The Role of Illness Beliefs and Social Networks in South Asian People with Diabetes: a Mixed Methods Study

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Contents

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Abstract

The University of Manchester
Abstract for thesis by Neesha Patel
For the degree of **PhD titled**: **'The Role of Illness Beliefs and Social Networks in South Asian People with Diabetes: a Mixed Methods Study'**
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Background: Diabetes is a serious condition affecting the UK South Asian (SA) population. Beliefs amongst a number of factors have been reported to impede on self-management behaviours. Social networks (SN) are known to be an important source of support for diabetes management. Yet little is known about *how* much and *what* types of diabetes 'work' is undertaken and the impact of SN in shaping beliefs about diabetes. The aim of this study was to explore and gain knowledge about the association between illness beliefs and SN in British SA adults with diabetes.
Methods: A mixed methods approach was used. Firstly, a systematic review was conducted to assess the feasibility of using standardised questionnaires to measure diabetes-related beliefs in this target population. Secondly, using a cross-sectional design, a Postal Health Survey (PHS) explored illness beliefs (Brief Illness Perception Questionnaire-BIPQ) and health outcomes (health status, self-efficacy, normalisation and self-care) in a sample of (N=67) recruited using random, purposive and snowball sampling. A Social Network Survey Interview (SNSI) with (N=37) (who completed the PNS), identified SN in each participant's network using concentric circles, and closed-questions on the amount of 'work' done by the network. A topic guide, specific to the aims of the Qualitative Study (QS) was embedded within the SNSI to explore the social, cultural and religious context related to diabetes management. Participants who completed the SNSI also completed the QS. Data was collected during 2010 and 2011.
Results: Five studies meeting the review criteria were identified from the systematic review. The results supported the need to measure illness beliefs using standardised questionnaires. Certain social network characteristics: *size of the support network, number of supportive females, practical and emotional work* was related to diabetes-related beliefs. After multivariate analysis, *emotional work* remained a significant predictor of *concern* and *emotional distress* related to diabetes. The qualitative study identified six themes: *fatalism, normalising diabetes, social networks, alternative food therapies, and travel back home to the East and religion* related to beliefs and management practices. The QS also complemented and extended some of the findings of the cross-sectional study, related to social networks and fatalism beliefs.
Conclusion: This study provides a unique contribution to the research on diabetes management in British SA, using a mixed methods approach. It has addressed the gap in knowledge with regards to illness beliefs about diabetes in British SA, as measured by five dimensions of the CS-SRM (Leventhal et al, 1980) and described the importance of the social context, particularly the family in being at the forefront of 'work' related to diabetes management. Future studies need to establish utility of the BIPQ in the UK South Asians to ensure it is appropriateness to the experience of diabetes in SA. Policy guidelines on diabetes may need to move beyond the notion of 'self' to include support and education for the SN, with a recognition of the impact of cultural and religious beliefs on diabetes management.

Declaration

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

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Dedication

In loving memory of my late father for whom witnessing this thesis would have been a dream come true. Although you are not insight, you are my guardian angel: always in my thoughts, every day of my life and in everything that I do. Thank you for always giving me the strength to make my dreams come true.

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Abbreviations

BIPQ	Brief Illness Perceptions Questionnaire
CDSMP	Chronic Disease Self-Management Program
CLAHRC	Collaboration of Applied Leadership in Health Research and Care for Greater Manchester
COPE	Normalisation
EPP	Expert Patient Programme
GP	General Practitioner
HEiQ	Health Education Impact Questionnaire
LTC	Long Term Conditions
NHS	National Health Service
PN	Practice Nurse
RCT	Randomised Controlled Trial
SDSCA	Summary of Diabetes Self-Care Activities
SF-12	Short Form Health Status
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus

Chapter 1

Introduction to the Thesis

1.1 Introduction

This chapter begins by providing a brief overview of the author's personal experience of living with a family member with diabetes, studying the condition within the context of health psychology and working for a UK health charity for people with diabetes, before embarking on the journey of undertaking this thesis. Following on from this is a working definition of the term 'South Asian', and a justification for the research. The final part of the chapter will provide an overview on health psychology together with a critique and definition of 'health beliefs' relevant to this study.

1.2 The author

Diabetes is a word that entered my vocabulary at a very young age, just like the words headache, cold and stomach ache. From a young age I kept hearing this word because my father had Type 1 Diabetes Mellitus (T1DM), but strangely it was my mother who used this word more often than my father. My mother was responsible for his diet and used to tell him when dinner was ready so that he could go and take his insulin injections before food. I remember when my father used to go to work in the mornings; I used to see an apple and banana on the dining room table, which my mother left out for him. I soon came to learn, that diet was an important part of his life. My father migrated to the UK from East Africa in 1972. Not long after coming to the UK, he was diagnosed with T1DM. At the age of 25, and as for most people diagnosed with T1DM, it was a life changing experience and one, which was as far as I remember, managed with dignity. However, towards the latter years of his life, my father really suffered with his diabetes especially during the night. On several occasions my father used to have a hypoglycaemic episode and I remember jumping out of bed because I could hear him shouting for 'sugar 'or talking deliriously about wanting some food. I remember frantically searching for Mars bars and running downstairs and fetching the tub of sugar from the cupboard and running back upstairs and my mother giving my father several spoons of sugar in water until he came out of the hypoglycaemia. It was very frightening to see my father in that state and not knowing what to do apart from reach for sugar and on a few occasions phone for an ambulance. Sugar seemed like the only cure at the time. The next day my father would tell us not mention his hypoglycaemic of the night before to the extended family members and he would often worry about the consequences of hypos causing some sort of brain damage, but I never knew the answers to his concerns. In the early hours of one cold morning in December 1996 my father died of a major heart attack, the day after returning from a family trip to India with my mother and brother. My only understanding of his sudden death was because of his diabetes, and at the time it felt like diabetes took his life, because towards the latter end of this life he was really battling with diabetes control. In my experience the last few years before my father passed away I could see this sadness in his eyes, he became withdrawn and exhausted with life and frustrated with his diabetes, especially his medication regime, the lack of support from his GP, and the frequent hypoglycaemic episodes he was having at night time.

During my Masters course, in Health Psychology at University College London (2005-6), my stomach used to turn during the lectures on diabetes and chronic illnesses because of what I had witnessed in my childhood and in my early teenage years. I refrained from studying this specific condition in any detail, as I did not want to bring to life the memories associated with diabetes but that soon changed. In 2007 I was offered a job at Diabetes UK, and initially I hesitated to accept the job because of my emotional connection with this condition. I feared that I would not be able to fulfil my duties without detaching myself from the sad memories of what my father went through with his diabetes. Eventually I resulted to thinking that this job was part of my destiny or perhaps a signal from my father to work for an organisation, which he was not only a member of, but also an organisation from which he once gained support; support which he felt he did not get from the health services. I worked as an Information Assistant for the national health charity Diabetes UK, Healthcare Policy department for two years before commencing my PhD at University of Manchester in 2009. My main role was to assist with research into the health inequalities of diabetes services and engage with people with diabetes across the UK to improve access to services. I soon realised that something that once made me feel weak inside had now turned into my strength and determination to help improve self-management support, especially for people from the South Asian community. Thus my experience together with my knowledge and understanding of this community has set the foundation for this thesis.

1.3 Diabetes Mellitus

Diabetes Mellitus is a life-long chronic and progressive condition. The World Health Organisation (2010) has defined diabetes as '*a chronic disease that occurs either when the pancreas does not produce enough insulin, or when the body cannot effectively use the insulin it produces*' (Insulin is a hormone that regulates blood sugar). Hyperglycaemia, or raised blood sugar is a common effect of uncontrolled diabetes and over time can lead to serious damage to many of the body's systems, especially small nerves and blood vessels leading to heart disease, kidney disease, blindness and amputation. Hypoglycaemia occurs when the blood sugar levels are too low and symptoms include sweating, palpitations, and weakness. Extremely low blood sugars can be harmful and if un-treated can lead to unconsciousness and death. There are two forms of diabetes: Type 1 (T1DM), also known as insulin-dependent or childhood onset diabetes and is characterised by a lack of insulin production in the pancreas. Type 2 diabetes (T2DM), also known as non-insulin dependent, is caused by the body's ineffective use of insulin and has been linked with obesity, sedentary lifestyle and physical inactivity (Diabetes UK, 2012). However, irrespective of the type of oral glycaemic medication used for the treatment of T2DM, it is common for patients to move on to insulin injections at a later stage of diabetes due to progressive loss of beta cells (responsible for insulin production) in the pancreas over time (Prospective Diabetes Study Group 1995).

