develop this, including learning around culture and faith in relation to health and wellbeing.  This is relevant both to clinicians as well as those involved in healthcare from management perspectives within both primary and secondary care.

Training and collaboration may include upskilling GPs in areas of faith and culture, and what services are available in the community, including culturally and faith sensitive services. Conversely, a training need may include cultural and faith leaders having a greater understanding of emotional distress, its management and signposting to GPs and primary care services when appropriate.

### 8.7.4 Implications for policy

Reducing the health inequality in people from ethnic minority communities, and specifically with regards to mental health and wellbeing, are national priorities as highlighted in a number of policy documents. The NHS Long Term Plan prioritised health inequality as a focus of the Plan (NHS 2019a). The Commission for equality in mental health perceived mental health as built in communities and the need for all elements of civic society including businesses, faith groups and charities to be involved (Commission for Equality in Mental Health 2020). The NHS Race & Health Observatory rapid review of ethnic inequalities in healthcare recommendations for working with ethnic minority organisations included recommendations to provide high quality services for ethnic minority groups within mental health (Kapadia et al., 2022). The King’s Fund Ethnic Health Inequalities paper for the NHS Race & Health Observatory to accelerate and diversity leadership with people from ethnic minority communities, prioritising health inequality and investing in communities to develop and deliver culturally competent services and to build trust between services and communities, and situating the work within a broader approach to deal with the social determinants of health including racism (Robertson et al., 2021b). Health Foundation’s A Matter of Life and Death: Explaining the Wider Determinants of Health in the UK described a need to shift the focus on the wider determinants of health, including racism and discrimination (L’Hôte et al., 2022).

A clear policy implication for reducing health inequality is the need to focus on developing community-based services *with* underserved communities, *for* underserved communities, and *in* venues suitable and accessible for underserved communities. This applies for services around mental health and wellbeing as well as other healthcare services. The needs to be a long-term plan and not just Long Term Plan in funding and supporting such services whereby trust is built within these communities, community members are upskilled and supported as members of teams in the delivery of such services, building cultural health capital within underserved communities. Via these means, culturally sensitive services, linguistically appropriate services and the services needed for underserved communities will not only be developed, but maintained. Cultural capital must not be about imposing paradigms of health on SAs and other underserved groups, but working together to develop appropriate services. Services need to be response to local populations and changes that may occur over time. This approach focuses on developing trust and long-term relationships with underserved communities from a perspective of patients, families and communities.

There is a need for social prescribing and signposting people from ethnic minority communities to appropriate activities. Specific to SAs, services to support emotional wellbeing and mental health should use non-medical terminology such as ‘tension’ as opposed to ‘mental health problems.’ Faith-centred and culturally sensitive services, as well as services in SA languages should be supported and developed when appropriate.

### 8.7.4 Implications for other sectors

An implication for the voluntary and community sector is set up and apply for funding for localised services appropriate for the communities, without leaving behind cultural nuances and faith-based adaptations from these. They should work with policy makers to build sustainable services developing cultural health capital and cultural safety. Members of underserved communities must be supported and development opportunities facilitated so that they can lead in the development and implementation of such services, and will be more likely to stay beyond the time period of people from outside these communities who may then move on with different jobs to other roles and organisations stagnate.

## 8.8 Future research

A number of research priorities have been highlighted by this study. Firstly, a model has been developed of the 3Cs for co-navigating emotional distress in SA men with LTCs. This model needs to be further refined, developed, tested and evaluated within primary care. This may be done by bringing together a practical intervention which at the same time is theoretically grounded in concepts such as the social determinants of distress, intersectionality, living with a LTC, de-medicalising distress, negotiating multiple identities, faith and culture, co-navigating care, cultural health capital and cultural safety. Interventions based on this model should be developed and evaluated not just for SA men with LTCs suffering from emotional distress, but for people suffering from emotional distress within underserved communities. On the clinician level, what can be done in a ten-minute consultation with the patient in front of them? On a practice level, how can practices develop structures and systems for this? Key questions may include:

- How can the 3Cs for co-navigating emotional distress in SA men with LTCs be developed as a tool for GPs to use within General Practice?
- What is it's applicability to distress and wellbeing in general?
- What is it’s applicability to underserved communities in general?
- What models of consulting can facilitate the 3Cs, such as consulting as families and group consulting?

Since co-navigating care is a new concept, the first step for such research will be to develop its conceptualisation, such as via interviews with relevant parties, including patients, GPs, commissioners. Further to this, training could be provided to practices on the 3Cs model and outcomes could be measured against practices who do not use the model, to assess if care is improved.

Research is needed to further conceptualise and develop the specific elements of the model, such as:

- What does cultural health capital mean in general practice contexts and how can this be developed and utilised to improve care?
- What do culturally safe general practices look like and how do they differ from other practices?
- What do culturally appropriate healthcare services for emotional distress look like, for whom and in which circumstances?
- What role can primary care play in treating the social determinants of distress?
- What role can community groups (such as faith centres) play in supporting men of SA origin with emotional distress?
- How applicable is the 3Cs model to SA women with emotional distress as well as people from different cultures and ethnic minority groups?
- How do faith leaders view their role as a resource to support people experiencing emotional distress, and how can a model of treatment be co-developed with clinicians in primary care?
- How can collaboration between faith leaders and clinicians be optimised to support the management of people with emotional distress?

Cultural safety has not been explored within primary care mental health. The first step of research for this would be to do a scoping review of cultural safety in primary care and community mental health, followed by the development of a model of culturally safe care for primary care mental health. This can again be assessed against usual practices and outcomes measured between culturally safe care and usual practice.

Training models need to be developed and evaluated to teach skills around co-navigating care in underserved communities, ethnic minority health and health inequality from a perspective of not only looking at the problems, but also how solutions can be implemented and evaluated.

## 8.9 Chapter summary

I conducted this research to explore how males of SA origin with long-term physical conditions (LTCs) understand, experience and seek help for emotional distress.  A model has been developed 3Cs for emotional distress in men of SA origin with LTCs; contextualising distress including the social determinants of distress, intersectionality, living with a LTC conceptualising distress including de-medicalising distress, negotiating multiple identities, faith an culture, and consulting with distress including co-navigating care, cultural health capital and cultural safety. There are several implications resulting from my research, for SAs, clinicians, training, policy and other sectors. I have described future directions for research have been described. I hope that this research will act as a platform for further work to improve healthcare for SA men with LTCs suffering from emotional distress, as well as implications for underserved communities in general.

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# Appendices

## Appendix 1 Medline search strategy for systematic review

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) <1946 to September 1, 2021>
Search Strategy:

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1 ASIA/ (27506)
2 "ASIA, WESTERN"/ (1916)
3 West* Asia*.ti,ab,kf. (2190)
4 "ASIA, SOUTHEASTERN"/ (7748)
5 ((South East* or Southeast*) adj Asia*).ti,ab,kf. (20400)
6 SAARC.ti,ab,kf. (48)
7 AFGHANISTAN/ (3100)
8 Afghan*.ti,ab,kf. (6271)
9 BANGLADESH/ (10394)
10 Bangladesh*.ti,ab,kf. (14066)
11 ((South or Southern) adj Asia*).ti,ab,kf. (14544)
12 BHUTAN/ (419)
13 Bhutan*.ti,ab,kf. (805)
14 exp INDIA/ (99606)
15 India*.ti,ab,kf. (154503)
16 Maldiv*.ti,ab,kf. (350)
17 NEPAL/ (7659)
18 Nepal*.ti,ab,kf. (9989)
19 PAKISTAN/ (16608)
20 Pakistan*.ti,ab,kf. (20061)
21 "SRI LANKA"/ (5776)
22 "Sri Lanka*".ti,ab,kf. (6947)
23 or/1-22 (290228)
24 exp Myocardial Ischemia/ (421473)
25 ((ischaemi* or ischemi*) adj4 heart).ti,ab,kf. (46407)
26 coronary.ti,ab,kf. (389553)
27 exp Coronary Disease/ (213686)
28 exp Myocardial Infarction/ (171819)
29 (heart adj4 infarct*).ti,ab,kf. (12391)
30 exp Angina Pectoris/ (43028)
31 angina.ti,ab,kf. (53017)
32 exp Heart Diseases/ (1098741)

33 myocard*.ti,ab,kf. (379904)

34 cardiac*.ti,ab,kf. (590192)

35 (heart adj4 disease*).ti,ab,kf. (187180)

36 CAD.ti,ab,kf. (37633)

37 CHD.ti,ab,kf. (24496)

38 or/24-37 (1609944)

39 exp diabetes mellitus/ (412928)

40 IDDM.ti,ab,kf. (6855)

41 diabet*.ti,ab,kf. (611140)

42 NIDDM.ti,ab,kf. (6979)

43 MODY.ti,ab,kf. (1250)

44 exp glucose intolerance/ (8425)

45 noninsulin* depend*.ti,ab,kf. (1458)

46 insulin* depend*.ti,ab,kf. (29554)

47 Insulin* resistance*.ti,ab,kf. (78376)

48 exp insulin resistance/ (79976)

49 (T1DM or T2DM).ti,ab,kf. (22420)

50 (DMi or "DM i").ti,ab,kf. (4386)

51 (DM1 or "DM 1").ti,ab,kf. (2884)

52 (DMii or "DM ii").ti,ab,kf. (130)

53 (DM adj2 type*).ti,ab,kf. (4763)

54 (DM2 or "DM 2").ti,ab,kf. (2588)

55 or/39-54 (736535)

56 38 or 55 (2249238)

57 Qualitative Research/ (50165)

58 Interview/ (28821)

59 (theme$ or thematic).mp. (101392)

60 qualitative.af. (233379)

61 Nursing Methodology Research/ (16338)

62 questionnaire$.mp. (708523)

63 ethnological research.mp. (7)

64 ethnograph$.mp. (10443)

65 ethnonursing.af. (113)

66 phenomenol$.af. (25563)

67 (grounded adj (theor$ or study or studies or research or analys?s)).af. (11305)

68 (life stor$ or women* stor$).mp. (1303)

69 (emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or participant observ$.tw. (22436)

70 (social construct$ or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or post modern$ or post-modern$ or feminis$ or interpret$).mp. (511262)

71 (action research or cooperative inquir$ or co operative inquir$ or co-operative inquir$).mp. (4096)

72 (humanistic or existential or experiential or paradigm$).mp. (148016)

73 (field adj (study or studies or research)).tw. (15854)

74 human science.tw. (242)

75 biographical method.tw. (17)

76 theoretical sampl$.af. (660)

77 ((purpos$ adj4 sampl$) or (focus adj group$)).af. (61319)

78 (account or accounts or unstructured or open-ended or open ended or text$ or narrative$).mp. (616784)

79 (life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp. (14847)

80 ((lived or life) adj experience$).mp. (10720)

81 cluster sampl$.mp. (7067)

82 observational method$.af. (735)

83 content analysis.af. (26076)

84 (constant adj (comparative or comparison)).af. (4377)

85 ((discourse$ or discurs$) adj3 analys?s).tw. (2114)

86 narrative analys?s.af. (1191)

87 heidegger$.tw. (641)

88 colaizzi$.tw. (659)

89 spiegelberg$.tw. (79)

90 (van adj manen$).tw. (400)

91 (van adj kaam$).tw. (37)

92 (merleau adj ponty$).tw. (211)

93 husserl$.tw. (238)

94 foucault$.tw. (784)

95 (corbin$ adj2 strauss$).tw. (317)

96 glaser$.tw. (966)

97 (mix$ adj2 (method$ or design$)).af. (26392)

98 or/57-97 (2222661)

99 emoti*.ti,ab,kf. (189860)

100 mental*.ti,ab,kf. (357246)

101 distress*.ti,ab,kf. (118070)

102 affect.ti,ab,kf. (636767)

103 affective.ti,ab,kf. (55218)

104 feeling*.ti,ab,kf. (58722)

105 depress*.ti,ab,kf. (445809)

106 anxi*.ti,ab,kf. (199269)

107 angry.ti,ab,kf. (4525)

108 anger.ti,ab,kf. (14322)

109 shame*.ti,ab,kf. (5001)

110 fear*.ti,ab,kf. (77893)

111 (well being or wellbeing).ti,ab,kf. (85213)

112 sad*.ti,ab,kf. (25666)

113 agitat*.ti,ab,kf. (19276)

114 apath*.ti,ab,kf. (6111)

115 (grief or grieve*).ti,ab,kf. (6819)

116 hopeless*.ti,ab,kf. (5595)

117 (lonel* or alone).ti,ab,kf. (539727)

118 mood.ti,ab,kf. (71304)

119 thinking.ti,ab,kf. (38282)

120 (adjustment adj3 disorder*).ti,ab,kf. (2009)

121 psych*.ti,ab,kf. (830206)

122 worr*.ti,ab,kf. (21389)

123 dysthimi*.ti,ab,kf. (15)

124 phobi*.ti,ab,kf. (11584)

125 panic.ti,ab,kf. (14353)

126 stress.ti,ab,kf. (716270)

127 ptsd.ti,ab,kf. (23533)

128 despair*.ti,ab,kf. (2399)

129 frustration.ti,ab,kf. (8326)

130 guilt.ti,ab,kf. (6852)

131 bipolar*.ti,ab,kf. (62362)

132 (mania or manic).ti,ab,kf. (17924)

133 aggressi*.ti,ab,kf. (199650)

134 exp mood disorders/ (118711)

135 exp anxiety disorders/ (77688)

136 exp "bipolar and related disorders"/ (39429)

137 exp "disruptive, impulse control, and conduct disorders"/ (8489)

138 exp "trauma and stressor related disorders"/ (38823)

139 exp Behavioral Symptoms/ (355352)

140 exp emotions/ (232545)

141 hostil*.ti,ab,kf. (13160)

142 catastrophis*.ti,ab,kf. (293)

143 (cope* or coping).ti,ab,kf. (95150)

144 pessimism/ (166)

145 pessimism.ti,ab,kf. (1455)

146 exp Emotional adjustment/ (953)

147 or/99-146 (3767980)

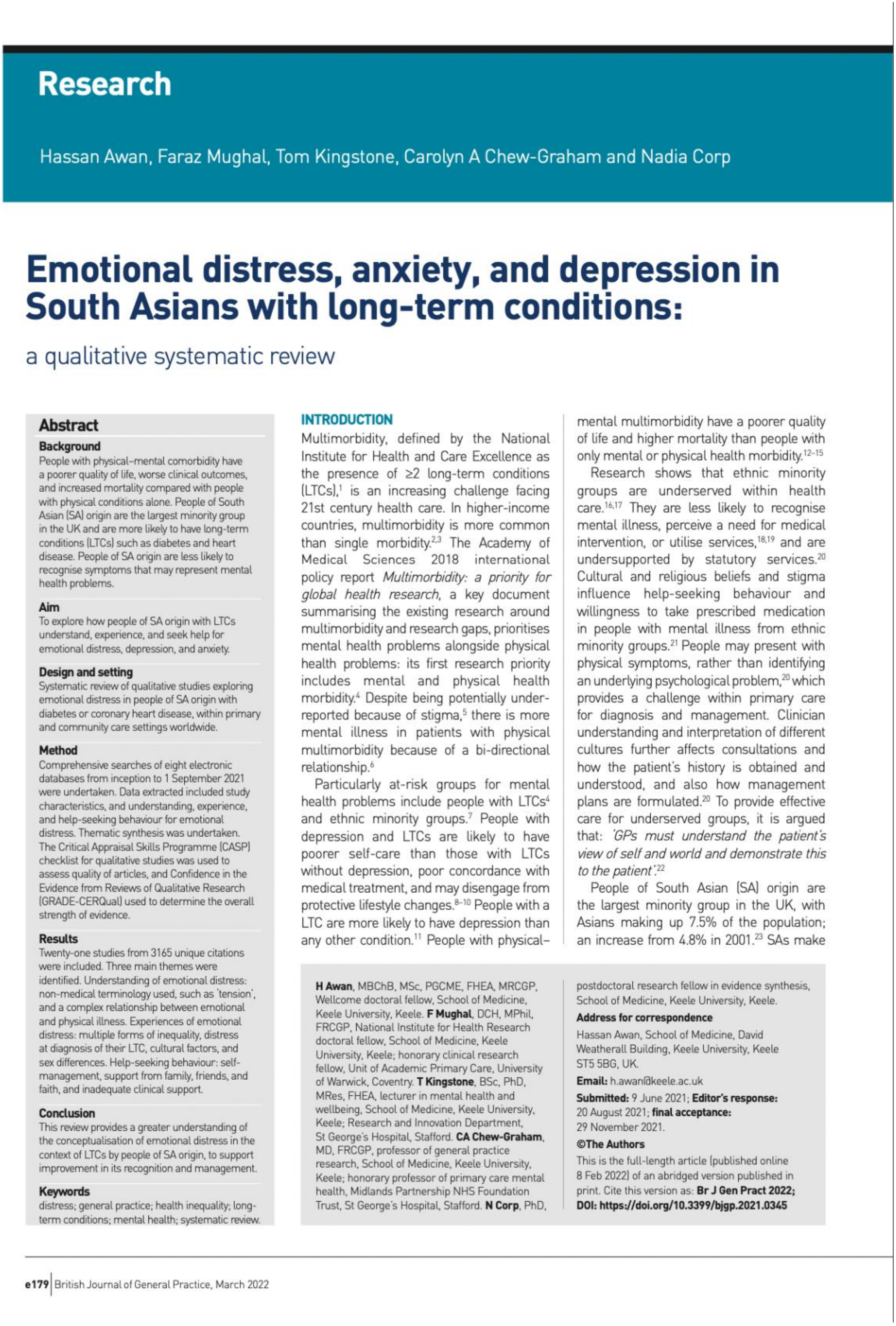
148 23 and 56 and 98 and 147 (689)