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1.4 Defining the term 'South Asian'

The South Asian population in this context refers to people from the Indian subcontinent. It is diverse, encompassing seven sub-ethnic groups: Indian, Pakistani, Bangladeshi, Sri Lankan, Bhutanese, Nepalese and Mauritius (Johnson et al, 1999). This population cannot be considered a homogenous group due to differences in religion, culture, beliefs, and attitudes between them (Bhopal et al, 1999). In terms of differences in health, various health outcomes, social and economic measures in studies between Indian, Pakistani, Bangladeshi and European men and women (aged 25-74 years) have found that Indians were least and Bangladeshis, followed by Pakistanis have the most disadvantage in a range of coronary risk factors (Bhopal et al, 1999). Another important difference to note here is between the generation groups. The South Asian population in the UK can be sub-divided into first generation migrants and second generation British born. The migrant South Asian group has received most attention in the literature, due to the difficulties of language comprehension

(Greenhalgh et al, 1998; Hill, 2006), yet the difference between the two generations, is not always made explicit in research studies. However, in this study the broad term South Asian was used despite the majority of the sample being from the Indian and Pakistani origin. This term is also widely used in academic health research, notwithstanding its limitations. Where possible, efforts were made to distinguish between the sub-ethnic South Asian groups during the quantitative and qualitative analyses to account for any differences within the sample, despite there being no significant relevance for a finer distinction within the South Asian category of this in terms of the aims and research questions.

1.5 Context and Justification for the Research

The next section presents information on the prevalence of diabetes in the UK and in the South Asian population, the risk factors of this condition, self-management and education for diabetes, as well as barriers to effective diabetes management.

1.6 Prevalence of diabetes in the UK

It is estimated that 2.9 million people in the UK are diagnosed with diabetes, with around 90% of these diagnosed with T2DM (Diabetes UK, 2012). It has been suggested that 855,000 people are likely to be undiagnosed, and prevalence is increasing due to an ageing population and increases in obesity and changes in lifestyle (Diabetes UK, 2012). It has been estimated that by 2025 five million more people will be diagnosed in the UK. This condition has been reported to represent a serious clinical and financial challenge to the NHS, especially since 10% of the annual NHS budget, approximately £10 billion, is being spent on diabetes services (Diabetes UK, 2012). However, diabetes is a serious problem in the UK South Asian population. The UK epidemiological data for diabetes shows that people from the South Asian population have a higher prevalence of T2DM than the majority of Caucasians in the UK (Health Survey for England, 2004).

1.7 Prevalence of diabetes in the UK South Asian population

The South Asian population is the largest and most established ethnic minority group in the UK, comprising over 4% of the total UK population (ONS Census, 2005). T2DM is up to six times more common in the South Asian population and they experience up to 50% higher mortality from coronary heart disease and stroke compared to Caucasians (Gholap et al, 2011). In addition to the higher prevalence in this group, onset can be 5 to 10 years earlier and the risk of chronic complications (e.g. retinopathy and neuropathy) much greater than in the Caucasian population (Bellary et al, 2009). Amongst the UK South Asians, T2DM is four times more common in the Pakistani and Bangladeshi group (Health Survey for England, 2004), but whether the difference in prevalence is due to genetic or environmental factors remain unclear (Bellary & Barnet, 2009). For example, the epidemiology of diabetes in UK South Asians has been recently reviewed by Wild & Chaturvedi (2009) who highlighted the paucity of robust epidemiological data on T2DM in UK South Asians and a need for a large, population based studies to identify the current trends in prevalence of diabetes and proportion of undiagnosed cases in this population.

1.8 Risk factors

The individual risk factors for diabetes are multi-factorial and include: age, poor diet, sedentary lifestyle, leading to obesity, and a genetic pre-disposition (Diabetes UK, 2012). Raised Body Mass Index (BMI) and/or waist circumference and those with a family history of T2DM and certain ethnic groups such as the South Asian group have a higher risk of diabetes (Diabetes UK, 2012). Overall, there are no specific, coherent and clear explanations for this high prevalence in South Asians; however, weight and physical activity have been stated as potential causes. Whilst the South Asian diet has also been strongly associated with the high incidence of diabetes, Bhopal (2013) argues that the South Asian diet is not unhealthy and better for various reasons than those consumed by other ethnic groups. He also argues that physical activity is slow in South Asians, but this does not provide conclusive explanations for the risk of T2DM in South Asians. To add to the current body of literature on the importance of genes and environmental interactions, Bhopal (2013) has designed a ‘four stage model’ to show the ethnic variations in diabetes.

South Asians have been suggested to have a higher genetic predisposition for developing diabetes (Rees et al, 2008), however it is still unknown which gene is actually responsible for the cause of diabetes. For example, the Transcription Factor 7-like (TCF7L2) and ‘the thrifty gene’ have both been claimed to contribute to the increased prevalence of diabetes in the South Asian migrants (Rees et al, 2008; Yajnik et al, 2009). In their study for increased insulin resistance, Hall et al (2008) explained that that the protective nature of these genes (thrifty gene) during times of low calorie intakes before migration become harmful due to the abundance of calorie intakes resulting from a high fat Western diet. Thus, the thrifty-genotype is now seen as a disadvantage in-migrant South Asians due to the disturbances in glucose metabolism and central obesity. For the same levels of Body Mass Index (BMI), compared to Caucasians, South Asians have been found to have significantly high body fat percentage in the abdominal area (Gholap et al, 2011) and develop insulin resistance at a much lower BMI by waist circumference and at a younger age than Caucasians (Mather et al 1998; McKeigue et al, 1992).

1.9 Self-Management of diabetes

After diagnosis, patients are advised by health professionals to manage their diabetes in the context of their everyday lives. Diabetes self-management has been stated as one of the most challenging regimes of any chronic illness (Mbaezue et al, 2010). This is due to the extensive number of tasks involved in managing blood sugar levels, for example eating regularly, adhering to medication and a healthy diet controlling body weight, and regular exercise (Hampson et al, 1990) to reduce the likelihood of developing serious complications and co-morbidities associated with diabetes as mentioned earlier (e.g. heart disease) (Bellary et al, 2008). Further details along with a working definition of self-management can be found in Chapter 3.

1.10 Education for people with diabetes

Diabetes education has been recognised as having a significant role to play in the management of diabetes by empowering patients to be involved in their own care. As mentioned earlier, self-management can have positive implications in terms of quality of life, metabolic control and risk reduction relating to complications associated with diabetes. There are currently two evidence-based education programmes for people living with diabetes: DAFNE (Dose Adjustment for Normal Eating) and DESMOND (2012) (Diabetes Education and Self- Management for On-going and Newly Diagnosed). Self-management education interventions in diabetes have indicated that positive results can be achieved for behaviour change and health outcomes in the general White population (Deakin et al, 2006; Campbell et al, 1996). For this reason, these education programmes have been adapted to have a more ethnic-specific focus to help reduce the burden of diabetes and empower self-management in the South Asian population. The overall aim was to increase the acceptability of the programmes in terms of content and delivery with a specific focus and understanding on cultural health beliefs, language barriers and attitudes related to diabetes in South Asians (Choudhary et al, 2008). Although the programmes have been successful in enhancing knowledge of diabetes, to date limited clinical effectiveness has been reported to improve biomedical outcomes as a result of culturally appropriate health education for diabetes, when compared to ‘usual care’ in South Asians (Khunti et al, 2008). Further research into the effectiveness of structured education programmes can be found in Chapter 2.

1.11 Barriers to effective self-management

A number of factors have been reported to impede day-to-day diabetes management. These include: socioeconomic status, social support, doctor-patient relationship, knowledge, health beliefs, culture, attitudes, health literacy (Nam et al, 2011) and emotional distress (Roy et al, 2012; Anderson et al, 2001). However, factors such as migration, communication (Eakin et al, 2002;Glazier et al 2006; Muhib et al, 2001), language difficulties (Hawthorne, 2001) and religious health beliefs (Fleming & Gillibrand, 2009) have been reported as additional barriers to self-management in the

South Asian population. These barriers have been suggested to impact on access to services, information and advice, as well as the uptake and attendance to diabetes education programmes (Hawthorne et al, 2009). Identifying barriers to effective management is important to improve the quality of diabetes care, including the improvement of metabolic control, and overall diabetes self-management. For this reason, some studies exist which have examined the ethnic differences in self-management of diabetes and found that compared to Caucasians, South Asians have poor knowledge and perceptions of the seriousness of diabetes, and diverse health beliefs (Baradaran & Knill-Jones, 2003). Further differences have been reported in terms of lower perceived awareness of diabetes and its complications, poor knowledge about diet, poor adherence to medication and a lack of awareness on the impact of missing routine health appointments in South Asians (Pardhan & Mahomed, 2004). To date, most of the studies in this field have either examined barriers to self-management predominantly in the Caucasian and European populations or studied single ethnic groups, which makes it difficult to directly compare and understand any additional differences in self-management behaviours between South Asians and other ethnic groups with diabetes. However, of the barriers presented, health beliefs, in particular the role of diabetes-related beliefs in the context of health psychology is of most interest in study and the reasons for this will be outlined in the next section.

1.12 Health psychology and health beliefs

Health psychology is concerned with the study of psychological processes involved in health and illness (Kaptein & Weinman, 2004). The *biopsychosocial* model (Engel, 1977) has been influential in health psychology in that it highlights the importance of biological, psychological and social factors in the study of health and disease. Within this discipline, health beliefs have been pivotal in predicting health behaviours, as well as understanding the way in which people think about their behaviour. A number of theories have been developed within this discipline to explain how beliefs develop, and how they relate to the management of disorders and self-care behaviours (Harvey & Lawson, 2009). These will be discussed in further detail in Chapter 3.

There is not one universal definition of health beliefs, as other disciplines (e.g. medical sociology and medical anthropology) have examined beliefs about health using lay theories and lay representations (Ogden, 2007). Health psychology does not appear to have a single definition that encompasses the complexities of health beliefs, especially within the South Asian population. Thus, for the purposes of this study the following definition of health beliefs has been chosen.

> *'Socially acquired and shared expectancies that reflect, among others, thoughts about the attributes of some situation or condition, as well as consideration of outcomes of specific courses of action'* (de Wit and Stroebe, 2004, p. 54).

The rationale for selecting this definition is two-fold. First, this definition stems from the health psychology literature and since the focus of this study is within the context of this discipline, it is important to use a definition from this field for consistency. Second, this definition highlights the importance of the social context and 'others' in shaping beliefs. This suggests that beliefs cannot be solely attributed to the individual, and can develop from exposure to a variety of social sources (Ogden, 2007). However, it can be argued that this definition is more of a 'generic' definition of beliefs because of its lack of specificity to health or illness. The definition lacks any reference to the wider cultural and religious context in which beliefs may also be acquired for some South Asians. Whilst these factors may also relate to some of the groups in the Western culture, there are still some factors unique to the South Asian culture and practices, which have been found to influence diabetes management and are not captured by this definition. For example, diet and lifestyle behaviours are often influenced by cultural and religious practices in South Asians. Family members and close friends are often obliged to participate in performing care duties for the person living with an illness (Fleming & Gillibrand, 2009). In addition to health beliefs, fatalistic beliefs have also been suggested to lead to poor diabetes control (Egede & Bonadonna, 2003; Lange & Piette, 2006) and poor quality of life in South Asians (Fleming & Gillibrand, 2009). Additionally, the definition fails to capture the psychological and emotional aspects of health and illness which patients with diabetes have been known to often experience (Anderson et al, 2001). Although the evidence concerning the psychological distress in South Asians has been inconclusive due to the cultural and linguistic differences in the understanding and expressions of problems such as ‘anxiety’ and/or ‘depression’ (Lloyd et al, 2012), these experiences may still exacerbate the perceived severity of symptoms and distress related to diabetes amongst South Asians (Sheikh & Furnham, 2012).

Although health psychology aims to take account of the social and cultural factors in research, these factors are often under examined. Very few studies in this field have explored health beliefs in the context of diabetes management in the South Asian population using psychological theory (Patel et al, 2012a), or conducted research with non-English speaking people (Vara & Patel; 2012). Research in this discipline has been criticised for a lack of creativity, and poor efforts in capturing real-life experiences related to understanding health behaviour (Kaptein, 2011; Karzarian & Evans, 2001). Crossley (2000) argues that one potential reason for this limited perspective is the predominance of quantitative methods and pre-defined theoretical models to measuring behaviour. Although quantitative methods have many advantages (de Leewu, 2008) in that they enable a large population to be sampled efficiently and provide comparable data across population groups, to date, most research into diabetes-related beliefs in the South Asian population has been carried out in other social science disciplines (e.g. sociology) using qualitative methods, such as focus groups, interviews (Lawton et al, 2007;Lawton et al, 2006) and storytelling narratives (Greenhalgh et al, 2005). This will be discussed in further detail in Chapter 5.

Kaptein (2011) argues that being more critical about health psychology models is one step closer to studying ‘real’ life behaviour and developing more interesting research questions. Theories such as the Common-Sense Self-Regulatory Model (CS-SRM) by Leventhal et al (1980; 1984) state the importance of addressing the social and cultural factors for understanding beliefs about illness, but has not been successful in providing information on the impact of contextual factors on beliefs about diabetes, especially in the South Asian population. For this reason, recommendations have been made to target more Black and Minority Ethnic (BME) groups in to the future of health psychology research (Patel, 2012a) (see Appendix 1). This is important because the current approaches to self-management for diabetes directed at empowering patients through providing education and information (e.g. structured education, Expert Patient Programme) have had limited success (Blickem et al, 2011; Khunti et al, 2008;

Griffiths et al, 2005;Kennedy & Rogers, 2009;Wilson et al, 2012) in improving diabetes management.

This thesis seeks to utilise a combination of both qualitative and quantitative methods, concepts and theory from health psychology to explore and identify the precise role of diabetes-related beliefs, as well as the social, cultural and religious factors influencing diabetes management in the South Asian population. This will yield new knowledge relevant to self-management of diabetes in this target population.

The next section provides information on the programme of research in which this PhD was conducted.

1.13 Greater Manchester CLAHRC – People with Long term conditions

This PhD was conducted as part of the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) (CLAHRC, 2012) for Greater Manchester and it is therefore pertinent to give a summary outline of the CLAHRC background, aims and objectives in order to set the context for this thesis.

The Greater Manchester CLAHRC is five-year collaboration between the University of Manchester and 22 NHS Trusts across Greater Manchester. The overall aim of the programme is to improve healthcare and reduce inequalities in health for people with cardiovascular disease (diabetes, heart disease, stroke and kidney disease). This PhD was embedded within the University of Manchester Primary Care Research Group, Self-Management department and the CLAHRC People with Long Term Conditions (LTC) theme. For the purposes of this thesis, this will be abbreviated to CLAHRC LTC. The CLAHRC LTC theme aims to improve self-care support for socially and economically deprived populations by shifting the emphasis from professional and individually-focussed approaches to self-care to more community and networks-centred approaches (Rogers et al, 2011), which have greater potential to address structural and contextual factors which impact on self-care (Blickem et al, 2011;Glazier et al, 2006). This research has been carried out by exploring the role of social networks in LTC and the personal resources people draw on to manage their health.

The aim of CLAHRC LTC programme stems from the current challenge of linking and understanding the social, psychological and emotional context of how people cope with living with chronic health problems outside of the health service (Rogers et al, 2011; Vassilev et al, 2010). The wider aims of the CLAHRC LTC programme are:

- To develop, implement and evaluate self-care support resources and interventions, which are tailored to reflect people's personal circumstances and their stages of illness.
- To gather evidence on how community and voluntary organisations and social networks impact on people's health.

1.14 Objectives of CLAHRC LTC programme

The CLAHRC LTC programme has three phases and six projects developed to achieve six main objectives by December 2013 (Appendix 3).

The first two objectives are most relevant to this PhD:

1. To explore the experiences, practices and long-term condition management needs of socially and health disadvantaged people living with diabetes.
2. Assess lay people's systems of support and access to material, social and personal resources, which may influence engagement with services, information and coping strategies.

1.15 CLAHRC LTC Methods

To achieve these objectives, the CLAHRC LTC team utilised mixed methods. A questionnaire was developed which incorporated validated measures of health-related outcomes and innovative methods to map social networks of participants and measure the amount of support received from members of a social networks by ego (Appendix 15, 16 and 19).

Further detail on the methods and contents of the questionnaire and social networks interview can be found in Chapter 6.

1.16 The unique contribution of the work described in this thesis work to the CLAHRC LTC programme

The unique contribution this thesis brings to the CLAHRC LTC programme is two-fold. First, the thesis is focussed on the South Asian population with diabetes and where possible, efforts have been made to explore the differences between the sub South Asians groups. Second, methods, concepts and theories from health psychology were drawn on to measure diabetes-related beliefs. Initial scoping of the literature and the systematic review in Chapter 5 found a lack of research using validated, theory-based questionnaires to assess beliefs in this population, especially in the UK. Although the quantitative study in this thesis draws on the CLAHRC LTC questionnaire and survey interview to examine the relationship between social networks and diabetes-related beliefs; the qualitative study was unique to the wider programme and explored the social, cultural and religious factors which have been known to influence health beliefs and behaviours in South Asians, as mentioned earlier.

The aims and objectives of this study are presented in Chapter 4.

1.17 The Structure of this Thesis

Following on from this Introduction, Chapter 2 begins with an overview of the UK health policy for diabetes, and then considers the education and barriers to self-management for South Asians in further detail, drawing on evidence from a range of literature. Chapter 3 provides an overview of the theories in health psychology, which examine individual beliefs and the evidence, related to social support and social networks for health and illness management will also be presented. Chapter 4 details the aims and objectives of this study and the justification for using a mixed methods approach. Chapter 5 presents a systematic review of the literature concerning measuring beliefs about diabetes using questionnaires. Chapter 6 describes the methods used in the quantitative study and Chapter 7 describes the methodology and methods for the qualitative study. Chapter 8 presents the results of the quantitative study and Chapters 9 and 10 describe the results of the qualitative study. Chapter 11 integrates and discusses the results of the quantitative and qualitative studies, with considerations for the implications for future policy, education and training practice and research. Finally, Chapter 12 provides a reflection of the journey of this PhD.