***************************

Explanation of syntax:

| | |
|---|---|
| / | Index term |
| exp | All subheadings of this term were selected |
| ti | Search for a term in title |
| ab | Search for a term in abstract |
| kf | Search for a term in key words |
| adj | Search for two terms adjacent to each other |
| adj*n* | Search for two terms where they appear within *n* words of each other |
| */$ | Truncation |

# Appendix 2 Systematic review publication



Research

Hassan Awan, Faraz Mughal, Tom Kingstone, Carolyn A Chew-Graham and Nadia Corp

# Emotional distress, anxiety, and depression in South Asians with long-term conditions:

## a qualitative systematic review

## Abstract

### Background

People with physical–mental comorbidity have a poorer quality of life, worse clinical outcomes, and increased mortality compared with people with physical conditions alone. People of South Asian (SA) origin are the largest minority group in the UK and are more likely to have long-term conditions (LTCs) such as diabetes and heart disease. People of SA origin are less likely to recognise symptoms that may represent mental health problems.

### Aim

To explore how people of SA origin with LTCs understand, experience, and seek help for emotional distress, depression, and anxiety.

### Design and setting

Systematic review of qualitative studies exploring emotional distress in people of SA origin with diabetes or coronary heart disease, within primary and community care settings worldwide.

### Method

Comprehensive searches of eight electronic databases from inception to 1 September 2021 were undertaken. Data extracted included study characteristics, and understanding, experience, and help-seeking behaviour for emotional distress. Thematic synthesis was undertaken. The Critical Appraisal Skills Programme (CASP) checklist for qualitative studies was used to assess quality of articles, and Confidence in the Evidence from Reviews of Qualitative Research (GRADE-CERQual) used to determine the overall strength of evidence.

### Results

Twenty-one studies from 3165 unique citations were included. Three main themes were identified. Understanding of emotional distress: non-medical terminology used, such as 'tension', and a complex relationship between emotional and physical illness. Experiences of emotional distress: multiple forms of inequality, distress at diagnosis of their LTC, cultural factors, and sex differences. Help-seeking behaviour: self-management, support from family, friends, and faith, and inadequate clinical support.

### Conclusion

This review provides a greater understanding of the conceptualisation of emotional distress in the context of LTCs by people of SA origin, to support improvement in its recognition and management.

**Keywords**

distress; general practice; health inequality; long-term conditions; mental health; systematic review.

## INTRODUCTION

Multimorbidity, defined by the National Institute for Health and Care Excellence as the presence of $\geq 2$ long-term conditions (LTCs),[1] is an increasing challenge facing 21st century health care. In higher-income countries, multimorbidity is more common than single morbidity.[2,3] The Academy of Medical Sciences 2018 international policy report *Multimorbidity: a priority for global health research*, a key document summarising the existing research around multimorbidity and research gaps, prioritises mental health problems alongside physical health problems: its first research priority includes mental and physical health morbidity.[4] Despite being potentially under-reported because of stigma,[5] there is more mental illness in patients with physical multimorbidity because of a bi-directional relationship.[6]

Particularly at-risk groups for mental health problems include people with LTCs[4] and ethnic minority groups.[7] People with depression and LTCs are likely to have poorer self-care than those with LTCs without depression, poor concordance with medical treatment, and may disengage from protective lifestyle changes.[8–10] People with a LTC are more likely to have depression than any other condition.[11] People with physical–mental multimorbidity have a poorer quality of life and higher mortality than people with only mental or physical health morbidity.[12–15]

Research shows that ethnic minority groups are underserved within health care.[16,17] They are less likely to recognise mental illness, perceive a need for medical intervention, or utilise services,[18,19] and are undersupported by statutory services.[20] Cultural and religious beliefs and stigma influence help-seeking behaviour and willingness to take prescribed medication in people with mental illness from ethnic minority groups.[21] People may present with physical symptoms, rather than identifying an underlying psychological problem,[20] which provides a challenge within primary care for diagnosis and management. Clinician understanding and interpretation of different cultures further affects consultations and how the patient's history is obtained and understood, and also how management plans are formulated.[20] To provide effective care for underserved groups, it is argued that: *'GPs must understand the patient's view of self and world and demonstrate this to the patient'*.[22]

People of South Asian (SA) origin are the largest minority group in the UK, with Asians making up 7.5% of the population; an increase from 4.8% in 2001.[23] SAs make

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## How this fits in

Mental health is reported to be poorer among people with long-term conditions (LTCs) and people of South Asian (SA) origin, but little is known about their experiences. This research found that people of SA origin with LTCs describe emotional distress using non-medical terminology, even when describing suicidality. This may be related to their cultural understanding of the world. This study highlights the importance of cultural competence to prevent clinicians from being viewed as not understanding their patients and irrelevant as a possible means of support.

up 24.9% of the world population and have significant populations in different countries throughout the world.[24] SAs share cultural features both as indigenous and immigrant populations, which is important given the intrinsic relationship of culture and health.[25] SAs have a higher prevalence of LTCs such as diabetes, with a prevalence of 14% compared with 7% in the general population,[26] and coronary heart disease, with a prevalence of 11% compared with 5% in Europeans.[27] Diabetes and coronary heart disease can be considered as exemplars of LTCs for this research given their higher prevalence in people of SA origin, the similar pathologies, and crossover in symptoms and management of chronic disease. 'Emotional distress' can be defined as upset and negative emotions that do not fit diagnostic criteria for mental illness.[28] This is in contrast to mental health diagnoses such as anxiety and depression; a lack of awareness of mental health conditions and presenting with primarily physical as opposed to mood symptoms may otherwise lead to reduced labelling and diagnosis.[16,19,29] Furthermore, within general practice there is ongoing debate as to whether classifying mental disorders is of benefit to the management of people with distress.[30]

There is a gap in the literature about the experiences of people of SA origin with LTCs, and their experiences of emotional distress. This systematic review asked: how do people of SA origin with long-term physical conditions understand, experience, and seek help for emotional distress, depression, and anxiety?

## METHOD

This systematic review was conducted and reported according to the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (see Supplementary Table S1 for ENTREQ checklist)[31] and the protocol was registered with the International prospective register of systematic reviews (PROSPERO; reference: CRD42019151217).

### Eligibility criteria

Inclusion criteria:

- 'South Asian' populations (people of origin of India, Pakistan, Bangladesh, Afghanistan, Sri Lanka, Maldives, Nepal, Bhutan, or Indian Ocean Islands) with diabetes and/or coronary heart disease;
- studies that describe understanding, experience, or help-seeking behaviour for emotional distress including depression or anxiety;
- primary care, community care, and any community settings worldwide (where distress is experienced in the community);
- studies in any language; and
- qualitative design or mixed-methods studies with a qualitative element.

Exclusion criteria:

- full text not available;
- studies of schizophrenia, psychosis, and dementia;
- paediatric populations (aged 0–17 years) only;
- solely exploring carer experiences;
- quantitative studies, conference abstracts, reviews, editorials, opinion pieces; and
- secondary and tertiary healthcare settings.

### Search methods

Comprehensive searches of eight databases were conducted from inception to 1 September 2021: Medline, Embase, PsycINFO, ASSIA, CINAHLPlus, AMED, Web of Science (Social Science citation index and Conference Proceedings Citation Index — Social Science and Humanities), and Index Medicus for the South-East Asia Region. Searches utilised database subject headings and text words (title, abstract, and keywords) combining terms for 'South Asian' *and* 'diabetes' *or* 'heart disease' *and* 'emotional distress' *and* 'qualitative research' (see Supplementary Table S2 for the Medline search strategy). In addition, reference checking and citation tracking of included studies was also undertaken. Search results were downloaded and imported into Proquest RefWorks (https://refworks.proquest.com). Duplicates were

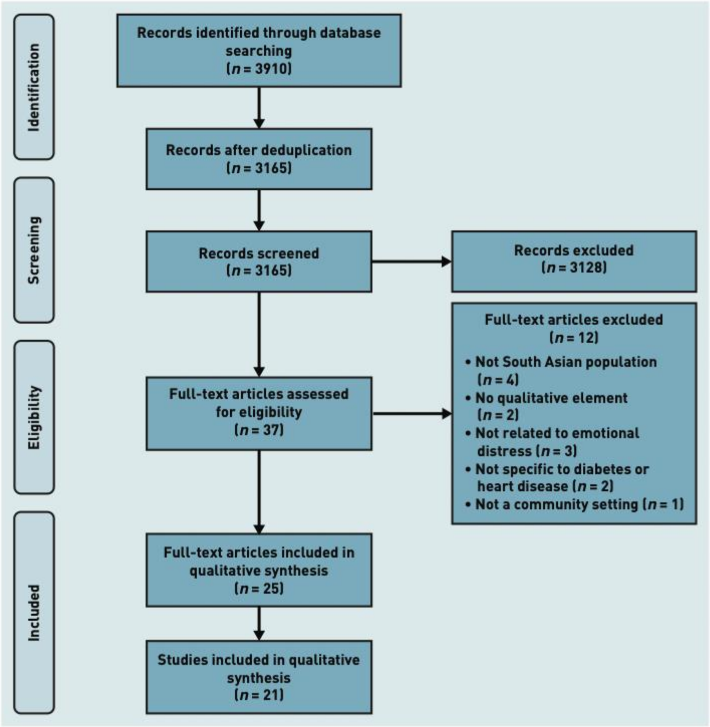


***Figure 1. PRISMA flow diagram.***

removed and screening undertaken within RefWorks.

### Study screening and selection

Two independent reviewers screened titles and abstracts according to the eligibility criteria. Full texts were screened independently and reasons for excluding articles were recorded. At both stages, disagreements were resolved through discussion or referral to a third reviewer.

### Data extraction and quality assessment

Included studies were subject to data extraction and quality appraisal. Data extracted included participant quotes as well as author descriptions of findings. Data were extracted from the abstract, results, and discussion sections if relevant. A data extraction form was developed and piloted using Microsoft Excel. Information was extracted regarding: the study aim, design, data collection methods, method of analysis, participant demographics, setting, number of participants, understanding, experience, help-seeking behaviour for emotional distress, and language of data collection. This formed the data for the synthesis.

Quality assessment of each study was completed alongside data extraction using the Critical Appraisal Skills Programme (CASP) checklist for qualitative data.[32] Disagreements were resolved through discussion to achieve consensus.

Although quality assessment is required to identify biases within the research that could distort findings, studies were not excluded on the basis of quality to allow for broad insights.[33] Confidence in the Evidence from Reviews of Qualitative Research (GRADE-CERQual: https://www.cerqual.org), was used to review the overall confidence in the strength of evidence, initially by the first author and reviewed by all of the authors.

### Thematic synthesis

A thematic synthesis was conducted based on Thomas and Harden,[34] and involved three stages:

- coding of text line-by-line according to its meaning and content;
- translatable concepts from the primary studies were then used to develop descriptive themes; and
- analytical themes were then formed that generated new meaning and explanations.

Subsequent studies were coded into pre-existing codes, and new codes were created when deemed necessary.

An inductive approach was used, allowing the data to determine the themes. The first author kept a reflexive diary throughout the process and the research team discussed reflections on their backgrounds and preconceived ideas around the topic and its effect on the development of the themes.

Descriptive themes were developed, reviewed, and refined iteratively by all members of the research team allowing for members to view raw data and support the generation of analytical themes. The research team consisted of three academic GPs, two of whom are SA, a systematic review specialist, and a social scientist. The first author initially undertook the coding and thematic synthesis using NVivo (version 12) software analysis to facilitate the thematic synthesis.

### Patient and public involvement and engagement

A patient advisory group (PAG) of SAs played a key role during the systematic review process. Members of the PAG worked with the reviewers to refine the systematic review question and discussed key search terms and the methods used. The PAG also discussed the results of the systematic review in detail, including the themes that were found and relevancy to themselves, as well as themes they may have expected which were absent.

## RESULTS

The search identified 3165 unique articles, of which 21 were included for synthesis, depicted in a PRISMA diagram in Figure 1, (see Supplementary Table S3 for characteristics of included studies).

### Study characteristics

Supplementary Table S3 provides the characteristics of the 21 included studies. Studies were from: India ($n = 7$),[35–45] Nepal ($n = 2$),[46,47] Pakistan ($n = 2$),[48,49] Bangladesh ($n = 1$),[50] UK ($n = 4$),[51–54] Canada ($n = 1$),[55] US ($n = 1$),[56] Australia ($n = 1$),[57] Norway ($n = 1$)[58] and Qatar ($n = 1$).[59] Eleven studies included people with diabetes,[35–41,45,48–50,52,57,59] three with diabetes in pregnancy,[45,51,58] one with diabetes and heart disease,[43,44] and six studies were about people with coronary heart disease.[42,47,53–56]

Four of the articles from India with people with diabetes were based on the same initial cohort of patients and have been considered as one study.[35–38] Two of the articles from India with people with diabetes and coronary heart disease were based on the same initial cohort of patients and have been considered as one study.[43,44] One study included 30 participants of four ethnicities (including non-SA) and did not state how many participants were of each ethnicity,[57] and one study had participants with four different diseases and did not state how many had diabetes and heart disease,[43,44] leading to an approximation of 580–606 participants of South Asian origin included, 575–601 participants with diabetes, 93 participants with coronary heart disease and 2–39 participants with diabetes and heart disease.

Study methods used were semi-structured interviews ($n = 6$),[46,48,52–54,56] in-depth interviews ($n = 7$),[39,43–45,47,49,50,57] focus groups and in-depth interviews ($n = 3$),[40,41,58] focus groups ($n = 2$),[42,59] semi-structured interviews and case studies ($n = 1$),[35–38] group story-sharing sessions and individual biographical life narrative interviews ($n = 1$),[51] and narrative interviews ($n = 1$).[55]

Ages ranged from 24 to 88 years. Although some described ethnicity broadly as SA, for the majority of studies that gave more specific details, Indian participants were of the largest numbers, with participants from Bangladesh, Nepal, Pakistan, and Sri Lanka also included.

### Quality appraisal

The quality appraisal of the studies according to the CASP criteria is outlined collectively in Figure 2 and individually for each study in Supplementary Table S4. This addresses the 10 questions from the CASP checklist for qualitative data questions based on three areas: if the results are valid, what the results are, and if they will help locally. The questions can be answered as yes (✓), no (×), or partial (p).

### Themes

Three main themes were identified of:

- understanding emotional distress;
- management of emotional distress; and
- help-seeking behaviour for emotional distress.

These three themes were constituted of 10 subthemes, which are presented in Figure 3. The GRADE-CERQual assessment of strength of evidence for each theme are presented in Supplementary Table S5, as well as contributing studies to each theme. The contribution of studies to each theme highlighted the value of the different studies to this systematic review, which was considered according to the quality of the studies.

### Understanding emotional distress

Two main themes emerged regarding understanding of emotional distress: using the terminology of tension to describe emotional distress, and causation and complexity with emotional and physical illness.

*Using the terminology of tension to describe emotional distress (high confidence — 14 studies).* Terminology used regarding emotional distress was noticeable by a lack of use of medical terminology such as depression, anxiety, or distress. In one study the authors described:

> *'People rarely described these emotional crises as "depression." They did not necessarily associate their sadness, sense of hopelessness or despondency with depressive illness.'*[57]

Not only were episodes of emotional distress not considered as mental health episodes, they were not associated with a mental health diagnosis by the South Asian participants. Emotional distress was instead defined primarily as tension:

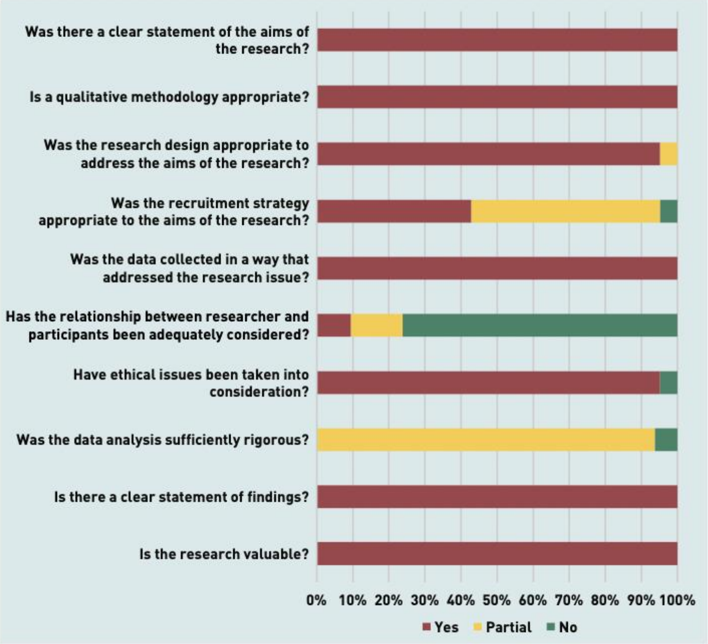
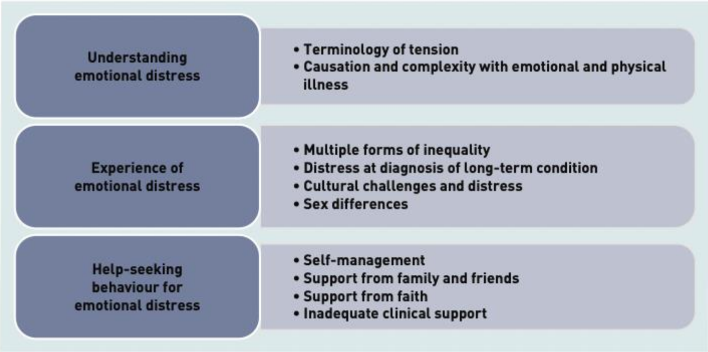


***Figure 2. Overall quality appraisal based on 10 questions from the Critical Appraisal Skills Programme checklist for qualitative data.***

***Figure 3. Main themes.***



*'I got it* [diabetes] *from tension after my husband's death.'*[39]

Other terminology used to describe emotional distress included specific emotions, such as stress[35] and anger.[42]

*Causation and complexity with emotional and physical illness (high confidence — 18 studies).* SAs with LTCs described a complex and interrelated relationship between emotional distress and physical illness. Emotional distress was described as causing physical illness, from both acute and chronic stress. For example, an Indian participant stated:

*'I got diabetes because of tension only. It's not because of food habits or lifestyle.'*[39]

Another participant ascribed his heart attack to his perpetual psychological inclination towards anger.[54]

As well as being a causative agent of physical illness, emotional distress was further felt to cause a deterioration in physical illness, as a Bangladeshi participant who had experienced a heart attack stated that:

*'Worry make you worst don't it.'*[53]

Physical illness was felt to cause emotional distress. One study described how:

*'Participants also considered that diabetes "caused" stress in relation to controlling the condition and preventing complications, and in response to doctors' comments.'*[57]

Numerous elements were thought to lead to physical illness causing emotional distress. This included regret and not making lifestyle changes earlier,[56] symptoms of the LTC such as physical restrictions caused by shortness of breath,[47] stress of making lifestyle changes,[41] anxiety around tests such as checking blood sugar,[36] and taking medication, in particular insulin.[59] For women with diabetes in pregnancy, distress stemmed from the stress of health consequences for the participant, their baby, and managing a busy schedule of multiple clinic appointments and regular testing.[45,51,58]

Participants reported that positive emotional health reduced physical illness.[52] When physical health was good, this also had a positive impact on emotional wellbeing:

*'When my blood sugar level is normal I become very happy.'*[48]

## Experience of emotional distress

Four main themes emerged regarding experiences of emotional distress: multiple forms of inequality, distress at diagnosis of the LTC, cultural challenges and distress, and sex differences.

*Multiple forms of inequality (high confidence — 10 studies).* SAs described multiple forms of inequality as a source of distress throughout studies from different contexts worldwide, as well as being a direct cause of physical illness. Poverty was described throughout all studies internationally:

*'Poverty causes illness and illness causes poverty, it is a cycle in this way ... in my experience chhinta* [angst/anxiety] *and poverty gave me the gift of sugar.'*[46]

The extent of suffering from poverty was so severe that a female Nepalese participant described attempting suicide because of severe poverty and not being able to manage her diabetes.[46]

A combination of being SA, having a LTC, poverty, and COVID-19 lead to feelings of helplessness and emotional distress from loss of income:

*'The income is stopped so this is natural worry. That's the tension which I have on every 3rd or 4th day.'*[44]

Participants were anxious about attending hospital care because of their higher risk of mortality with COVID-19 given their LTC. A participant with diabetes described:

*'Everyone scares us saying that it is difficult for the diabetic. So I didn't want that to happen. Because they had the spread the awareness that diabetics, old aged people have a problem during this corona. And yes I was scared.'*[44]

*Distress at diagnosis of the LTC (high confidence — 10 studies).* Participants felt a wide range of emotions related to the diagnosis of a LTC; this was felt to be a life-defining moment. These included being 'scared',[45] 'shocked',[52] 'fear',[47] and 'a disaster'.[59] Some participants described a negative change in aspects of their personality after diagnosis, such as lacking confidence and motivation, which was more profound in participants with coronary heart disease:

*'Yes, there is one change that I have noticed, if there emerges any small or bigger issue at home or the workplace, I get anxious.'*[42]

Emotional distress relating to a LTC tended to reduce over time with participants *'getting used to'*[36] their illness.

*Cultural challenges and distress (high confidence — 14 studies).* Culture was found to play an important role in experience of emotional distress. One participant described how it was part of Indian culture to have high levels of stress:

*'yes in our Indians we take on a lot of tension.'*[55]

Acculturation (the process of adjusting to a new culture) was described in many forms; one example of this was from people of SA origin who were in a higher socioeconomic demographic in their country of origin who had to adapt to changing roles and more manual work in their country of destination.[55]

Within SA culture, there was a greater level of stigma felt for people with LTCs, such as gestational diabetes being viewed as occurring as a result of lack of self-discipline,[58] and discrimination felt by participants with coronary artery disease[42] and if they contracted COVID-19.[44] One participant described that:

*'Near my home in my area they speak very bad about diabetes people.'*[41]

Cultural differences were identified. Indian men were found to normalise symptoms of cardiac events, for example, stating after a heart attack, *'I feel that nothing happened to me'*;[53] whereas Bangladeshi participants experienced more anxiety, low mood, less positivity, and a greater fear of lifting heavy objects.[52]

*Sex differences (moderate confidence — eight studies).* Differences were found between the experience of male and female people of SA origin with LTCs. Female participants tended to have stronger emotional reactions, in particular to diagnosis, and related negative feelings to experiences of family members. One female participant stated:

*'Yes it was shock, because I saw my brother* [who had diabetes]*, he was really bad.'*[52]

Men perceived having less control of their health, describing an external locus of control in different manners[59] and greater emotional distress with regards to their employment:

*'Obviously as a man, obviously if you have family, obviously the first thing you think about is money ... I don't want for someone to support me. I feel humiliated.'*[53]

**Management of emotional distress**

Four main themes emerged regarding management of emotional distress: self-management, support from family and friends, support from faith, and inadequate clinical support.

*Self-management (high confidence — 13 studies).* A key area described before seeking help for emotional distress was self-management. Self-management began with having a positive mindset. One participant described the power of positive thinking, stating:

*'It's your thinking that makes your body feel sick. It's all in the mind.'*[35]

Some participants made proactive lifestyle changes after coping with emotional distress from their LTC, such as going from multiple jobs to one job after a coronary event.[56]

Other lifestyle modifications included stress-reduction techniques, as well as exercise, yoga to reduce stress, prayer, voluntary work, listening to music, and reducing smoking and alcohol intake.[47]

*Support from family and friends (moderate confidence — eight studies).* Family and friends were described as great sources of support during distress, in particular children who were active in their parents' lives:

*'My son lives not far from my house. I see him every day … When you can count on somebody, even in the back of your mind, you relax.'*[53]

One study found the involvement of family and friends the most important mechanism of maintaining emotional wellbeing and physical health.[47] Advice from peers was *'familiar, meaningful, and morally resonant.'*[51]

*Support from faith (moderate confidence — six studies).* A strong theme across ethnic groups was a faith in a higher being and emotional support from the higher being as well as their spiritual community, be it from the temple or mosque community.[55] This was strongest among the Bangladeshi community, as one participant stated:

*'It all depends how much faith you have on the Almighty … people who, they have weak faith they're more worried … If you have strong faith that gives you strength in order to endure the situation and overcome it and adjust to it.'*[53]

Practically, acts of worship such as 'Dhikr' (saying formulas of remembrance of God), were felt to reduce distress:

*'Dhikr of Allah gives relief to hearts and because of this our sugar is under control. Whatever it is, it is from Allah and we have to accept it heartedly.'*[48]

Some participants displayed reticence and frustration with the higher being. One participant struggling with eyesight complications from diabetes described how:

*'Now I feel sad with the thought that Allah is depriving me from many things with time.'*[48]

*Inadequate clinical support (moderate confidence — seven studies).* Participants of all ethnicities were critical of clinical support, for both their psychological issues and their medical issues, for example:

*'Doctors are not helping us.'*[59]

Another participant described how:

*'Doctors never explain why I am feeling down.'*[59]

Some participants described clinicians being rude, discriminatory, and uncaring within hospital settings.[45,53] Health education advice was felt to be unfamiliar, using medical jargon and devoid of empathy and cultural meaning.[51] Conversely, participants from all ethnic backgrounds who had a heart attack stated they would like access to psychological support following the event.[53]

Participants also described visiting traditional healers for psychological as well as physical problems in SA countries.[40]

### PAG feedback

The results were discussed with the PAG, providing a further layer of credibility, and the PAG agreed with all of the themes. However, the PAG discussed a number of culturally common beliefs that were not found in the findings, such as black magic and envy as causes of emotional distress, and faith leaders as a source of support.

## DISCUSSION

### Summary

This review synthesised evidence regarding the understanding, experience, and help-seeking behaviour for emotional distress, depression, and anxiety in people of SA origin with LTCs. Distress is understood in terms of tension and emotions such as stress and anger, with medical terminology such as depression of less relevance. Emotional distress and physical illness have a complex and interrelated relationship.

With regards to experiences of emotional distress, multiple forms of inequality lead to emotional distress, such as poverty, being SA, and having a LTC. The period of time when they receive a diagnosis of a LTC is particularly difficult.

Adapting, with regard to specific aspects of SA culture, is a significant cause of emotional distress. Sex differences have been identified. In terms of management, people of SA origin self-manage via activities such as stress-reduction exercises, prayer, and exercise.

Family and friends can be an excellent source of support. Generally, spiritual and religious support is felt to be important, and clinical support is felt to be of limited benefit and devoid of cultural meaning.

### Strengths and limitations

To the authors' knowledge, this is the first systematic review to explore the understanding, experiences, and help-seeking behaviour for emotional distress in people of SA origin with LTCs. It highlights a gap between the need of this group for support for emotional distress and the services offered by clinicians. The GRADE-CERQual assessment of themes ranged from high to medium, providing confidence in the strength of evidence. This review has the potential to lead to improvement in the recognition and management of emotional distress. It also has the potential to influence policymakers and commissioners about service provision for this patient group.

An ethnically appropriate PAG was another strength of this review. The PAG discussed causes of potentially missing data, such as black magic and envy as causes of emotional distress, and faith leaders as a source of support. The group suggested these concepts may not have been mentioned because of censorship, participants may not have felt comfortable discussing such concepts with interviewers, or they may not have been considered in topic guides. The group felt that these concepts may not be elicited except through direct questioning with interviewers who understand SA culture.

A limitation is the challenge of comparing the experiences of people of SA origin within and outside of SA. Although cultural aspects may remain consistent, different contextual factors mean that comparisons must be made with caution. Furthermore, although there are many similarities across people of SA origin, they encompass a diverse group living in different geographical areas, with differing languages and religions, and there is a level of heterogeneity and difference between the experience of SAs of different backgrounds that could be further explored.

### Comparison with existing literature

This review builds on previous systematic reviews of emotional distress and mental health problems in people of SA origin,[29] and also the experiences of living with LTCs in people of SA origin.[60–62] It provides new understanding in exploring emotional distress in people of SA origin with LTCs by bringing together multiple studies. The review shows that the relationship between emotional distress and physical illness is complex and interrelated. This leads to something greater than just the addition of two (or more) separate illnesses, but instead a new entity of comorbidity greater than the sum of its parts, and is directly affected by the cultural context and social factors within a person's life. This is consistent with the concept of syndemics, in which the social reality a person experiences shapes their experience of their illness, based on social, cultural, and economic factors.[39]

This review highlights how multiple forms of inequality act as a key contributing factor to both emotional and physical distress in people of SA origin who have LTCs. The social determinants of health are intertwined with ethnicity, for example, the Marmot report describes the lower life expectancy of people of Pakistani and Bangladeshi origin in the UK is primarily due to poverty rates, with 46% of people of Pakistani origin and 50% of people of Bangladeshi origin living in poverty.[63] Ethnic minority groups with mental health problems may require greater attention as part of 'proportionate universalism' to reduce this health inequality and improve their health.

The NHS Long Term Plan[64] prioritises the reduction of health inequality and the NHS Mental Health Implementation Plan 2019/20–2023/24 calls for increased funding and the development of a Patient and Carer Race Equality Framework (PCREF) to improve ethnic minority health outcomes.[65] However, there is a significant policy gap to integrating physical–mental health services. A King's Fund report highlights the need for a more integrated approach and 'joined-up services' for a significant number of people with both mental and physical multimorbidity, after years of underinvestment and neglect of mental health services funding.[66] Until these multiple forms of inequality are addressed, gains in health improvement may be minimal.