Chapter 2

Understanding management of diabetes in the UK South Asian Population

2.1 Introduction

This chapter will begin with the definitions of self-management and self-care in relation to diabetes. An overview of UK policies for tackling health inequalities and support for diabetes, the role of primary care and education for South Asians and whether current policies for diabetes account for the need of this target population will be discussed. Cultural factors involved in the conceptualisation of diabetes will be considered, together with some of the barriers, (as mentioned in Chapter 1) which have commonly been known to influence self-management of diabetes in the South Asian population.

2.2 Self-management of diabetes

There are a few definitions of self-management in the literature but the one used in this thesis is by Barlow et al, (2002):

> *'Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition' (Barlow et al, 2002) (p.178).*

Historically, outside of healthcare services, people with diabetes have had to rely on their own efforts or those of their family or carers to manage their illness (Brown et al, 2002) in the context of their everyday lives. This involves controlling what they eat, taking medication and incorporating exercise into their daily routine in order to maintain optimum blood glucose levels, and to reduce the complications associated with diabetes such as heart and kidney disease (Bellary et al, 2008).

The self-care policy for people with long-term conditions was introduced by the Department of Health in 2005 and defined self-care as:

> *'The care taken by individuals towards their own health and wellbeing: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term conditions; and to prevent further illness or accidents' (Department of Health 2005, pp. 1).*

Both concepts; self-management and self-care relate to the way in which people with long-term conditions such as diabetes, are active providers of their care (Wilson et al, 2006). The subsequent self-care policy for supporting people with long-term conditions to self-care in 2006 (Department of Health 2006) states the importance of understanding patients beliefs, attitudes and confidence with the assumption that people who have a clear understanding of their illness will be more likely to take control and engage in self-care behaviours. The terms self-management and self-care are often used interchangeably. For the purposes of this thesis, the term 'self-management' will be used interchangeably with 'diabetes management'. The reason being is that most of the literature related to diabetes in this target population informs on and uses the term 'self-management' or 'diabetes management'. Using these terms therefore also ensures consistency with the literature.

2.3 UK policies for diabetes and health inequalities

The focus of this section is to provide a brief overview of the key policies that are currently in place for people with diabetes in the UK. A historical overview into how and why UK health policy makers realised the need to account for the needs of ethnic minority groups in the UK will be the starting point of this chapter.

2.4 Health inequalities

The need to reduce health inequalities has been on the agenda of the policy for public health in the UK since the publication of 'The Black Report' in 1980 (Department of Health and Social Security 1980). The Black Report was written by Sir Douglas Black in 1977 and reported on health inequalities in the UK, with economic inequality reported as the main cause of this disparity. The report showed socioeconomic differences in death rates (MacIntyre, 1997); for example, men in the lower social class had higher death rates than men in a higher social class, and that the gap was set to rise. Unfortunately until the late nineties, The Black Report recommendations remained low on the government's public health agenda due to the estimated costs of tackling the recommendations made in the report (Sim & Mackie, 2006).

2.5 Policies to tackle health inequalities

Prior to the Wanless report (*'Securing our future health: Taking a Long-Term View',* Wanless, 2002); reducing health inequalities in the UK had mainly focused on housing, families with children and income (Acheson, 1998). The Wanless report (Wanless, 2002) reviewed the long-term trends affecting the health services in the UK and made suggestions to invest in strategies to support self-care and health promotion to reduce health cost. The report called for more evidence based research to provide a stronger link between health and socioeconomic status to determine public health expenditure decisions. The subsequent report in 2004: *Securing good health for the whole population* (Wanless, 2004) stated the importance of accounting for the wider determinants of health in ethnic minority groups and identified social deprivation as a major factor of health status. Recent health policy reports, for example '*Fair Society Healthy Lives'* acknowledges the lack of consideration given to the health of ethnic minority groups in the UK (Marmot, 2010).

> *'The conceptualisation of health inequalities underpinning the current target does not capture the more complex patterning of health associated with other groups (for example, ethnic groups) and giving consideration to the specific health needs of certain populations is essential'.* (Marmot, 2010, pp. 142).

The importance of the Marmot (2010) report is the recommendation for health behaviour policies to extend beyond the individual and address the social determinants of health as a strategy to reduce health inequalities:

> *'Aiming interventions at individuals will not by themselves reduce health inequalities; 'responsibility for better health should be shared between society and the individual'. (*Marmot, 2010, pp. 142*).*

In addition, The Equity and Excellence: Liberating the NHS White Paper (Department of Health, 2010b) also reports on allocating funds to tackle inequalities in access to healthcare:

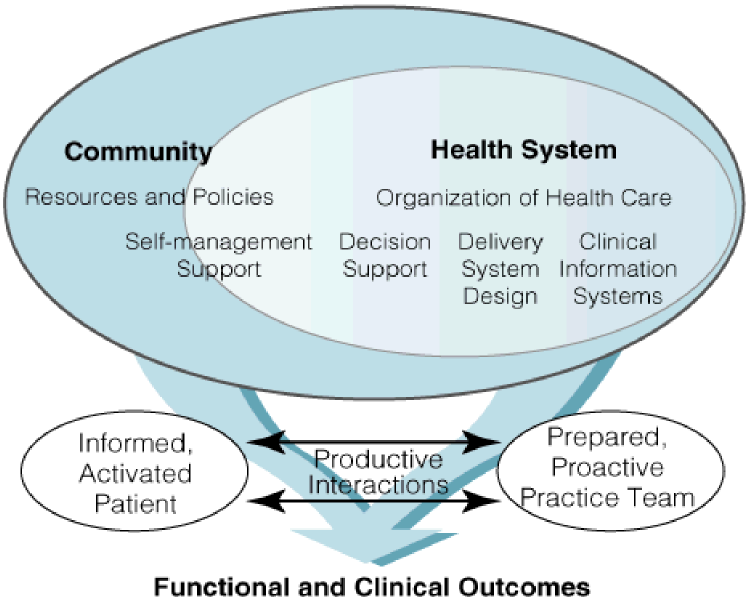
> *'Include a new "health premium" designed to promote action to improve population-wide health and reduce health inequalities'. (*Department of Health, 2010b, pp.13*).*

The report also recognises the importance of research in providing new knowledge to improve health outcomes and reduce inequalities. However, the report is very generic and does not provide any specific information in relation to the strategies to employ in order to reduce health inequalities with the UK South Asian population and in specific conditions such as diabetes. The '*Good Care for All'* working group has been established as part of the National Service Framework for Diabetes to address the specific health inequalities in diabetes care (Department of Health 2010a). The aim of this group is to ensure co-ordination between the Department of Health, NHS Diabetes and key stakeholders when addressing inequalities in diabetes care. Despite nearly three decades of research into diabetes management of the UK South Asian population, the recent recommendations for tailoring policies to the needs of people from this target population remains sparse.

2.6 Chronic Care Model

To ensure people receive the support they need to manage their condition within the context of their own home, international frameworks such as the Chronic Care Model (CCM) (Wagner, 1998)(Figure 2.1) have been a primary feature of the UK self-management policy (Wilson et al, 2006). The CCM is an evidence-based framework developed in the USA, intended to guide quality improvement and enhance disease management (Wagner et al, 2001). The CCM comprises of six elements: community resources, health care organisation, self-management support, delivery system design, decision support, and clinical information systems. The aim of the CCM model is to improve chronic illness in primary care, and interactions between providers and patients using a multidisciplinary team.

Figure 2.1: The Chronic Care Model (Wagner, 1998)



Source: Model for improvement of chronic illness care (Wagner, 1998)

This model highlights that patients need information, skills and confidence to make the best use of involvement with the practice team.

Self-management is one of the key drivers of improvement in the model (Bodenheimer et al, 2002) and has been shown to improve patient care and outcomes (Coleman et al, 2009). More recently the CCM has been reported to be a useful tool to guide the planning of culturally appropriate health care services for South Asians (Dhatt et al, 2012)

In parallel to the above policy reforms, the Expert Patient Programme (EPP) was an anglicised version of the American Chronic Disease Self-Management Program, (CDSMP) (Lorig et al, 1996) that was launched into the NHS in 2002. The aims of the programme were to help patients with chronic conditions to take control of their lives (Lorig, 2003), improve health status, and reduce the burden of health care resources in the NHS (Department of Health, 2001). The rationale for the CDSMP stems from Bandura’s theoretical model of self-efficacy (Bandura, 1977). Self-efficacy refers to an individual's belief in their ability to successfully complete a task or adopt behaviour successfully, such as taking medication (Sutton, 2010).

A Cochrane systematic review assessing effects of the EPP based on 17 Randomised Controlled Trials (RCT) has reported short-term improvements in patient confidence to manage their condition and perceptions of their own health. The EPP programmes were not successful in altering the use of health services (Foster et al, 2007). For example, the national UK evaluation of the EPP (Kennedy et al, 2005; Rogers et al, 2005) have found small to moderate impact in reducing health services utilisation within the general population, which was one of the major aims of this programme (Richardson et al, 2008). The EPP has also been criticised for its 'one-size fits all' notion to self-care and failing to account for wider determinants such as the individual's social context (Gately et al, 2007; Kennedy et al, 2007; Rogers et al, 2011). Despite the programmes being adapted for use by different ethnic groups (Fu et al, 2003; Griffiths, 2005), the evaluations have also highlighted the difficulties of reaching out to minority groups (Rogers et al, 2005) with only one study directed at the South Asian population. In their RCT, Griffiths et al (2005) explored the effectiveness of using a culturally adapted lay-led version of the EPP for Bangladeshi adults with diabetes, cardiovascular disease, respiratory disease or arthritis, in Tower Hamlets, East London. Self-efficacy, self-management behaviour, communication with clinicians, depression and healthcare use were assessed by blinded interviewer-administered questionnaires in Sylheti, before and 4 months after randomisation. The findings of this study reported improvements on self-efficacy and self-care behaviour, but the effects on health status were marginal and limited by moderate uptake and attendance of the programme by Bangladeshis. However, the longer-term impacts of the EPP on health status, metabolic and physiological outcomes in South Asians with diabetes remain unclear and require further research (Griffiths, 2005). Further evidence on education programmes for diabetes will be presented later in this chapter.

2.7 Promoting partnership working and responsibilities for diabetes care in UK primary care

Almost everyone living in the UK is registered with a General Practice. General Practitioners (GP) and Practice Nurses (PN) provide the majority of diabetes care in primary care. For this reason, primary care has been suggested to be an appropriate setting to increase patients' personal responsibility to manage their condition within their own homes, using information sources provided by their GP or PN (Department of Health, 2006). GPs and PNs in the UK are expected to take on the roles of health educator, and counsellor roles which may be different from those developed during their medical education (Bensing, 2004). The GP role in primary care has been suggested to be pivotal in ensuring that all patients receive effective diabetes care (Diabetes UK, 2005a). However, there has been a shift from GP-led consultations towards `shared decision-making' and 'patient-centred consultations', which aim to focus on understanding patients experiences of their illness, and any relevant social and psychological factors (Stevenson et al, 2000). It involves healthcare providers employing active listening skills in order to encourage patients to express their agendas, help patients make informed decisions to achieve their goals, providing education, advice and support, as well as working with patients to reach a common ground regarding management (Funnell & Anderson, 2004). The main purpose of patient-centred care is to increase `patient empowerment' (Kennedy et al, 2007;Thabit et al, 2009). Funnell et al (1991) define patient empowerment as:

> *'Helping patients discover and develop the inherent capacity to be responsible for one's own life' (p.3)*.

They state that patients are empowered when they have adequate knowledge, skills, resources, attitudes, self-awareness and education to effectively manage their diabetes and influence their own behaviour. However, Bodenheimar et al (2005) provides a useful definition of self-management support and what it means in terms of changed relationships and partnership working:

> *'Self-management support is the assistance caregivers give patients with chronic disease in order to encourage daily decisions that improve health related behaviours and clinical outcomes. Self-management support can be viewed in two ways: as a portfolio of techniques and tools that help patients*

> *choose healthy behaviours; and a fundamental transformation of the patient-caregiver relationship into a collaborative partnership.'(p.4).*

Thus, the goal of increasing personal responsibility is to empower patients to manage their health and illness in the context of their everyday lives. The concept of empowerment is not the focus of this thesis. However, as alluded to earlier, certain concepts and developments in policy (e.g. *self-management, empowerment*) may not always be easily translated into practice by GPs or PNs understood by South Asian patients. For example, the current evidence suggests that GPs are aware of the concept of self-management but have been slow to operationalise it in practice (Blakeman et al, 2006). Hibbard et al (2010) piloted a new measure to assess clinicians' beliefs (Clinician Support or Patient Activation Measure -CS-PAM) about patient self-management and found that clinicians strongly believed that patients should comply with medical advice but were in least favour of patients as 'independent actors' of their health. Furthermore, Blakeman et al (2010) explored and conducted a comparative analysis of interview data of primary care consultations with healthcare professionals and patients with long-term conditions. The finding of this study reported on the difficulty GPs experienced when embedding discussions related to self-management behaviours during consultations. The tensions related to maintaining self-other relations, technological demands and division of labour in primary care were also reasons stated for self-management discussions becoming marginalised during consultations. A recent study by Bower et al (2011) found that these tensions are often exacerbated in patients with multimorbidity whereby clinicians in primary care have to deliver care to meet quality targets as well as fulfilling the patients agenda. The division of labour for chronic disease management in primary care amongst GPs and PNs has been suggested to further contribute to the difficulty of operationalising self-management in consultation. This is largely due to the new general practice contract in the UK that has increased PNs responsibility for supporting patients with chronic diseases (Charles-Jones et al, 2003). In their study with 25 PNs, MacDonald et al (2008) found that nurses seemed more confident in dealing with patients in the early stages of diagnosis, but despite being aware of the challenges patients faced with managing their condition, the PNs lacked resources beyond their regular consultation and were more likely to develop heuristic notions of patients as ‘good and bad self-managers’. MacDonald et al (2008) called for more education and training on delivering self-management for PNs in primary care, as well as training on the social, emotional and psychological factors which may impact on self management for some patients.

2.8 Barriers to promoting partnership working and responsibilities for diabetes care in South Asians

Establishing and promoting partnership between South Asian patients and healthcare professionals may prove difficult (Griffiths et al, 2001). In addition to the factors mentioned earlier are those concerning culture, ethnicity and communication, which may add an additional layer of complexity to the operationalisation of self-management in consultation (Stone et al, 2005). Although it is not within the remit of this thesis to discuss in detail the issues of communication in consultation between healthcare professionals and South Asian patients, it is important to highlight the key evidence which suggests that these patients may have unrealistic expectations of the doctor-patient relationship, which may lead to misunderstanding in the consultation context, and hinder a working partnership (Greenhalgh et al, 2005b). It can be argued that some Caucasian, as well as South Asian patients may perceive the doctor as the ‘expert’ and anticipate a passive role in consultation (Darr et al, 2008). However, in 2007, the Department of Health examined variations in the self-reported views of NHS patients from different ethnic minority groups from primary care services. The report found that patients from ethnic minority groups (e.g. some South Asians), in comparison to their Caucasian counterparts were less comfortable in taking responsibility regarding self-care for their illness (Department of Health, 2009). It has been suggested that if given a choice, South Asians might choose to continue with a paternalistic approach, in which the healthcare professional takes the dominant role in making decisions relating to their diabetes care (Chandarana & Pellizzari, 2001).

One possible reason for this is that effective medication is what some South Asian patients, especially migrants from the Indian subcontinent desire and perceive to be more important than quality of interaction with their healthcare professional (Hunte & Sultana, 1992). Unlike the NHS in the UK, healthcare in the Indian subcontinent has to be paid for resulting in patients from lower socio-economic classes commonly self-medicating or using alternative treatments (Datye et al, 2006). In interviews with 21 Pakistani patients with diabetes, Bissell et al (2004) found that patients had difficulty in understanding what negotiation, discussion and partnership might mean in practice. There was a strong preference and familiarity of a ‘doctor-centred’ model of health care interactions as opposed to patient-centred care. The idea that the patient might have an equal say in the consultation seemed unfamiliar to many patients in this study. Rather poverty, material disadvantage and gendered roles emerged as important factors in treatment regimen. Bissell et al (2004) only studied Pakistani patients; therefore it is not possible to compare these findings with other South Asian sub groups. However, Stone et al (2005) in their qualitative study with South Asians and Caucasians found that South Asians (compared to Caucasians) had a low motivation to become partners in diabetes management, but a high preference for education related to diabetes. Furthermore, Ali et al (2006) explored the similarities and differences in which Caucasian and South Asian patients communicate with Caucasian GPs using qualitative interviews of videotaped consultations. Their findings showed that, in comparison to the Caucasian patients, South Asian patients were dissatisfied with the amount of time the GP spent with them in consultation, the lack of social conversation and information provided, and were generally not content with the communication that took place in the consultation process. Similar findings were noted in a qualitative study by Ahmed (2010), which explored the perceptions and experiences of diabetes consultations from the perspectives of Pakistani patients, healthcare professionals and interpreters (when one was involved). Data from 10 case studies found that patients tended not to raise health concerns related to their diabetes, which often led to GPs making inappropriate treatment recommendations. Furthermore, patients were often ‘passive’, and ‘got by’ in their consultation by guessing what the GP was asking, with some GPs being unaware of patients poor English and of how little they had understood during the consultation.