Religion as a coping mechanism for emotional distress has a rich history within SAs as well as other communities,[67] and is being increasingly researched as a potential area of intervention and improving care, such as culturally adapted psychotherapy for depression.[68] There is potential for such developments to be situated in primary care. However, this review found that people of SA origin with LTCs who are experiencing emotional distress generally found clinical services of little benefit, and had significant scepticism about medical professionals because of their lack of cultural awareness and understanding. Mistrust of medical professionals in ethnic minorities has been described in African Americans for example, as a result of a historical narrative of persecution,[25] which parallel some historical narratives with SAs and may be a cause of the mistrust of healthcare professionals found in people of SA origin.[69] A qualitative study looking at barriers to managing depression in people with LTCs in primary care found uncertainty in labelling depression in patients with LTCs that would facilitate shared understanding and future management.[70]

Developing cultural competency in clinicians could potentially reduce health inequalities,[71] which is a mandatory aspect of medical education in the US;[72] however, in other countries such as the UK it is not.

### Implications for research and practice

There is a lack of research around males of SA origin with emotional distress, yet clear sex differences have been identified. A priority for future research is to explore the understanding, experience, and help-seeking behaviour in men of SA origin with emotional distress, in particular regarding areas that members of the PAG felt were missing from the systematic review. Furthermore, given that primary care is perceived by people of SA origin to be culturally inappropriate in supporting them, the perspectives of clinicians within primary care, in particular GPs, is needed to understand this perceived gap, and perspectives from clinicians trying to support this group.

A key implication for clinical practice is the need for clinicians within primary care to develop a level of cultural competency so that people of SA origin with emotional distress feel comfortable and willing to seek help from them. Health education must have meaning within the culture of the patient for them to gain benefit from it. Until this happens, this group of people may not engage with primary care and services to support them. There is the need for clinicians to consider emotional distress in people of SA origin with LTCs when the patient uses culturally specific terminology such as tension to describe their mental state.

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**Provenance**
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Appendix 3 Recruitment poster for SA men

Version 0.8 14/04/20

# Are you a male of South Asian origin? Do you have diabetes and/or heart disease?

**Would you agree to take part in research which will help us understand how you deal with emotions, such as feeling low, anxious, stressed or depressed?**

## What is involved?

A single interview of around 45 minutes at a time and place convenient for yourself, in person or online.

You will receive a £20 voucher for your time as well as reasonable travel expenses.

## How will your interview be used?

Your interview will be completely confidential and will write it up and make it anonymous.

Your contribution will improve care of men of South Asian origin with long-term conditions and emotional distress.

## Interested to participate?

For more details please email Dr Hassan Awan, a GP and Wellcome PhD student at Keele University h.awan@keele.ac.uk or ring 01782 732 936.

Appendix 4 Participant information sheet for SA men

# Participant Information Leaflet for Males of South Asian Origin with Diabetes or Heart Disease

**How do men of South Asian origin with long term physical conditions understand, experience and seek help for emotional distress?**

We invite you to take part in our research study entitled "How do men of South Asian origin with long term physical conditions understand, experience and seek help for emotional distress?" Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve.

**Please take your time to read this information sheet carefully.** Should you have any questions please contact Dr Hassan Awan (Tel: 01782 732 936 or Email: h.awan@keele.ac.uk).

## Who is carrying out this research?

This study is being carried out by Dr Hassan Awan, a GP and Wellcome PhD fellow under the supervision of Professor Carolyn Chew-Graham, Dr Tom Kingstone and Dr Nadia Corp at the School of Primary, Community and Social Care, Keele University.

## Summary:

- This study is being carried out by researchers at Keele University
- Your participation is voluntary
- The research has been approved by Keele University Research Ethics Committee
- Participation involves a single interview, lasting approximately 45 minutes, at a location convenient for you
- Your consent to take part will be recorded prior to the interview
- Your personal information will be made anonymous so that what you say in the interview cannot be linked back to yourself

## What is the reason for this research?

The reason for the research is to find out what men of South Asian origin with diabetes and heart disease feel causes them to become distressed, how they get help and what help they would like when they feel distressed. We hope that this study will help to find, support and treat emotional distress in men of South Asian origin with long-term conditions.

## Why have I been invited?

As a male of South Asian origin with diabetes and/or heart disease, we would be interested in hearing your views and experiences.

This research is not suitable for people who are currently receiving inpatient hospital care, have dementia or who lack capacity to agree to be involved in the research.

## Do I have to take part?

You do not have to take part in this study. Participation is entirely voluntary. You are also free to withdraw at any time during the interview, without giving any reason and without your rights, treatment or the care you receive being affected. If you would like to withdraw, email h.awan@keele.ac.uk stating you would like to withdraw from the study. You may withdraw your interview data up to four weeks after the date consent was provided (i.e. the date of your interview); this data will then be destroyed.

## What does taking part involve?

You are invited to attend an interview conducted by Dr Hassan Awan. The interview will be held at a place and time convenient to you (e.g. at your home address or Keele University or other place). The interview can take place in person, but if this is not possible, or if you would prefer, then a telephone or online interview (via Google Hangouts) can also be arranged.

You will be asked to sign a consent form stating that you agree to take part in the study. This is to record that you have read this information sheet, understand what the research study is about, and that you agree to take part as described.

During the interview we will discuss your personal experiences of emotional distress, with a particular focus on how you understood it and if you sought help. We will also discuss how the COVID-19 pandemic has affected your emotional wellbeing and care of your diabetes and/or heart disease. With your permission, we will audio-record the interview and write this up for our analysis. We expect the interview to last around 45 minutes.

## Will I be reimbursed for my time?

You will receive a £20 voucher to recompense your time, and reasonable travel expenses will be reimbursed.

## What are the benefits/risks of taking part?

There may not be an immediate benefit of taking part in this study, although some individuals may find it helpful to talk through their experiences. Your contribution will be valuable in enabling us to learn more about emotional distress in men of South Asian origin with long-term physical conditions. We expect this to lead to advances in research and make healthcare services better at supporting men of South Asian origin with long-term physical conditions.

Whilst there are no expected risks, some individuals may find talking about their personal experiences distressing. If during the interview you feel distressed or get upset, you can ask to take a break or end the interview. The researcher will provide information about services that you may wish to access (e.g. counselling services).

## Who will have access to information about me?

Your participation will be kept confidential so no else will know you have taken part (in exceptional circumstances where there is a risk of harm, relevant professionals will be informed). Keele University is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Keele University will keep identifiable information about you for up to 6 months.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. Your personal data will be processed in accordance with Keele University Standard Operating Procedures and in line with the General Data Protection Regulation (GDPR). You can find out more about how we use your information at https://www.keele.ac.uk/informationgovernance/checkyourinformationisbeinghandledcorrectly/privacynotice-researchparticipants/.

Prior to the interview, Dr Hassan Awan will request your written permission to audio-record the interview and transcribe it. The anonymised research data will be stored for a minimum of 10 years.

Please note, in exceptional circumstances during the course of your participation in this research, where a research team member has any safety concerns about you or others the team may need to breach confidentiality to share these concerns with appropriate services.

## What will happen to the results of the study?

We will write up what we find out from the interviews for a professional research journal so that the findings are shared with other academics and healthcare professionals. We also intend to present the findings at conferences that are open to members of the public and circulate summary reports to local voluntary organisations. Your personal information will not be used in any of these documents or presentations. This study will form an important foundation to develop further research into managing emotional distress for men of South Asian origin with long-term physical conditions.

## Who is funding the research?

This research project is funded by The Wellcome Trust as part of Dr Hassan Awan's PhD fellowship.

## Has the research study been ethically approved?

Yes, this study has been ethically approved by Keele University's Keele University's Research Ethics Committee.

## Who do I contact if there is a problem?

To speak to the lead study supervisor, please contact:

**Professor Carolyn Chew-Graham**
School of Primary, Community and Social Care, Keele University, ST5 5BG
Email: c.a.chew-graham@keele.ac.uk
Telephone: 01782 734 717

To make a complaint or speak to someone outside of the research team, please contact:

**Dr Tracy Nevatte**
Directorate of Research, Innovation and Engagement
Innovation Centre Building 2, Keele University, ST5 5NH
Email: research.governance@keele.ac.uk
Telephone: 01782 733 371

## For all other enquiries or to arrange an interview please contact Dr Hassan Awan

School of Primary, Community and Social Care, Keele University, ST5 5BG
**Email**: h.awan@keele.ac.uk
**Telephone**: 01782 732 936

Appendix 5 Email to GP Practices

## Recruitment email for Practice Managers and GPs

### Recruitment email for Practice Managers:

Dear [name of practice manager],

I am a GP and Wellcome PhD researcher at Keele University. I appreciate it is a challenging and unprecedented time in General Practice which has adapted incredibly well during the COVID-10 pandemic. I am conducting a qualitative study to better understand how males of South Asian origin with long-term physical conditions understand and seek help for emotional distress. The study involves interviewing GP partners or salaried GPs who see males of South Asian origin with long-term physical conditions to better understand their experiences managing emotional distress, for an interview of approximately half an hour in their place of preference. The interview will also explore their views on the impact of COVID-19 on the management of long-term conditions and emotional distress. The interview can take place in person, but if this is not possible, or if you would prefer, then a telephone or online interview (via Google Hangouts) can also be arranged.

I appreciate that GPs are very busy, to help offset their time financial renumeration will be provided for GPs' time at a rate of £88 per hour. Further details are attached in the participant information sheet. A recent BJGP Live video I was involved in shows the relevance of this work for GPs (https://bjgplife.com/2020/06/05/the-importance-of-cultural-competencies-to-improve-care-for-all/). I would be very grateful if you could forward my email to the GPs at your practice. If they would be willing to take part in my study, please email me at h.awan@keele.ac.uk or ring 01782 732 936. They will have the chance to find out more about the study before coming to any decision. They would be under no obligation to take part.

The use of email to recruit participants for this study has been approved by the Keele University Research Ethics Committee as well as the NHS Health Research Authority.

Best Regards,

Dr Hassan Awan

Wellcome Research Fellow, Keele University

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**Recruitment email for GPs:**

Dear Dr,

I am a GP and Wellcome PhD researcher at Keele University. I appreciate it is a challenging and unprecedented time in General Practice which has adapted incredibly well during the COVID-10 pandemic. I am conducting a qualitative study to better understand how males of South Asian origin with long-term physical conditions understand and seek help for emotional distress. The study involves interviewing GP partners or salaried GPs who see males of South Asian origin with long-term physical conditions to better understand their experiences managing emotional distress, for an interview of approximately half an hour in your place of preference. The interview will also explore your views on the impact of COVID-19 on the management of long-term conditions and emotional distress. The interview can take place in person, but if this is not possible, or if you would prefer, then a telephone or online interview (via Google Hangouts) can also be arranged.

I appreciate that GPs are very busy, to help offset your time financial renumeration will be provided for your time at a rate of £88 per hour. Further details are attached in the participant information sheet. A recent BJGP Live video I was involved in shows the relevance of this work for GPs (https://bjgplife.com/2020/06/05/the-importance-of-cultural-competencies-to-improve-care-for-all/). I would be very grateful if you would be willing to take part in my study.  If you are interested, please email me at h.awan@keele.ac.uk or ring 01782 732 936. If you do so, you will have the chance to find out more about the study before coming to any decision. You would be under no obligation to take part.

The use of email to recruit participants for this study has been approved by the Keele University Research Ethics Committee as well as the NHS Health Research Authority.

Best Regards,

Dr Hassan Awan

Wellcome Research Fellow, Keele University

Appendix 6 Participant information sheet for GPs

# Participant Information Sheet for General Practitioners

**How do men of South Asian origin with long term physical conditions understand, experience and seek help for emotional distress?**

We invite you to take part in our research study entitled "How do men of South Asian origin with long term physical conditions understand, experience and seek help for emotional distress?" Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve.

**Please take your time to read this information sheet carefully.** Should you have any questions please contact Dr Hassan Awan (Tel: 01782 732 936 or Email: h.awan@keele.ac.uk).

## Who is carrying out this research?

This study is being carried out by Dr Hassan Awan, a GP and Wellcome PhD fellow under the supervision of Professor Carolyn Chew-Graham, Dr Tom Kingstone and Dr Nadia Corp at the School of Primary, Community and Social Care, Keele University.

## Summary:

- This study is being carried out by researchers at Keele University
- Your participation is voluntary
- The research has been approved by Keele University Research Ethics Committee and NHS Health Research Authority
- Participation involves a single interview, to last approximately half an hour, at a location convenient for you
- Consent to take part will be recorded prior to the interview
- Your personal information will be anonymised (i.e. interview data cannot be linked back to you on publication)

## What is the purpose for this research?

The aim of the study is to explore how men of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress. We hope that this study will improve the recognition, referral and management of emotional distress in males of South Asian origin with long-term conditions. In this study we will be conducting one-to-one interviews with up to 20 GPs who see South Asian male patients with long-term conditions. This study will add to existing knowledge about how GPs recognise and manage emotional distress in males of South Asian origin with long-term physical conditions. The findings will inform UK healthcare provision and future research.

## Why have I been invited?

As a GP partner or salaried GP who sees males of South Asian origin with long-term physical conditions, we would be interested in hearing your views and experiences.

This research is not suitable for GP trainees and locum GPs who are not attached to practices.

## Do I have to take part?

You do not have to take part in this study. Participation is entirely voluntary. You are also free to withdraw at any time during the interview, without giving any reason and without your rights, treatment or the care you receive being affected. You may withdraw interview data up to four weeks after the date consent was provided (i.e. the date of your interview); this data will then be destroyed.

## What does taking part involve?

You will be invited to attend an interview conducted by Dr Hassan Awan. The interview will be held at a place and time convenient to you (e.g. at your work address or Keele University). The interview can take place in person, but if this is not possible, or if you would prefer, then a telephone or online interview (via Google Hangouts) can also be arranged.

You will be asked to sign a consent form stating that you agree to take part in the study. This is to record that you have read this information sheet, understand what the research study is about, and that you agree to take part as described.

During the interview we will discuss your experiences managing emotional distress in South Asian males with long term physical conditions, with a particular focus on how they present and barriers and facilitators to care. The interview will also explore your views on the impact of COVID-19 on the management of long-term conditions and emotional distress. With your permission, we will audio-record the interview and write this up for our analysis. We expect the interview to last approximately half an hour.

## Will I be reimbursed for my time?

You will receive £88 per hour to recompense your time and reasonable travel expenses will be reimbursed.

## What are the benefits/risks of taking part?

There may not be an immediate benefit of taking part in this study. Your contribution will be valuable in enabling us to learn more about managing emotional distress in males of South Asian origin with long-term physical conditions. We expect this to lead to important advances in research, healthcare provision and policy.

Whilst there are no expected risks, some individuals may find talking about experiences with patients distressing. If during the interview you feel distressed or get upset, you can ask to take a break or end the interview. The researcher will provide information about services that you may wish to access.

## Who will have access to information about me?

Your participation will be kept confidential (in exceptional circumstances confidentiality may need to be breached). Keele University is the sponsor for this study. As we will be collecting information from you as part of the study, Keele University will act as the data controller for this information. This means that the research team (on behalf of Keele University) are responsible for looking after your information and using it properly. Keele University will keep identifiable information about you for up to 6 months.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. Your personal data will be processed in accordance with Keele University Standard Operating Procedures and in line with the General Data Protection Regulation (GDPR). You can find out more about how we use your information at https://www.keele.ac.uk/informationgovernance/checkyourinformationisbeinghandledcorrectly/privacynotice-researchparticipants/.

Prior to the interview, Dr Hassan Awan will request your written permission to audio-record the interview and transcribe it. The anonymised research data will be stored for a minimum of 10 years.

Please note, in exceptional circumstances during the course of your participation in this research, where a research team member has any safety concerns about you or others the team may need to breach confidentiality to share these concerns with appropriate services.

## What will happen to the results of the study?

We will write up what we find out from the interviews for a professional research journal so that the findings are shared with other academics and healthcare professionals. We also intend to present the findings at conferences that are open to members of the public and circulate summary reports to local voluntary organisations. Your personal information will not be used in any of these documents or presentations. This study will form an important foundation to develop further research into managing emotional distress in males of South Asian origin with long-term physical conditions.