To date most of the research into patient-practitioner communication in GP consultation stems from patients who speak English as a first language, and who often share the same class and educational backgrounds as their healthcare professionals. A few studies exist that have questioned and evolved the quality of communication between South Asians and their healthcare professional (Ahmed, 2010).

2.9 Role of Quality and Outcomes Framework (QOF) in Primary Care

The Quality and Outcomes Framework (QOF) (The Information Centre, 2012) was introduced in the UK in 2004 as a financial incentive to reward good practice for GP Practices in England. The clinical domain for diabetes consists of 17 indicators and each indicator provides an indication of the overall achievement of a practice through a point score system. GPs and health professionals are encouraged to make improvements in managing patient care and to deliver high quality care to prevent complications of diabetes (The Information Centre, 2012). In addition, Doran et al (2008) argue that QOF has the potential to reduce health inequalities in deprived areas. In their analysis of 7637 GP Practices in England using the 2006 general medical statistics data (2004-2007) Doran et al (2008) found a steady increase in achievement in practices during this period. In particular, findings showed that the variation in the quality of care related to deprivation was also reduced during the first three years of the financial incentive scheme. Although QOF has been suggested to be a powerful tool for systematically monitoring registered patients in primary care (Marmot, 2010); access to diabetes care still remains problematic for some South Asians (Alam et al, 2008; Wilson et al, 2012) and the recommendation for recording ethnicity routinely in primary care to improve access still remains sparse (Chauhan et al, 2009). For example, Sultana & Sheikh (2008) searched the database – Directory of Clinical Database (DoCDat); a large database consisting of 162 local and national health data, which routinely record health statistics, patient demographics and clinical data. Results of this study reported minimal evidence of ethnicity or religion being routinely recorded into this database. Information on both ethnicity and religion has the potential to help understand the nature of health inequalities and provide opportunities to assess disease prevalence, health service utilization and clinical outcomes across and between ethnicity and faith groups (Sultana & Sheikh, 2008). Recent evidence suggests that some patients adapt to chronic illness and manage their health through religious coping (Thuné-Boyle et al, 2006; Swinton et al, 2011). Thus recommendations for training healthcare professionals on the differing needs of diverse patient groups to provide a more sensitive and tailored health service to South Asian patients have also been made to improve care and services (Chauhan et al, 2009).

2.10 Barriers to self-management in South Asians

It is unrealistic to assume that self-management of diabetes will be acceptable for all patients. The difficulties people face in managing their diabetes and the challenges of the provision of self-management activities in primary care consultation is not restricted to South Asians *per se*. However, language barriers, lack of knowledge and understanding about how the healthcare system operates, and the changes in the model and delivery of care may be a possible reason for the preference for a paternalistic approach to their care, as mentioned earlier. Baradaran & Knill-Jones (2003) designed a questionnaire (translated in to relevant South Asian languages) to measure knowledge, attitudes and practices related to T2DM in South Asians and Caucasians with T2DM and found that knowledge of diabetes in South Asians was poor, compared to the Caucasian group. Health beliefs and perceptions of the seriousness of diabetes also varied between ethnic groups. For example, South Asians had a negative attitude towards the seriousness of T2DM and diabetes control, compared to the Caucasian group. Pardhan & Mahomed (2004) examined variations in the awareness of various issues related to self-management of diabetes in South Asians and Caucasian patients attending diabetes clinics and found that South Asians, compared to Caucasians, had a lower perceived awareness of diabetes and its complications, nutritional content of their diet, were less worried about missed appointments and had poor adherence to their treatment for diabetes.

Government health policy has begun to consider the cultural needs of South Asians e.g. tailoring existing information and education programmes into native languages, providing translators and link workers within primary care services to improve access to services (NHS Direct, 2012). Notwithstanding these developments, and health services being available `free of charge' in the UK, the access to and uptake of diabetes services remain problematic in some parts of the UK, and especially within the

Bangladeshi population (Alam et al, 2008; 2012). The social pressures of conforming to cultural norms have been stated to affect health behaviours for this group (Grace et al 2008). Greenhalgh (1997) argues that the differences in attitudes and behaviour in South Asians cannot be explained by cultural or religious reasons as factors such as lower socio economic status, together with lower structural and material resources have to be considered as well. Socio-economic deprivation has been one of the important predictors of the use of health care services in the South Asian population (Hawthorne, 1994). In particular, socio-economic status (SES) has been found to vary between subgroups of the South Asian population (Health Survey England, 2004), with the Indian population reported to have better SES, lower prevalence of diabetes and lower levels of material deprivation than the Pakistani and Bangladeshis groups (Nazroo 1998; Simmons et al, 1989).

2.11 Diabetes education

In the UK, patients with diabetes are encouraged to undertake structured education in order to engage and involve themselves in their own diabetes care. The aim of structured education is to improve people's skills, knowledge and confidence to take control of their own condition, and help them to gain a better quality of life (Yates, 2008; Diabetes UK, 2005b; NICE 2003; 2009). As mentioned earlier in Chapter 1, there are currently two evidence-based education programmes DAFNE (Dose Adjustment for Normal Eating) and DESMOND (2012) (Diabetes Education and Self- Management for On-going and Newly Diagnosed). In the general population, RCTs have found support for the short-term effectiveness of self-management education for people with diabetes (Norris et al 2002), compared to the long-term effectiveness. However, this study did not include South Asians with diabetes. Similarly, a review of the above education programmes has also found positive results in behaviour change and health outcomes, but in Caucasians only (Deakin et al, 2006). A recent review by Blickem et al (2011) suggests that the impact of informational strategies for supporting people with LTC is moderated by contextual and cultural factors such as ethnicity, language, health literacy, especially for those from disadvantage backgrounds. The structured education programmes (DAFNE and DESMOND), originally developed with the Caucasian population have been adapted for use with South Asians based on the hope that these will be more acceptable, both in terms of content and delivery if they are informed by an understanding of specific cultural needs and attitudes. Stone et al (2005) have described the process of adapting and initially piloting the DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) module for use in South Asian populations. This modified version was delivered through interpreters with a range of visual resources. Similarly, Choudhury et al (2008) evaluated a version of the X-PERT Programme modified for people of Bangladeshi origin. Education sessions were conducted in Sylheti by a peer educator and included the use of interactive posters to explain diabetes. Furthermore, a trial conducted in 21 inner city general practices in the UK included enhanced practice nurse contact and support from a link worker rather than a structured education programme. The primary outcome measures were changes in blood pressure, total cholesterol and HbA1c levels after two years of follow-up. However, only minimal benefits were identified with a lack of cost- effectiveness and it was concluded that stricter targets are needed in primary care, together with additional measures to motivate patients (Bellary et al, 2008). Khunti et al, (2008) conducted a systematic review to explore the effectiveness of tailoring education programmes for South Asian patients with diabetes. Despite increases in knowledge of diabetes, there has been a minimal impact of tailored education interventions on long-term clinical outcomes of diabetes when compared to ‘usual care’. Furthermore, factors such as language, literacy and attitudes to questionnaire completion have been stated as difficulties in evaluating the effectiveness of such educational interventions Choudhury et al (2008).

Recent reviews on this topic also report on the lack of high quality data on the effectiveness of culturally appropriate diabetes health education programmes across a broad range of ethnic minority groups (Hawthorne et al, 2010; Zeh et al, 2012). For example, Hawthorne et al (2010) conducted a Cochrane systematic review with meta-analysis to determine if culturally appropriate health education is more effective than ‘usual’ health education for people with diabetes from ethnic minority groups living in high- and upper-middle-income countries. Data were collected on glycated haemoglobin (HbA_{1c}), blood pressure, and quality-of-life measures. HbA_{1c} showed an improvement at 3 months and 6 months post intervention but lost at one-year post intervention. Knowledge scores also improved in the intervention groups at 6 months across all groups. Culturally appropriate health education was more effective than ‘usual’ health education in improving HbA_{1c} and knowledge in the short to medium term. Similarly systematic review by Zeh et al (2012) examined the evidence on culturally competent interventions tailored to the needs of people with diabetes from ethnic minority groups. The review found that 10 out of 11 studies had tailored diabetes education interventions and considered factors such as culture, language, religion and health literacy skills. These interventions had a positive impact on a range of clinical and psychosocial outcomes related to diabetes outcomes in the interim. The authors also developed and used a ‘culturally competent assessment tool’ for healthcare interventions in ethnic minority groups, and have made recommendations for cultural competency training to be integrated into the health services in order to overcome these barriers (Zeh et al, 2012). The eight cultural competencies identified are:

1. Strong adherence to culture in diet, exercise, social identities and interactions.
2. Strong adherence to religious beliefs.
3. Linguistic differences between patients and health workers.
4. Low health literacy levels amongst patients.
5. Different beliefs about health and illness.
6. Diverse perceptions of professional competency and professional support.
7. Low accessibility of culturally appropriate services and information.
8. Low compliance and concordance with professional advice.