## Who is funding the research?

This research project is funded by The Wellcome Trust as part of Dr Hassan Awan's PhD fellowship.

## Has the research study been ethically approved?

Yes, this study has been ethically approved by Keele University's Keele University's Research Ethics Committee (REC) and the NHS Health Research Authority (HRA).

## Who do I contact if there is a problem?

To speak to the lead study supervisor, please contact:

**Professor Carolyn Chew-Graham**
School of Primary, Community and Social Care, Keele University, ST5 5BG
Email: c.a.chew-graham@keele.ac.uk

Telephone: 01782 734 717

To make a complaint or speak to someone outside of the research team, please contact:

**Dr Tracy Nevatte**
Directorate of Research, Innovation and Engagement
Innovation Centre Building 2, Keele University, ST5 5NH
Email: research.governance@keele.ac.uk
Telephone: 01782 733 371

**For all other enquiries or to arrange an interview please contact Dr Hassan Awan**

School of Primary, Community and Social Care, Keele University, ST5 5BG
**Email**: h.awan@keele.ac.uk
**Telephone**: 01782 732 936

Appendix 7 Interview consent form for males of SA origin with diabetes and/or heart disease

# Interview consent form for males of South Asian origin with diabetes and/or heart disease

## How do males of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress?

Keele university's data protection policy will be adhered to at all times (https://www.keele.ac.uk/informationgovernance/fortheuniversity/dataprotection/).

Please **initial** each statement
on the dotted line to
confirm that you agree

1. I have read and understood the participant information sheet (version 0.8 dated 18.04.2020) and have had the opportunity to ask questions and had these suitably answered. ............
2. I understand that taking part in this interview is voluntary and that I can withdraw at any time without giving any reason and without my legal rights being affected, and that I can withdraw my data from final analysis and dissemination up to four weeks after today. ............
3. I agree for the interview to be audio recorded and transcribed and that the recordings will be stored in a secure location and will bear no personal identifying information. ............
4. I understand that anonymous copies of transcripts will be kept for a minimum of 10 years after publication of the research and may be used in future research. ............
5. I understand that anonymised electronic data files will be stored for a minimum of 10 years. ............
6. I agree to my anonymised quotes being used in the publication of the results of the study. ............

7 I understand that my participation in this research study will be kept confidential. ............

8. I understand that if a research team member has any safety concern about me or others the team may breach confidentiality to share these concerns with appropriate services ............
9. I agree to take part in the interview. ............

**Please sign and date below:**

| | | |
|---|---|---|
| Name of participant | Date | Signature |
| Name of researcher | Date | Signature |

**One copy to be retained by researcher. One copy to be retained by participant.**

## Appendix 8 Interview consent form for GPs

# Interview consent form for General Practitioners

**How do males of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress?**

Keele university’s data protection policy will be adhered to at all times (https://www.keele.ac.uk/informationgovernance/fortheuniversity/dataprotection/).

Please **initial** each statement
on the dotted line to
confirm that you agree

1. I have read and understood the participant information sheet (version 0.7 dated 18.04.2020) and have had the opportunity to ask questions and had these suitably answered. ............
2. I understand that taking part in this interview is voluntary and that I can withdraw at any time without giving any reason and without my legal rights being affected, and that I can withdraw my data from final analysis and dissemination up to four weeks after today. ............
3. I agree for the interview to be audio recorded and transcribed and that the recordings will be stored in a secure location and will bear no personal identifying information. ............
4. I understand that anonymous copies of transcripts will be kept for a minimum of 10 years after publication of the research and may be used in future research. ............
5. I understand that anonymised electronic data files will be stored for a minimum of 10 years. ............
6. I agree to my anonymised quotes being used in the publication of the results of the study. ............

7 I understand that my participation in this research study will be kept confidential. ............

8. I agree to take part in the interview. ............

**Please sign and date below:**

| | | |
|---|---|---|
| Name of participant | Date | Signature |
| Name of researcher | Date | Signature |

**One copy to be retained by researcher. One copy to be retained by participant.**

Appendix 9 Participant thank-you letter

School of Primary, Community & Social Care
Keele University
Staffordshire
ST5 5BG

Date: xx/xx/xxxx

# Thank you for taking part in our study: ‘How do men of South Asian origin with long term physical conditions understand, experience and seek help for emotional distress?’

Dear xxxxxxx,

We are writing to thank you for taking part in an interview for the research study entitled: ‘How do men of South Asian origin with long term physical conditions understand, experience and seek help for emotional distress?’

Thank you for sharing your experiences during the interview. We will now combine the information that you provided with what others discussed. We will then analyse this information to identify key findings. Please be advised that your personal information will be replaced with a unique study identifier so that interview material (e.g. quotes) cannot be traced back to you in the publication of the study findings.

In the meantime if you have any queries about the research please contact Dr Hassan Awan by telephone on 01782 732 936 or by email at h.awan@keele.ac.uk.

Yours sincerely,

**Dr Hassan Awan**
Wellcome PhD Fellow

Appendix 10 Topic Guide for males of SA origin with diabetes and/or heart disease

## Topic Guide for Males of South Asian Origin with Diabetes and/or Heart Disease

### Welcome

- Explanation of the study.
- Do you have any questions?
- Record written consent prior to the start of the interview on two consent forms, one for the interviewer and one for the interviewee. If not given consent to digitally record then explain that I will take notes.
- Confirm contact details.

### Demographics

- Age
- Ethnicity
- Long-term condition(s) including date of diagnosis
- Educational attainment
- Occupation
- How long participant has resided in the UK
- Religion
- GP details
- Subjective classification if first/second/third generation South Asian.

### Introductory questions:

1. Who lives in your household?
2. Tell me how you spend your time outside work and with who.

   Probe: Who do you spend time with, outside of your household? Extended family, friends, community and religious groups, hobbies etc.
3. Tell me about your long-term condition.

   Probe: What caused their long-term condition to occur? What symptoms did they have? Diagnostic journey, management.
4. How has your long-term condition impacted your life?

Probe: How is it to live with your condition? How does it affect you as a person? Does it cause upset? Does it change identity? Work, personal life, hobbies, gatherings with friends. Has your long-term condition caused emotional distress?

5. How do your household members try to support you in managing your long-term condition?
6. Who else supports you managing your long-term condition?

   Probe: Diet, exercise, advice from friends, family, community or religious groups or leaders, GP, self-help and psychological therapies, medication, alternative medications.

**Emotional distress:**

7. What do you understand by emotional distress? Tension?

   Probe: What does distress mean to you? Language used e.g. tension, anxiety, depression, feeling down, sad, anxious, tension, tired, pain all over, feeling low, worrying, irritability, poor concentration and sleep problems. More than the stress of life. How is it different to mental illness?
8. Have you seen other people who are distressed? What sort of things help?
9. Have you experienced emotional distress related to your long-term condition? Tell me about this.

   Probe: Ask about general experiences of emotional distress
10. What causes these feelings?

    Probe: Biological, psychological, personality, loneliness, social, religious, individualistic society and comparing with others, cultural factors (black magic, sihr, nazar, hasad, ayn, damm, dua, jinn, jaddhu). Clash of cultures. Family stress. Media. Covid misinformation. Racism and prejudice. Discrimination does It include medical? Politics. Reduction in social contact. Does medical illness cause emotional distress? Early trauma? Identity and belonging?
11. How can emotional distress be helped?

    Probe: What is the treatment for this? Biological- antidepressants, psychological- counselling, CBT, social, religious, cultural factors, physical activity. What do they mean by the terms. Is the treatment different for emotional distress and depression, e.g. would antidepressants be acceptable if diagnosed with depression? Do they trust a mental health diagnosis if given by a health professional? What is the role of the GP in distress?
12. How is emotional distress/tension/anxiety perceived within your community?

    Probe: Stigma. What language is used? Pagal. Sin
13. Some people think that heritage and culture is important in managing physical and mental health. What do you think?

    Probe: What aspects of South Asian heritage/background/culture are important to you? How does it impact on your mood? How does it impact on your LTC? Identity and belonging. Religion vs culture.

**Help-seeking behaviour:**

14. Do you seek help when you feel emotionally distressed?

    Probe: Use the terms the participant uses.

15. Who or where do you seek help from?

    Probe: Friends, family, household members, community or religious groups or leaders, GP. Do they provide you with support? Complementary therapy, private therapy. Would you like your GP to ask about faith? Understand culture? See GP with family?

16. What, if any, help-seeking strategies do you use?

    Probe: Diet, exercise, advice from friends, family, community or religious groups or leaders, GP, self-help and psychological therapies, medication, alternative medications, hakeem, prayer/dua, Qur'an, ruqya

17. Can you tell me about the link between emotion/mood and physical health?

    Probe: Does culture affect this?

18. Do you seek help differently for emotional and physical problems?

    Probe: Do you seek help for both? From the same places and people? What are your expectations for treatment for both? Is there a hierarchy of one being more important?

19. Does the fact that you have a long-term condition (diabetes and/or coronary heart disease) affect how you seek help for emotional or physical problems?

    Probe: For people who don't have LTCs and who do, is there is any difference in the experience of emotional distress or help-seeking behaviour?

**Context of COVID-19:**

20. What impact has the COVID-19 pandemic had on you and your family?

    Probe: Work and lifestyle change, social distancing and not seeing friends/attending community centre/place of worship, anxiety, reliable and unreliable information, information overload. Bereavement.

21. Has the management of your long-term condition been affected by the COVID-19 pandemic?

    Probe: Primary care moving primarily to telephone/virtual, annual bloods and reviews being delayed, worry seeking help due to fear of COVID-19 or other reasons, challenges with pharmacy, food, exercise, other lifestyle challenges. Explore access to the GP.

22. Has your mood been affected by the COVID-19 pandemic?

Probe: Have you felt more emotional distress? Why? Social distancing, anxiety, reliable and unreliable information, information overload, government policy, conspiracy theories. What has helped them, such as support of family, friends, community, other organisations?

**Services:**

23. What services are currently available when you feel emotionally distressed?

    Probe: GP- what do you think of your GP? Why useful or not? Self-help and psychological services, community and faith-based services. What would make people consult a GP for help with mood/distress?

24. What sort of GP is right for you?

    Probe: GP of SA origin, non SA origin but aware of culture, one with a shared understanding, in/out group, confidentiality (concern if SA?), relationship, trust. What is the role of the GP in distress? Relationship-based care.

25. Are there gaps in services or other services you feel would better support yourself and other males of South Asian origin with LTCs with emotional distress? Training needs?

    Probe: Primary care, community services, secondary care, culturally or religion-appropriate services written or in-person such as psychological services, training of cultural and religious groups or leaders, interpreters, awareness events in community and religious centres. What specifically about these services? What would they look like? Integrated services? Men for men and women for women. Receptionists. Socialising centres.

**End of interview:**

- Before we finish, is there anything further you would like to add?
- What is your take-home or main message to researchers and GPs trying to support males of SA origin with LTC who experience emotional distress?
- Do you have any questions
- Thank you
- Would you like a summary of the results? If so, via email or post? This information will be kept it in a separate password-protected document not linked to your interview.
- Next steps

Appendix 11 Topic Guide for GPs

## Topic Guide for GPs

### Welcome

- Explanation of the study. Identify features in a group so hopefully not uncomfortable.
- Do you have any questions?
- Record written consent prior to the start of the interview on two consent forms, one for the interviewer and one for the interviewee. If not given consent to digitally record then explain that I will take notes.
- Confirm contact details

### Demographics

- Age
- Gender
- Ethnicity
- Languages spoken
- Area working as a GP
- Number of clinical sessions worked per week
- Years of experience as a GP
- Role (partner/salaried and extra roles such as GPwSI, CCG role)

### Introductory questions:

26. Tell me about the demographics of the practice you work in.

    Probe: Is it inner city, urban, suburban, rural, are there lots of elderly, drug users etc? How big? What about the demographics of your staff?

27. Have you had much exposure to different communities? What about people of South Asian origin?
28. Tell me about your experience of the management of long-term conditions in men of South Asian (SA) origin.

    Probe: Presentation, diagnostic journey, management. What do males of SA origin believe cause their LTCs? How well do they follow medical advice? How does it impact their lives? Experience of SAs. Differences in SAs? Is it different to others? Is there anything specific to this group? Are they motivated? Health literacy. Language barrier. Differences in different SAs? Late to seek help. Complexity.

29. What is emotional distress? What is the difference between emotional distress and mental illness.

    Probe: How important is it to diagnose/label? Some GPs have said acute vs chronic?

**Understanding of emotional distress:**

30. Tell me about your experience in managing emotional distress in males of SA origin with long-term conditions (LTCs)? If so, could you provide some examples? Does their LTC cause emotional distress? How?

    Probe: Is it something seen commonly or a rare occurrence? How do they present? Family presenting? Are treatment pathways adequate? Is it different to others? What terminology is used? Different from different countries and religions? Heartsink patients? If so, why, due to mood/language/culture? Refugees.

31. In your experience, what do males of SA origin with LTCs understand by emotional distress?

    Probe: Language used (feeling down, sad, anxious, tension, tired, pain all over).

32. In your experience, what do males of SA origin with LTCs understand think causes their emotional distress?

    Probe: Biological, psychological, social, religious, cultural factors (black magic, sihr, nazar, hasad, ayn, damm, dua, jinn, jaddu). Does their LTC cause emotional distress? Issues with sense of belonging? Social determinants of distress.

33. What do you think is the cause of their emotional distress?

    Probe: Biological, psychological, social, religious, cultural factors. Does their LTC cause emotional distress? How important are the social determinants of health? What can GPs do to help in this case? Sense of belonging? Trauma? Racism and prejudice.

34. In your experience, what do males of SA origin with LTCs understand think is the treatment or cure to their emotional distress?

    Probe: Biological, psychological, social, religious, cultural factors (prayer/dua, Qur'an, ruqya). Traditional healers. Does medical illness cause emotional distress? Family. Optimism?

35. What do you think is the treatment or cure to their emotional distress?

    Probe: Biological, psychological, social, religious, cultural factors. Does medical illness cause emotional distress? Interpreters need and benefit? What is the role of the GP in distress?

36. How do you think emotional distress is perceived within the SA community?

    Probe: Stigma. What language is used? Men role. Sign of weakness.

**Help-seeking behaviour:**

37. Do males of SAs origin with LTCs seek help when they feel emotionally distressed? How do they present?

    Probe: Presenting with non-psychological symptoms. Is it different to others? Them or the family? Candidacy

38. Who and where do they seek help from?

    Probe: Friends, family in place of psychological therapies, community or religious groups or leaders, alternative practitioners, GP, prayer/dua, Qur’an, ruqya. Trust in services?

39. What, if any, help-seeking strategies do they use?

    Probe: Diet. Exercise. Advice from Friends, family, community or religious groups or leaders, GP. Self-help and psychological therapies. Medication. Alternative medications. Case-finding was in QOF.

40. Do they seek help differently for emotional and physical problems?

    Probe: Do they seek help for both? From the same places and people? What are their expectations for treatment for both? Is there a hierarchy of one being more important? Is health important to them? Late presenting? Due to cultural reasons or family networks?

41. Does the fact that they have a long-term condition affect how they seek help for emotional or physical problems?

    Probe: For people who don’t have LTCs and who do, is there is any difference in the experience of emotional distress or help-seeking behaviour? Relationship with healthcare provider good/bad affects this? Recursivity. Excuse/ opportunity to open up if a probing GP.

42. What are the facilitators for clinicians in identifying and managing emotional distress in males of SA origin with LTCs? What does a good GP look like for them?

    Probe: E.g. clinician cultural or language awareness, interpreters, stigma, cultural or religious factors, different presentations focusing on physical complaints, patient trust of services. Does geopoliticohistorical context affect this? ‘Holding’, a doctor-patient relationship defined as establishing and maintaining a trusting, constant, reliable relationship that is concerned with ongoing support without expectation of cure, has previously been suggested as a management strategy for such patients. Doctor as a drug. Optimism? Intuition. Social care workers and mental care practitioners. Multilingual workforce. Relationship-based care. Family-based management. What is the role of GPs in managing emotional distress in this group? Trust, cultural awareness, continuity of care.

43. What are the and barriers to clinicians in identifying and managing emotional distress in males of SA origin with LTCs?

    Probe: Time, telephone and lacking rapport. Medical model of illness. GP human beings and personal approaches.

**Context of COVID-19:**

44. What impact has the COVID-19 pandemic had on males of SA origin with LTCs?

45. Have males of SA origin with LTCs presented with emotional distress during the COVID-19 pandemic?

    Probe: Have they presented more with emotional distress? In the same or different ways? Why? Social isolation, anxiety, reliable and unreliable information, information overload. What has helped them, such as support of family, friends, community, other organisations? Not seeing relatives when dying and giving final rites to dying. Feeling of suppression.

46. How has the management of their long-term condition been affected by the COVID-19 pandemic?

    Probe: Primary care moving primarily to telephone/virtual, annual bloods and reviews being delayed, challenged with pharmacy, food, exercise, other lifestyle challenges, access to GP and services, not being a priority. Telephone triage affecting rapport. Continuity of care and booking future appointments.

**Services:**

47. What services are currently available for males of SAs origin with LTCs when they feel emotionally distressed?

    Probe: GP, self-help and psychological services, community and faith-based services.

48. Are there gaps in services or other services you feel would better support males of SAs origin with LTCs with emotional distress?

    Probe: Primary care, community services, secondary care, culturally or religion-sensitive services written or in-person such as psychological services, training of cultural and religious groups or leaders, interpreters, awareness events in community and religious centres, leaflets in languages, group talking.

49. Are there any training needs for GPs in managing emotional distress for males of SA origin with LTCs?

    Probe: Cultural competency, relationship-centred holistic care

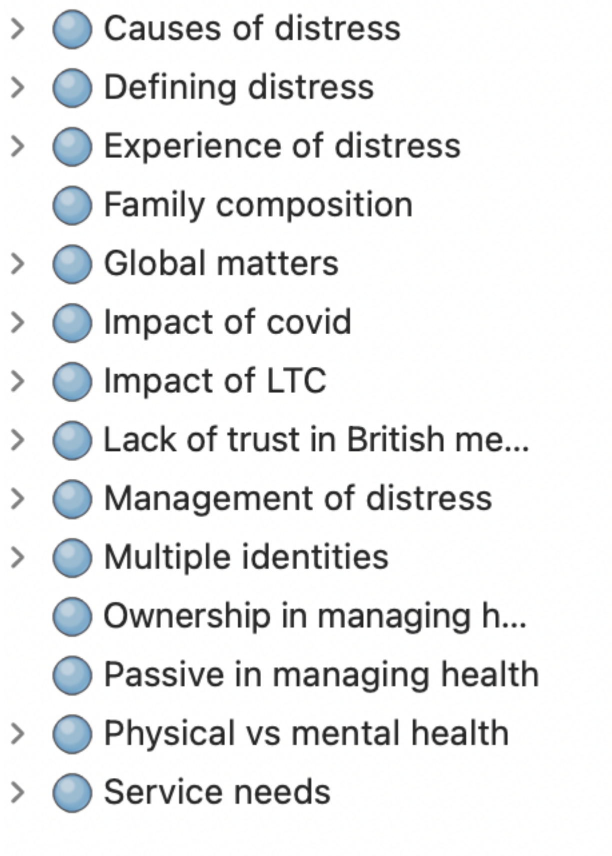
**End of interview:**

- Before we finish, is there anything further you would like to add?
- What is your take-home or main message to GPs supporting males of SA origin with LTCs who experience emotional distress?
- Do you have any questions?
- Thank you

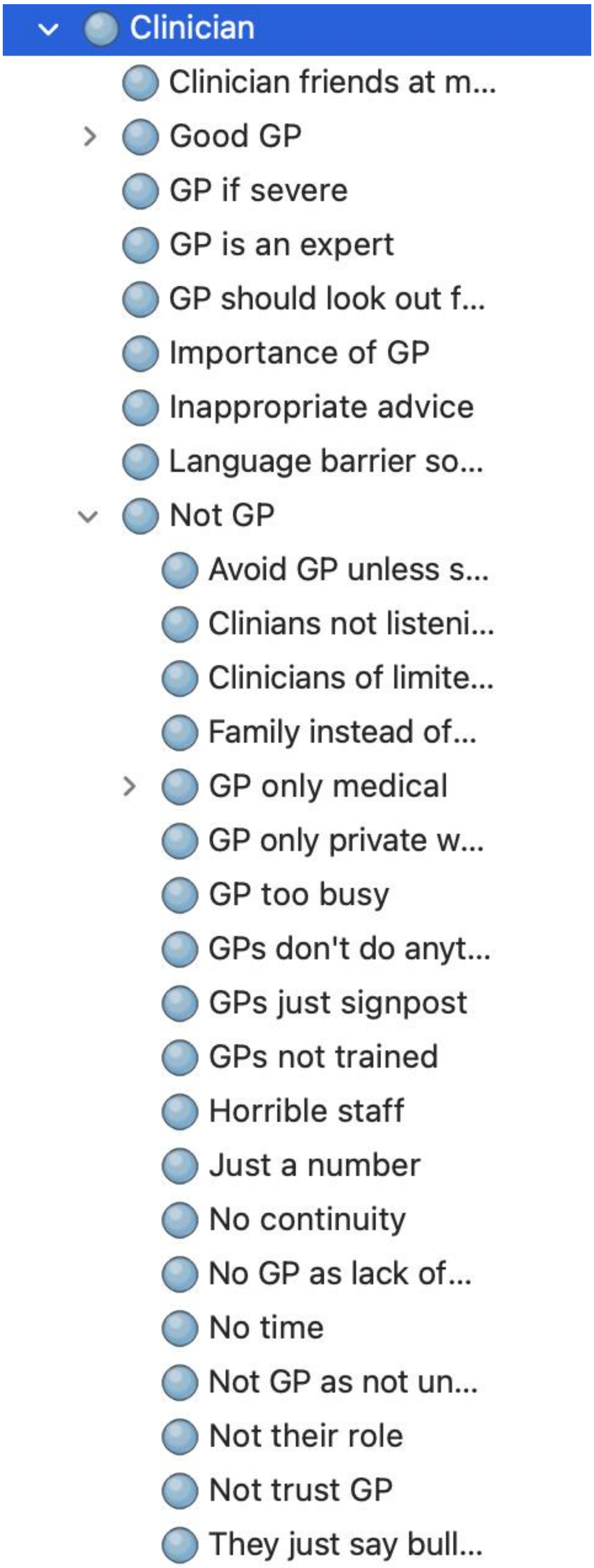
- Would you like a summary of the results? If so, via email or post? This information will be kept it in a separate password-protected document not linked to your interview.
- Next steps

## Appendix 12 Example of coding of separate groups for data analysis

Coding examles for SA men with LTCs

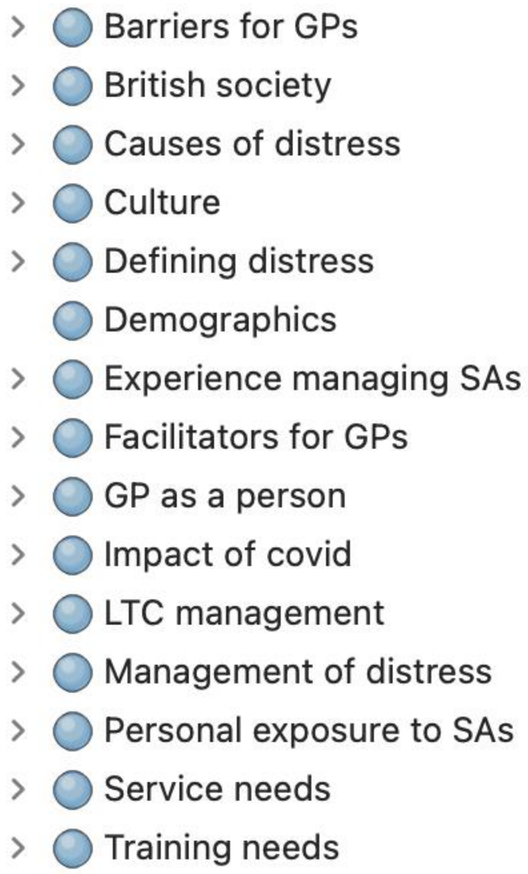


Causes of distress
Defining distress
Experience of distress
Family composition
Global matters
Impact of covid
Impact of LTC
Lack of trust in British me...
Management of distress
Multiple identities
Ownership in managing h...
Passive in managing health
Physical vs mental health
Service needs

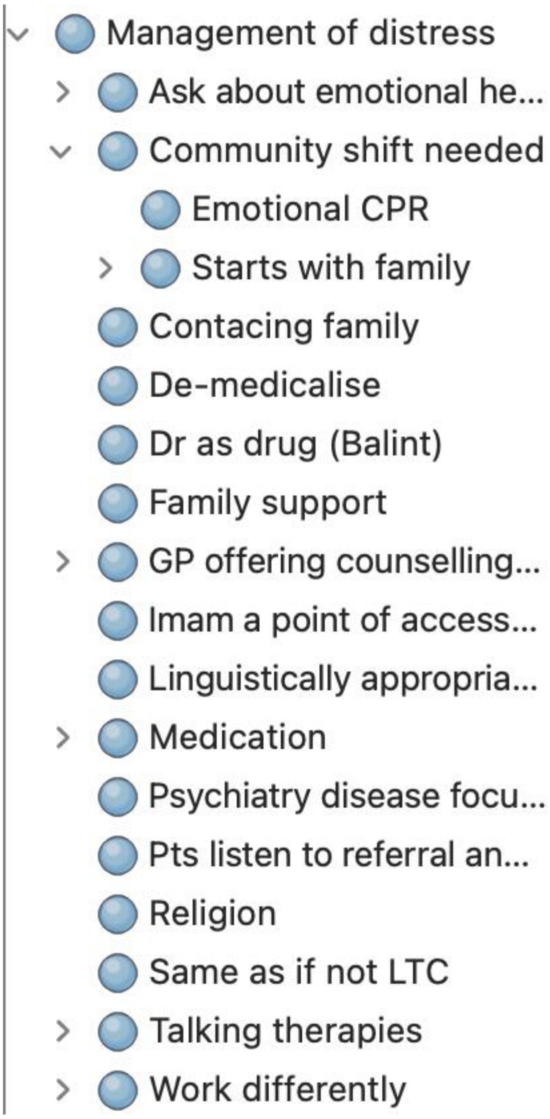


- Clinician
  - Clinician friends at m...
  - Good GP
  - GP if severe
  - GP is an expert
  - GP should look out f...
  - Importance of GP
  - Inappropriate advice
  - Language barrier so...
  - Not GP
    - Avoid GP unless s...
    - Clinians not listeni...
    - Clinicians of limite...
    - Family instead of...
    - GP only medical
    - GP only private w...
    - GP too busy
    - GPs don't do anyt...
    - GPs just signpost
    - GPs not trained
    - Horrible staff
    - Just a number
    - No continuity
    - No GP as lack of...
    - No time
    - Not GP as not un...
    - Not their role
    - Not trust GP
    - They just say bull...

Coding examples for GPs



- Barriers for GPs
- British society
- Causes of distress
- Culture
- Defining distress
- Demographics
- Experience managing SAs
- Facilitators for GPs
- GP as a person
- Impact of covid
- LTC management
- Management of distress
- Personal exposure to SAs
- Service needs
- Training needs



- Management of distress
  - Ask about emotional he...
  - Community shift needed
    - Emotional CPR
    - Starts with family
  - Contacing family
  - De-medicalise
  - Dr as drug (Balint)
  - Family support
  - GP offering counselling...
  - Imam a point of access...
  - Linguistically appropria...
  - Medication
  - Psychiatry disease focu...
  - Pts listen to referral an...
  - Religion
  - Same as if not LTC
  - Talking therapies
  - Work differently

## Appendix 13 Ethical Approval from Keele University

Keele University FMHS Faculty Research Ethics Committee
health.ethics@keele.ac.uk

28 August 2020

Dear Hassan,

| | |
|---|---|
| **Project Title:** | **How do males of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress?** |
| **REC Project Reference:** | MH-200132 |
| **Type of Application** | Main application |

Keele University's Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS FREC) reviewed the above project application.

**Favourable Ethical opinion**
The members of the Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

**Conditions of the favourable opinion**
The favourable opinion is subject to the following conditions being met prior to the start of the project.

| | |
|---|---|
| 1. | The participant information sheet should clearly describe the process on how to withdraw from the study. |
| 2. | A link to the data protection policy should be included in the consent form. |

**Reporting requirements**
The University's standard operating procedures give detailed guidance on reporting requirements for studies with a favourable opinion including:

- Notifying substantial amendments
- Notifying issues which may have an impact upon ethical opinion of the study
- Progress reports
- Notifying the end of the study

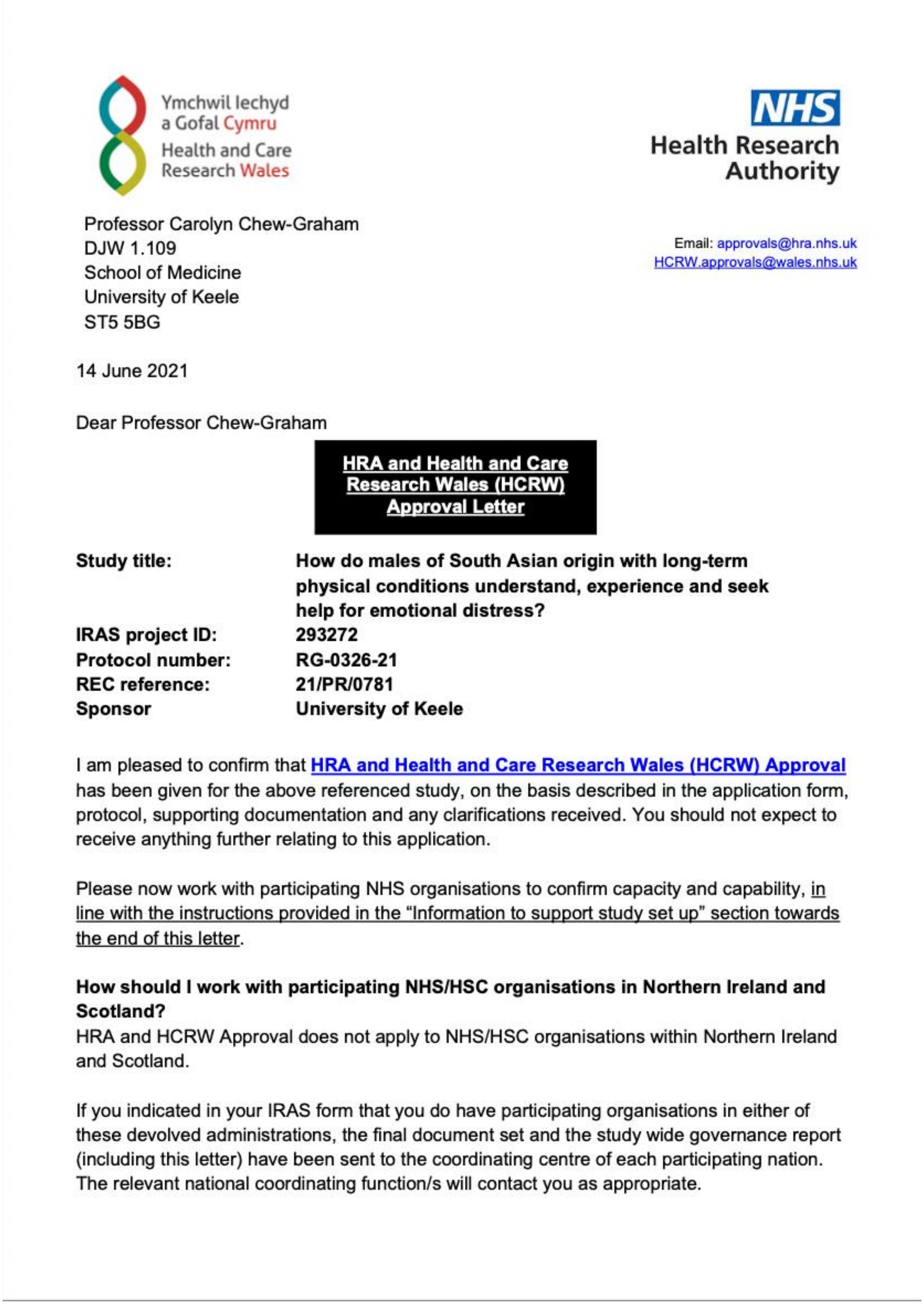
**Approved documents**
The documents reviewed and approved are:

| Document | Version | Date |
|---|---|---|
| Appendices 1-13 | 1 | 17 Jun 2020 |