However, one of the difficulties of including people from a range of ethnic minority groups, from a host of difference countries is that it makes it difficult to generalise the findings to UK South Asians *per se*. In addition to structured education programmes, recent developments of community-based peer-led education programmes have seen a rise in the number of Diabetes Community Champions (Diabetes UK, 2011). The aim of the champions programme is to raise awareness, disseminate and provide information on diabetes to the local community. Some champions also act as mentors to improve quality of life and management of diabetes (CLAHRC North West, 2012). To date, the effectiveness of these resources has not yet been evaluated.

This chapter has highlighted that although current health policy aims to overcome inequalities for the South Asian population, efforts to educate this population on diabetes management have been ineffective and understanding how to meet the needs of the South Asian population still remains a challenge to policy makers. Thus, considering how specific psychological factors, such as beliefs about diabetes may be influenced by culture and the social context may help to identify appropriate targets for future intervention and policy.

The next section of this chapter will discuss some findings from the literature in relation to some of the barriers (e.g. health literacy, stigma, cultural beliefs and migration) as mentioned earlier.

2.12 Health literacy

There are a number of definitions of health literacy (Sorensen et al, 2012). For example, Kickbusch et al (2006) defines health literacy as:

> *'Ability to make sound health decisions in the context of everyday life - at home, in the community, workplace, the healthcare system, the market place and political arena'. (p.3)*

Poor health literacy has been associated with poor knowledge of diabetes and outcomes in the general population (Nutbeam, 2000; Dewalt et al, 2004). Mbaezue et al (2010) found that patients with low health literacy had lower rates of self-monitoring blood glucose records and a poor understanding of the results. The ability to read simple text and write simple sentences is known as Functional Literacy (Protheroe et al 2009); health literacy additionally requires the skills of obtaining, understanding and using health information in both written and verbal format. It is often assumed that tailoring health information into the relevant South Asian language will produce desired health outcomes and that patients will be able to make rational decisions about their diabetes based on the information read. However, in the context of the South Asian population, the social norms and expectations held by their families have been shown to impact on how information is used (Lawton et al, 2007). The cultural context is often blamed for poor health literacy or non-adherence to medical advice in this population (Nazroo et al, 2009; Lawton et al, 2006a; 2006b) but there is a lack of evidence on *how* the culture and social context in which South Asians manage their diabetes may actually impact individual's beliefs about diabetes.

2.13 Stigma of diabetes

It is not uncommon for diabetes to be kept a secret from friends and extended family members in the South Asian community (Goenka et al, 2004) due to the stigma and fear of being perceived and labelled as eating too much sugar or being unhealthy. For example, Hawthorne's (1997) flashcard intervention found that participants were reluctant to disclose their diagnosis of diabetes to other participants in the study due to social stigma. Goffman (1963) defines stigma as the: *'sign or a mark that designates the bearer as "spoiled" and therefore as valued less than "normal" people (p.30).* There is a lack of studies into the stigma of living with diabetes in the South Asian population and the potential impact this may have on self-management. Studies have reported on factors such as poor communication, socioeconomic status and deprivation as barriers, rather than exploring the threat of being socially identified as having an illness such as diabetes in the South Asian population. Recent evidence suggests that stigma is related to a person's social identity and social context (Dovidio et al, 2000). People who fail to meet the expectations conveyed by their identity may also experience what is known as `Felt Stigma' (Kurzban & Leary, 2001), whereby the fears of being treated and labelled as different become the focus of one's personal evaluation and this may have important implications for adherence to medication, access to health services and diet regime in social situations (Greenhalgh et al, 1998). It is important to note that the stigma of having diabetes is not exclusive to the South Asian population *per se*. Studies across a wide range of chronic conditions, ethnic groups and cultures have reported stigma to be problematic and a potential barrier to diabetes management (Scambler, 2006; Weiss et al, 2006; Weiler & Crist, 2009).

2.14 Cultural beliefs and migration in the South Asian population

A patient’s cultural background has been reported to have an important influence on many aspects related to health behaviours, for example, beliefs, emotions, religion, family and attitudes (Helman, 2007 p.3). There are a number of definitions of ‘culture’ in the literature, but the one used in this thesis is by Giger & Davidhizar, (1999) which defines culture as:

> ‘*A meta-communication system based on non-physical traits e.g. beliefs, attitudes, customs, language and behaviours that are shared by a group of people and passed down generations through formal communication and imitation’* (p.3).

This concept has been useful in explaining how individuals from the South Asian population define and conceptualise diabetes using their cultural beliefs and practices. Despite claims which state lifestyle factors and obesity as causes of T2DM, the `sugar myth' still dominates the beliefs about cause and management of diabetes in the South Asian population (Dunning, 2004; Rai & Kishore, 2009). One possible reason for this could stem from how diabetes was first conceptualised in the East. For instance, a Hindu physician in India observed that ants and other insects were attracted to ‘sweet’ urine (Sebastian, 1999). Matthew Dobson confirmed the presence of sugar in urine and the blood and suggested that diabetes was a metabolic disorder (McGrew & McGrew, 1985). Thus, the presence of sugar became an important factor in the diagnosis and measure of diabetes globally. Some studies have explored such beliefs in relation to dietary behaviours and diabetes. For example, Lawton et al (2007) interviewed South Asian (Pakistani and Indian) and Caucasian people with T2DM and found that both groups stated excess sugar consumption as one of the main causes of diabetes. However, the consumption of sugary foods in the South Asian group was thought to be related to stress, poor living conditions, lifestyle and changes to diet after migration. For example, one South Asian participant in Lawton et al’s (2007) study stated that consuming too many `Mars bars' was due to the lack of food choice for vegetarians in the UK for migrant South Asians in the 1960s.

Migration has been defined as: ‘*a permanent or semi-permanent change in residence for a period of greater than one year’* (Jeeman et al, 2009). In the 1950s South Asians from Pakistan, India and Bangladesh migrated to the UK and the 1970s saw an influx of East African Indians migrate to the UK due to political upheavals in Uganda (Hanif & Karamat, 2009). Today, migration has become much more frequent with more global opportunities in business and technology. Migration has been linked to the onset of T2DM, due to changes in lifestyle and diet (Misra & Ganda, 2007; Jeeman et al, 2009). Furthermore, Lawton (2007) found that Pakistani and Indian respondents both stated their experiences of migrating to the UK and the emotions of leaving their native country and adapting to the UK as stressful and further causes of diabetes. Moreover, Rankin & Bhopal (2001) investigated the understanding of heart disease and diabetes in the South Asian community and found that the cause of diabetes was related to high consumption of sugar, thus controlling for and reducing sugar intake was stated to be key to preventing the onset and management of diabetes.

However, a recent qualitative study reported by Choudhary et al (2009b) conducted with Bangladeshis with T2DM explored issues of knowledge, management and information sources of diabetes. Choudhary et al (2009b) found that patients linked managing diabetes to controlling the intake of `sugar' and following the information and/or advice provided by the GP. Yet some patients were not aware of the cause of their diabetes and the purpose of living a healthy lifestyle. Although these studies highlight the importance of beliefs, this is partly in relation to causal beliefs (e.g. sugar associated with the cause of diabetes). The extent to which these beliefs and behaviours are influenced by the social context and the implications this has for diabetes management is unknown. The importance of this is that recent evidence suggests that self-management is just as much a social, cultural and emotional task as a clinical task. Social circumstances and emotional representations shape the perceptions people have of their condition and the way they care for it (Furler et al, 2008; Gallant et al, 2007). To date, most of the research exploring diabetes management in the South Asian population appears to have utilised a range of qualitative methods. Further investigation into the utilisation of quantitative methods (e.g. using questionnaires to explore beliefs about diabetes) is required for a complete view on the role of beliefs and diabetes. Therefore, exploring the underlying beliefs about diabetes and the factors influencing these beliefs using a combination of qualitative and quantitative methods is essential to:

- Tailoring care planning strategies and policies for diabetes, acceptable to the patient and family.
- Service design if healthcare professionals are to learn and give attention to social and cultural beliefs underpinning diabetes management.
- Designing of interventions to address the factors underpinning beliefs to improve support and change behaviours for optimum diabetes management.

2.15 Summary

This chapter has reviewed and presented some of the key policies for diabetes in the UK along with issues related to health inequalities. Despite the strategies currently in place to overcome language barriers, routinely recording ethnicity in primary care to identify patients from ethnic minority groups and provide tailored structured education programmes to address the needs of the South Asian population, the longer-term impact of these on self-management and health outcomes of diabetes still remains unclear. To date, research into beliefs in relation to diabetes management in the South Asian population appears to have been dominated by qualitative research. Although studies using this method have highlighted the importance of family and friends in the context of everyday life and diabetes management, more rigorous methods need to be used to explore the exact role of these networks, the amount of support given for diabetes and the impact this has on beliefs related to diabetes. A limited number of studies have provided information on knowledge levels, attitudes, health beliefs and practices that may affect South Asian people’s willingness and ability to play an active role in managing their diabetes. Given the increase risk of diabetes in South Asians, there is also a need to identify beliefs that may contribute to management behaviours as well as exploring the social, cultural and religious factors and the relationship between these factors on diabetes management.