Yours sincerely,

**Dr Gary Moss**
**Chair**

Appendix 14 IRAS and HRA Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Professor Carolyn Chew-Graham
DJW 1.109
School of Medicine
University of Keele
ST5 5BG

14 June 2021

Dear Professor Chew-Graham

**HRA and Health and Care Research Wales (HCRW) Approval Letter**

| | |
|---|---|
| **Study title:** | **How do males of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress?** |
| **IRAS project ID:** | **293272** |
| **Protocol number:** | **RG-0326-21** |
| **REC reference:** | **21/PR/0781** |
| **Sponsor** | **University of Keele** |

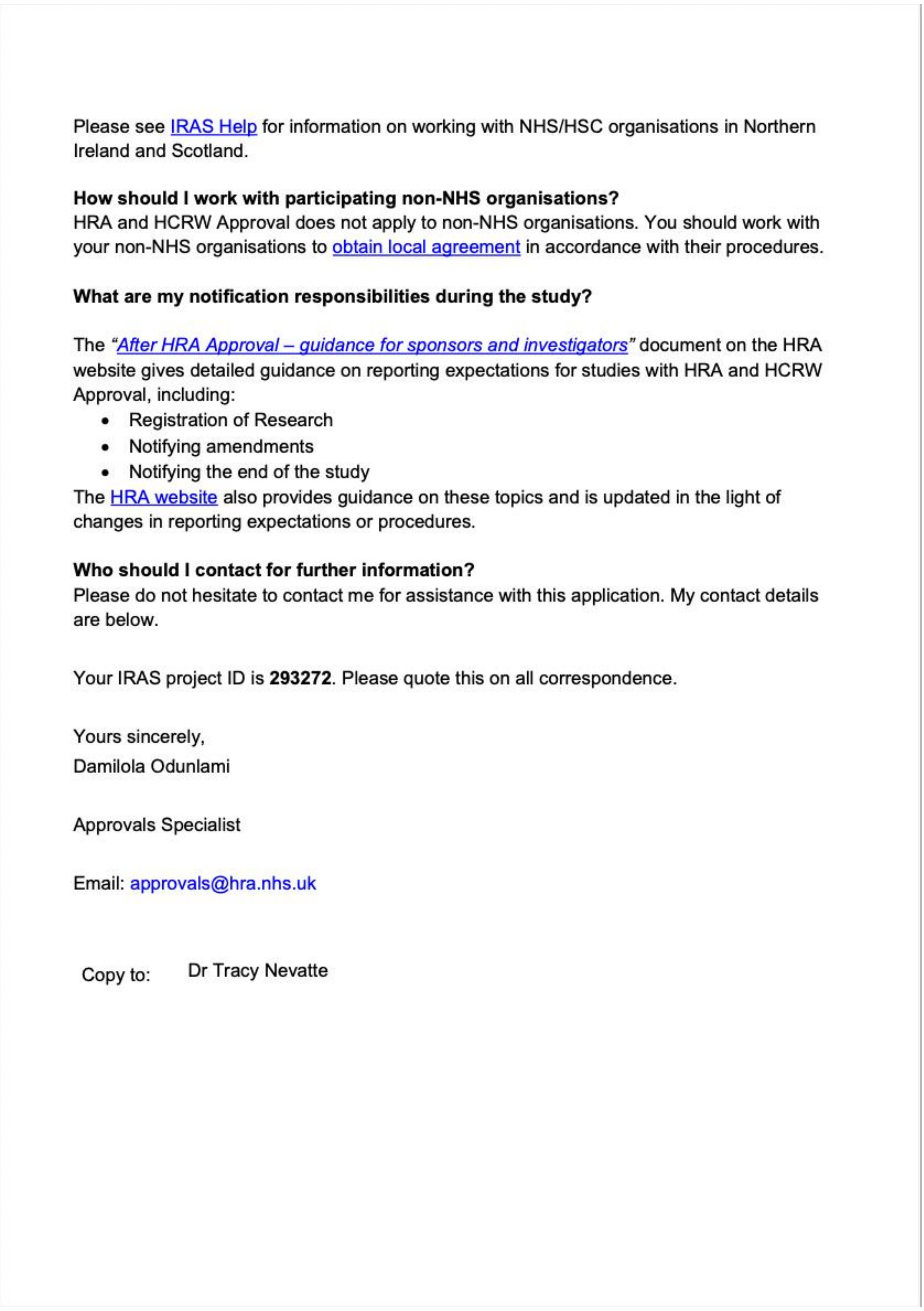
I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

**What are my notification responsibilities during the study?**

The *"After HRA Approval – guidance for sponsors and investigators"* document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**
Please do not hesitate to contact me for assistance with this application. My contact details are below.

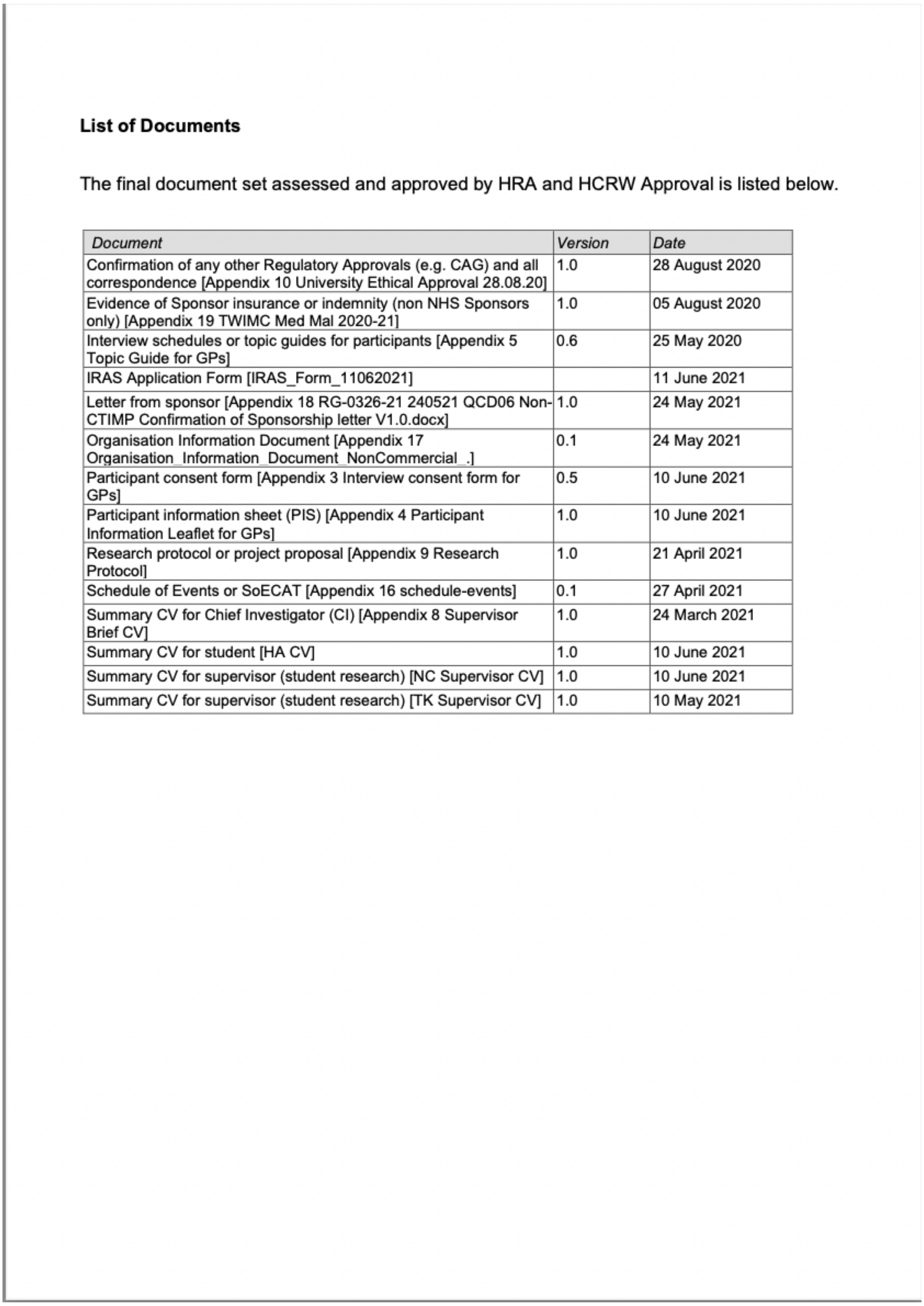
Your IRAS project ID is **293272**. Please quote this on all correspondence.

Yours sincerely,
Damilola Odunlami

Approvals Specialist

Email: approvals@hra.nhs.uk

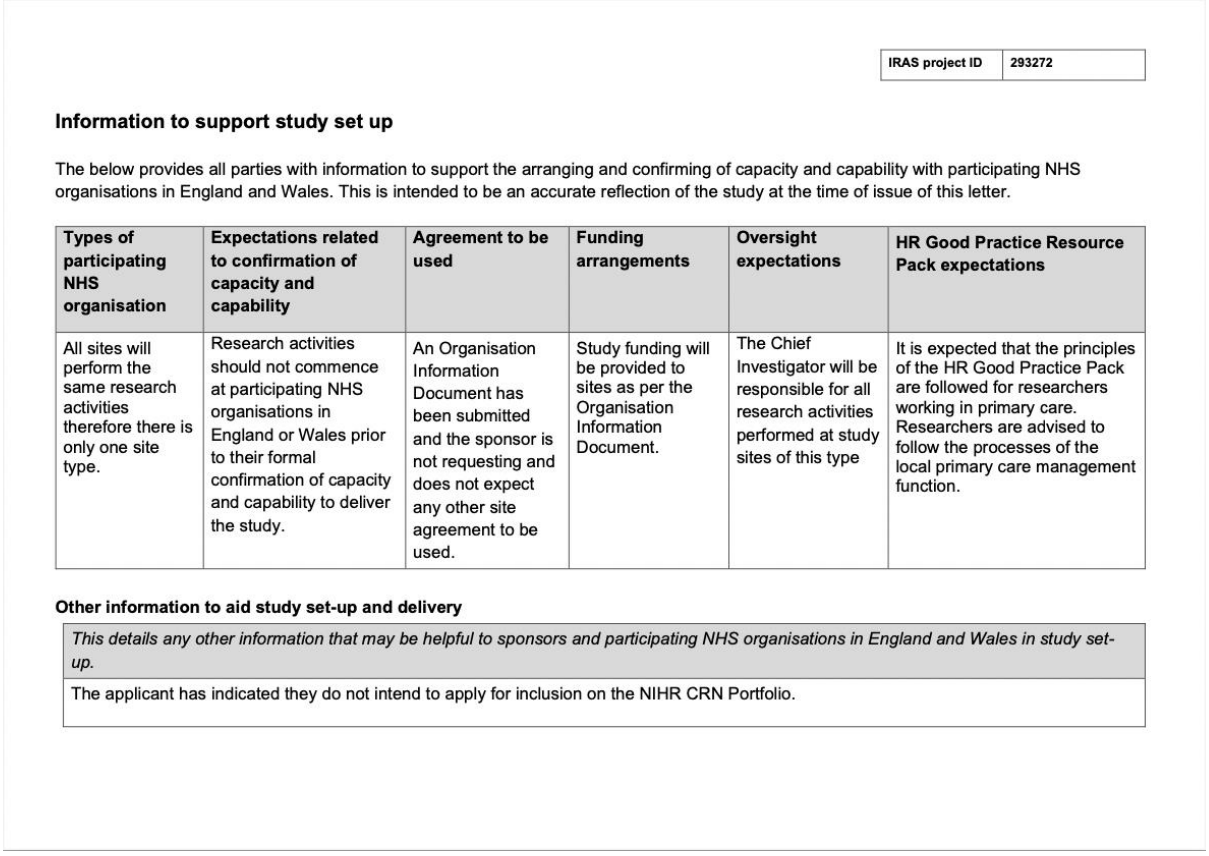
Copy to: Dr Tracy Nevatte



**List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

| *Document* | *Version* | *Date* |
|---|---|---|
| Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Appendix 10 University Ethical Approval 28.08.20] | 1.0 | 28 August 2020 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Appendix 19 TWIMC Med Mal 2020-21] | 1.0 | 05 August 2020 |
| Interview schedules or topic guides for participants [Appendix 5 Topic Guide for GPs] | 0.6 | 25 May 2020 |
| IRAS Application Form [IRAS_Form_11062021] |  | 11 June 2021 |
| Letter from sponsor [Appendix 18 RG-0326-21 240521 QCD06 Non-CTIMP Confirmation of Sponsorship letter V1.0.docx] | 1.0 | 24 May 2021 |
| Organisation Information Document [Appendix 17 Organisation_Information_Document_NonCommercial_.] | 0.1 | 24 May 2021 |
| Participant consent form [Appendix 3 Interview consent form for GPs] | 0.5 | 10 June 2021 |
| Participant information sheet (PIS) [Appendix 4 Participant Information Leaflet for GPs] | 1.0 | 10 June 2021 |
| Research protocol or project proposal [Appendix 9 Research Protocol] | 1.0 | 21 April 2021 |
| Schedule of Events or SoECAT [Appendix 16 schedule-events] | 0.1 | 27 April 2021 |
| Summary CV for Chief Investigator (CI) [Appendix 8 Supervisor Brief CV] | 1.0 | 24 March 2021 |
| Summary CV for student [HA CV] | 1.0 | 10 June 2021 |
| Summary CV for supervisor (student research) [NC Supervisor CV] | 1.0 | 10 June 2021 |
| Summary CV for supervisor (student research) [TK Supervisor CV] | 1.0 | 10 May 2021 |



| IRAS project ID | 293272 |
|---|---|

## Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

| Types of participating NHS organisation | Expectations related to confirmation of capacity and capability | Agreement to be used | Funding arrangements | Oversight expectations | HR Good Practice Resource Pack expectations |
|---|---|---|---|---|---|
| All sites will perform the same research activities therefore there is only one site type. | Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study. | An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used. | Study funding will be provided to sites as per the Organisation Information Document. | The Chief Investigator will be responsible for all research activities performed at study sites of this type | It is expected that the principles of the HR Good Practice Pack are followed for researchers working in primary care. Researchers are advised to follow the processes of the local primary care management function. |

**Other information to aid study set-up and delivery**

| *This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.* |
|---|
| The applicant has indicated they do not intend to apply for inclusion on the NIHR CRN Portfolio. |

Appendix 15 Risk Protocol

How do males of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress?

Risk Protocol

## Policy Statement

General Practitioners (GPs) are responsible for the on-going clinical care of study participants (males of South Asian origin with diabetes or coronary heart disease). Therefore, researchers have a duty of care to ensure that the GP is aware of suicide ideation expressed by study participants.

The interviewer (HA) is a GP with experience working in Psychiatry and has undertaken training and has significant experience assessing and dealing with distressed individuals. **The researcher must** initiate the suicide ideation protocol each time a study participant expresses thoughts of suicide or self-harm. This may be as a result of a study participant disclosing information during an interview that leads the researcher to believe that there is a suicide risk. In this instance, the researcher, with the study participant's permission, should inform the study participant's GP and notify the main supervisor.

If the study participant refuses permission for the researcher to inform the GP then the researcher should immediately consult the main supervisor who will then examine the study participant's data. If it is concluded that there is a significant risk[1], the study participant's GP will be notified **with or without** the study participant's consent. However, HA will contact the GP if the situation is urgent, again with or without the study participant's consent. In these cases the decision should be explained to the study participant as soon as possible.

## Definition of suicide ideation

In this study, suicide ideation is identified by:

- Study participants who disclose information during an interview, to a member of the research team indicating that they have attempted suicide or that they have been thinking of ways to commit suicide will be considered to have suicide ideation.

In this instance the suicide ideation pro-forma should be completed to convey these thoughts to the study participant's GP and to record the incident as detailed in **action required**. However, if the researcher believes for any other reason that the study participant is at risk of self-harm, the researcher should contact the main supervisor to discuss.

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[1] As per the protocol, those at risk of self-harm/ suicide will be assessed by HA (a clinician) as well as discussed with the main supervisor and also clinician (CCG) and will use their clinical judgement to decide if the participant is at significant risk and needs to be withdrawn.

**Action required**
A schematic of the suicide ideation pro-forma is shown in figure 1.

Before each contact with a study participant (either telephone, online or face-to-face), the researchers should review all previous data on suicide ideation and ensure that contact details for the main supervisor are current.

At the start of the interview, the researcher will obtain contact details of the study participant – explaining to the participant why these details are needed.

When the researcher becomes aware that a study participant has thoughts of suicide, they should first of all ascertain whether or not the study participant has talked to his GP about them. The researcher should reinforce the importance of maintaining a dialogue with his GP and ask for permission to pass the information to his GP. Suggested scripts are shown below.

If the study participant agrees to this communication, the researcher should telephone the study participant's GP within 48 hours** to pass on the information obtained. If the study participant's GP is not available then the researcher should ask to speak to the duty doctor. The researcher should make it clear to the GP that clinical responsibility for the study participants remains with GP. A fax or e-mail should be sent to the GP confirming this notification.

The researcher should inform the main supervisor by completing a disclosure report and passing this to him/her for approval.

If the study participant does not agree to GP being informed, the researcher should contact the main supervisor to discuss appropriate action.

**If the researcher believes the study participant is in immediate danger, the researcher must immediately contact the GP and/or emergency services and inform the main supervisor.

**Face-to-face/telephone/online interview with participant**

- If the study participant discloses information regarding suicide intent the researcher should discuss the importance of informing their GP using the suggested scripts below.
- If the study participant agrees to GP being informed, the researcher should action the suicide ideation pro-forma as detailed above.
- If the study participant does not agree to GP being informed, the researcher should contact the main supervisor to discuss action to be taken.

***Suggested Scripts:***

### *Disclosure during interview*

*I am concerned about some of the things you have told me. Have you spoken to your doctor about them? It is important that your doctor knows about the way you feel, as they will be able to make sure that you have the necessary support in place. Are you happy for me to mention to your doctor the things you have told me?*

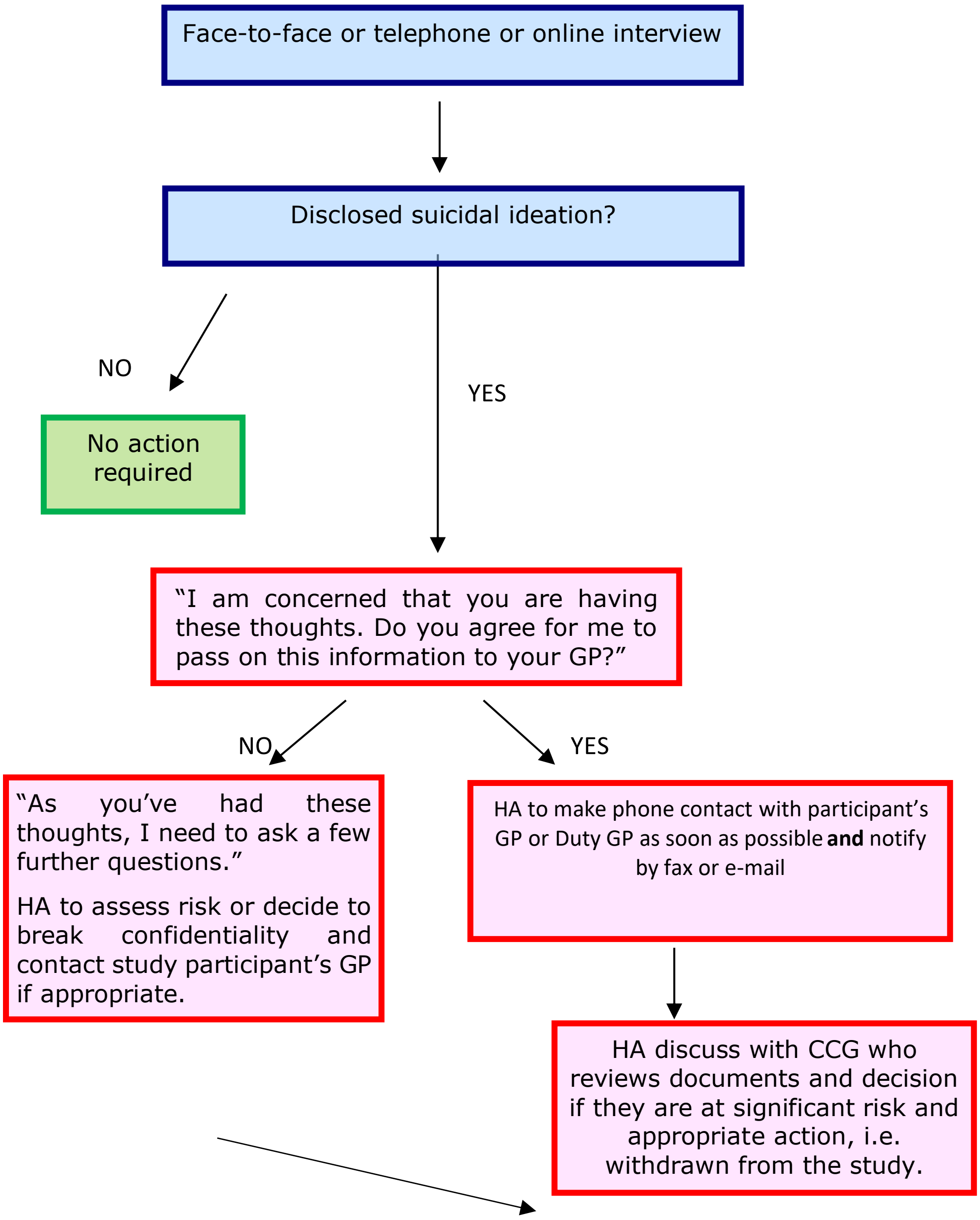
### *If study participant is hesitant or declines*

*Many people find it hard to bring these things up during a consultation, but your GP can offer you help with these feelings. If he/she knows how you are feeling, he/she will be able to talk to you about it and together you can decide on the best way to treat you.*

### *If study participant continues to declines*

*That fine, but as I am not your GP, I do have let my colleague know about the way you are feeling. They may phone you in the next day to have a talk to you about the way you are feeling.*

**Figure 1 – Suicide ideation pro forma**
The following action must be taken and recorded by a member of the research team whenever a study participant discloses suicide ideation to a researcher.



Face-to-face or telephone or online interview

Disclosed suicidal ideation?

No action required

"I am concerned that you are having these thoughts. Do you agree for me to pass on this information to your GP?"

"As you've had these thoughts, I need to ask a few further questions."

HA to assess risk or decide to break confidentiality and contact study participant's GP if appropriate.

HA to make phone contact with participant's GP or Duty GP as soon as possible **and** notify by fax or e-mail

HA discuss with CCG who reviews documents and decision if they are at significant risk and appropriate action, i.e. withdrawn from the study.

**Nominated member of study team: Main Supervisor: Prof Carolyn Chew-Graham** Tel 07425 620288

**Nominated Clinician: Prof Carolyn Chew-Graham** **Tel:** 01782 733922 **Mobile:** 07425 620228

GP name
Address line 1
Address line 2
Address line 3
Post code

Date
Research reference number

Dear Doctor,

How do males of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress?

## Notification of suicide ideation

**Patient's Name:……………………………  DOB: ……/……/……….**

The above patient is taking part in our study exploring South Asian Males with long-term chronic conditions' experiences of emotional distress. I am writing to notify you that the above patient reported thoughts of suicide ideation **<<*time period*>>** today.

The patient disclosed the following information during an interview with a researcher <researcher to add further detail>

We would remind you that on-going clinical care remains with you. It is part of our study protocol to inform you of such risks, so that you can take account of them in your care plan.

Yours sincerely,

<researcher name>
on behalf of the study team

**STRICTLY CONFIDENTIAL**

# Notification of Suicide Ideation Proforma

**PATIENT ID:** ______________ **DOB:** _________ **GP PRACTICE:** ____________________

**HISTORY:**

| Time point | Date | Risk Identified | Researcher | GP Informed | Name of GP | Date GP Informed | Disclosure | Significant Risk Identified[3] | Signature of clinician |
|---|---|---|---|---|---|---|---|---|---|
| **Interview** (face-to-face/telephone/online) | | **Yes/No** | | **Yes/No** | | | | **Yes/No** | |

**[3] As per the protocol, those at risk of self-harm/ suicide will be assessed by a nominated clinician who will use their clinical judgement to decide if the participant is at significant risk and needs to be withdrawn.**

## Please enter other relevant information overleaf

**Nominated Clinician: Prof Carolyn Chew-Graham Tel:** 01782 733922 **Mobile:** 07425 620228

## Other relevant information:

……………………………………………………………………………………………………………………………………………

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**Nominated Clinician**

| Site | Clinician | Telephone | Mobile |
|---|---|---|---|
| Keele University | Professor Carolyn Chew-Graham | [redacted] | [redacted] |

Appendix 16 List of outputs resulting from PhD

## List of outputs resulting from PhD

- Publications
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. South Asian Men with Long-Term Conditions, Emotional Distress and Primary Care: A Qualitative Study. The Annals of Family Medicine January 2023, 21 (Supplement 1) 3662; DOI: https://doi.org/10.1370/afm.21.s1.3662 2023
    - **Awan, H.,** Mughal, F., Kingstone, T., Chew-Graham, C.A, Corp, N., 2021. Emotional distress, anxiety and depression in South Asians with long-term conditions: a qualitative systematic review. *Br J Gen Pract BJGP.2021.0345* *https://doi.org/10.3399/bjgp.2021.0345*

- Oral Presentations
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. South Asian men with long-term conditions, emotional distress and primary care: A qualitative study. NAPCRG 2022
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. Emotional distress in South Asian men with long-term conditions: Patient and public involvement and engagement in a PhD. Society for Academic Primary Care (SAPC) North 2022
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. Emotional distress, anxiety, and depression in South Asians with long-term conditions. Presentation to Manchester Clinical Commissioning Group (CCG) Locality Sub-Group (LSG) 2022
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. What does relationship-based, holistic care look like for South Asian men with long-term conditions experiencing emotional distress? SAPC 2022
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. Building trust between GPs and South Asian men with long-term conditions experiencing emotional distress: a qualitative study. Royal College of General Practitioners (RCGP)/World Organisation of Family Doctors (WONCA) 2022
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. The impact of the social determinants of distress on South Asian males with long-term conditions: A qualitative study. Primary Care Mental Health Conference 2022
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. How do men of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress? Keele University 3 minute thesis final 2022
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. How do men of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress? Faculty of Medicine and Health Sciences (FMHS), Keele University 2022
    - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A Emotional distress, anxiety, and depression in South Asians with long-term conditions. Robert Darbishire Practice 2022

  - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A 13.03.22 Emotional distress, anxiety, and depression in South Asians with long-term conditions Cambridge Students for global health 2022
  - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. A qualitative study exploring perspectives of emotional distress in men of south Asian origin and GPs serving them. SAPC North 2021
  - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. Living well with multimorbidity: a qualitative study exploring perspectives of emotional distress in men of south Asian origin. Society for Academic Primary Care (SAPC) ASM 2021
  - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. Distress in men of South Asian origin with long-term conditions. SAPC Mental Health group presentation 2021
  - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. How do men of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress? 3 minute thesis presentation: Keele ILAS/KDA Conference 2021
  - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A. How do men of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress? 3 minute thesis presentation: Keele Faculty of Medicine and Sciences Conference 2021
  - **Awan, H.,** Mughal, F., Kingstone, T., Chew-Graham, C.A., Corp, N. How do people of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress? A systematic review. Oral presentation applied for: Primary Care Mental Health Research Conference 2020 (conference cancelled due to coronavirus outbreak; abstract available from https://sapc.ac.uk/sites/default/files/pcmh_conference_2020_abstract_collection_final.pdf)
  - **Awan, H.,** Mughal, F., Kingstone, T., Chew-Graham, C.A., Corp, N. How do people of South Asian origin with long-term physical conditions understand, experience and seek help for emotional distress? A systematic review. Oral presentation applied for: SAPC Annual Scientific Meeting 2020 (cancelled due to the COVID-19 pandemic; abstracts available from https://sapc.ac.uk/doi/10.37361/asm.2020.1.1)

- Poster presentations
  - **Awan, H.,** Kingstone, T., Corp, N., Chew-Graham, C.A Emotional distress in South Asian men with long-term conditions: Patient and public involvement and engagement in a PhD. NAPCRG 2022
  - **Awan, H.,** Chew-Graham, C.A., Kingstone, T. How do men of South Asian origin with long term physical health conditions understand, experience and seek help for emotional distress? Keele Postgraduate Research Conference 2019
  - **Awan, H.,** Chew-Graham, C.A., Kingstone, T., Corp, N. How do men of South Asian origin with long term physical health conditions understand,

experience and seek help for emotional distress? Cambridge University Global Muslim Mental Health Research Conference 2019

- Prizes
    - Winner of 1st place Keele University 3 minute thesis 2022
    - Winner of 3 minute thesis, Keele Faculty of Medicine and Sciences Conference 2022

- Blogs
    - Facilitating lay involvement of people in underserved groups in mental health research, SAPC 2021 https://sapc.ac.uk/content/facilitating-lay-involvement-of-people-underserved-groups-mental-health-research
    - The importance of cultural competencies to improve care for all, BJGP live video 2020 https://bjgplife.com/the-importance-of-cultural-competencies-to-improve-care-for-all/
    - Setting up a culturally sensitive patient advisory group, School for Primary Care Research (SPCR) 2020 https://www.spcr.nihr.ac.uk/news/blog/setting-up-a-culturally-sensitive-patient-advisory-group

- Animations, videos and podcasts
    - Animation video Emotional distress in South Asian men with long term conditions https://youtu.be/pSuTAf_JU1I
    - Video for British Journal of General Practice (BJGP) **Awan, H.,** Mughal, F., Kingstone, T., Chew-Graham, C.A, Corp, N., 2021. Emotional distress, anxiety and depression in South Asians with long-term conditions: a qualitative systematic review. https://www.youtube.com/watch?v=yiH_xzf8Who
    - Podcast for BJGP Live. **Awan, H.,** Mughal, F., Kingstone, T., Chew-Graham, C.A, Corp, N., 2021. Emotional distress, anxiety and depression in South Asians with long-term conditions: a qualitative systematic review. https://bjgplife.com/062

- Planned outputs
    - Social determinants of distress: A qualitative study of South Asian men with long-term conditions and GPs (submission planned for BJGP)
    - Co-navigating care: A qualitative study of South Asian men with long-term conditions and GPs (submission planned for BJGP)
    - PhD working with an underserved community of South Asian Men (submission planned for Health Expectations)