The next chapter specifically focuses on the health psychology theories that have been developed to examine individual beliefs about health and illness. The evidence related to social support and social networks for health and illness will also be discussed.

Chapter 3

Understanding beliefs about diabetes of the South Asian population in health psychology

3.1 Introduction

This chapter presents an overview of the theories in health psychology which have been developed to examine individual beliefs about health and illness and the rationale for selecting one of these theories to be utilised in this thesis will be provided. Similarly, the evidence related to social support and social network for health and illness management will also be discussed, and the rationale for using the exploring the role of social networks will be presented.

3.2 Health psychology theories

In health psychology, health and illness beliefs have been studied from a variety of theoretical perspectives. For example, the Attribution theory aims to understand 'a person's perceptions of what causes beliefs, feelings, behaviour and actions' (Weiner, 1986). One of the main assumptions of this theory is to determine why people do what they do, and how they interpret causes to an event or behaviour. A three-stage process underlies an attribution:

1. Behaviour must be observed/perceived
2. Behaviour must be determined to be intentional
3. Behaviour attributed to internal or external causes

The common idea is that people interpret behaviour in terms of its causes and these interpretations play an important role in determining reactions to behaviour (Weiner, 1985). Sissons-Joshi (1995) compared lay beliefs about diabetes with 108 diabetes patients in England and 55 diabetes patients in India using structured interviews. Patient's answers to questions concerning the cause of diabetes were coded into categories. Both groups held strong casual beliefs in relation to hereditary, stress and diet. Causal beliefs have been researched by cognitive-behavioural anthropologists (Garro, 2000) who have described some of the processes involved in linking culture to health behaviours (Helman, 2007). The limitations of focusing solely on *causal* beliefs is that it does not inform *how* people actually appraise symptoms, adhere to treatment, take responsibility for their condition, and the influence of the social and cultural context for illness management.

3.3 The Health Belief Model and Theory of Planned Behaviour

The Health Belief Model (HBM) was developed to understand why people failed to make use of disease prevention or screening tests (Becker et al, 1974). Later the model was extended to understand patient's responses to symptoms and compliance with or adherence to prescribed medical regimens (Janz & Becker, 1984; Stroebe, 2000). HBM is a subjective model which assumes the individual is a rational decision-maker who is able to weigh up his or her attitudes and values when evaluating the overall utility of the behaviour in question, e.g. setting goals. Although the HBM has been useful in predicting adherence to diabetes medication (Bond et al, 1992), and informing interventions on enhancing adherence to diabetes medication (Janz & Becker, 1984), the model does not study cognitions or emotions related to managing a chronic condition, such as diabetes. Another limitation of the HBM is that it simplifies health-related cognitions into broad constructs such as 'barriers' and 'benefits' without specifying the beliefs underlying these constructs (Horne & Weinman, 1998), with a lack of reference to the influence of the social context for health-related behaviour (Sheeran & Abraham, 1996). The Theory of Planned Behaviour (TPB) (Ajzen, 1991) is a social cognitive theory that was designed to help to understand the interaction between person, behaviour and environment, and the determinants of an individual's decision to enact a particular behaviour. TPB focuses on the link between intensions, behaviour, perceived behavioural control and claims that people tend to engage in behaviours they intend to perform. The TPB has previously been applied to self-monitoring of blood glucose levels with patients with T1DM (Povey et al, 2000) intensions to exercise and enhancing the intention to self-monitor diabetes (McGuckin et al, 2011). However, the TPB is unsuitable for this work because the focus of this study is on understanding the cognitions and the factors which influence beliefs about diabetes in South Asian people with diabetes not their intensions to self-manage and/or predict self-management behaviour *per se*.

3.4 Common-Sense Self-Regulation Model (CS-SRM)

To date, the most influential psychological theory in understanding one's beliefs about health and illness has been Leventhal et al (1980; 1984) Common Sense Self-Regulation Model (CS-SRM). Prior to its application to chronic illness, Leventhal and colleagues were interested in how patients evaluate and cope with health threats and what impact, if any, fear messages had on dealing with the threat (Leventhal & Niles, 1965). Through a series of experimental studies it was identified that people process information and cope with the threat of illness in two ways: using a behavioural response or an emotional response and this was understood using the parallel processing model. This parallel process was stated to be influenced by one's self-concept and self-perception of the health threat and operated through a process of self-regulation. The term 'self-regulation' largely refers to:

> '*Efforts by humans to alter their thoughts, feelings, desires, and actions in the perspective of such higher goals'* (de Ridder & de Wit, 2006 pp.2-3).

Later this led to the notion that patients have their own implicit Common Sense Model (CSM) about their illness (Leventhal et al, 1984) which consists of a number of discrete attributes that can be measured along five dimensions: *Identity, Cause, Consequences, Timeline and Control* (Figure 3.1*)* which provide procedures for dealing with a health threat (Leventhal et al, 1984). For the purposes of this work the latter concept of CS-SRM (Phillips et al, 2011; Leventhal et al, 2003) will be used in this thesis.

The five dimensions of this model are taken together to contribute to the behaviour and psychological outcomes in chronic illnesses as outlined in Box 3.1. Studies which have used the CS-SRM in relation to diabetes management will be presented later on in this chapter, section 3.8 and 3.9.

Box 3.1 Five dimensions of the Leventhal et al (1984) Common Sense-Self Regulation Model

Identity*:* Labelling or diagnosis beliefs.

Cause: Factors or conditions believed to cause the illness.

Timeline*:* Expected duration of illness which can vary from acute, to cyclic, chronic or long-term.

Consequences*:* Effects of an illness on physical, social and psychological well-being.

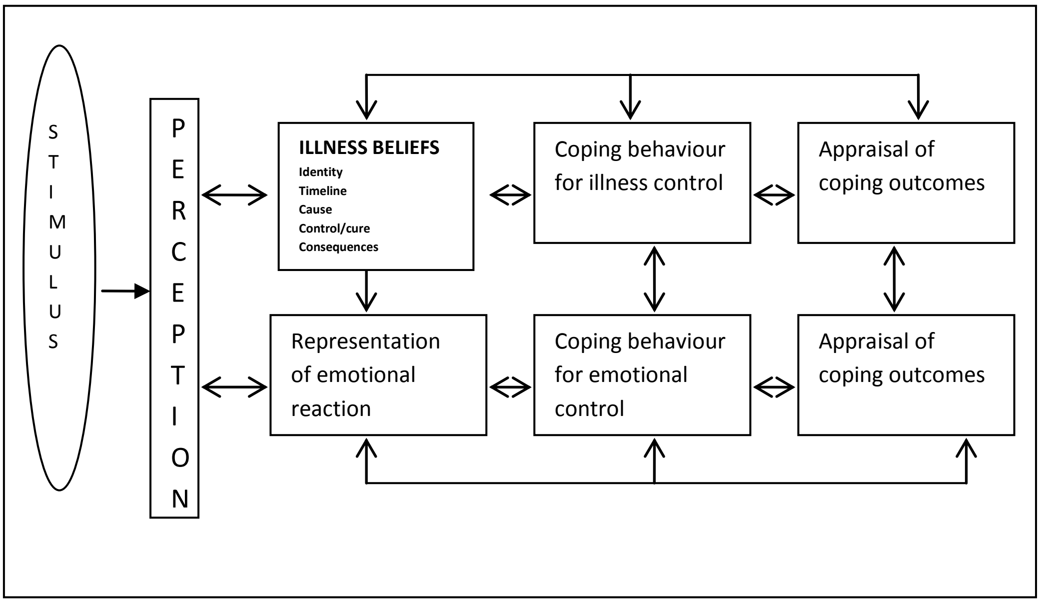
Control/Cure*:* Extent to which the individual perceives the illness can be controlled or cured through treatment measures and behaviours.

3.5 Assumptions of the CS-SRM

One of the major assumptions underlying the CS-SRM is that the patient is a rational decision maker, an active participant in their choices and has an active psychological system which leads to both a representation of illness and an emotional reaction to the illness (Leventhal et al, 1984) (Figure 3.4). Illness representations have been defined as: '*A set of organised beliefs regarding how the illness affects the body, it's likely impact on activities and experiences'* (Cameron & Moss-Moss, 2010 p.150). The CS-SRM focuses on how the individual selects and monitors their behaviour over time in order to make progress towards their goals. Although both the TPB and the HBM, mentioned earlier considers the individual as a rational decision maker, the advantage of the CS-SRM over these theories is that CS-SRM accounts for the emotional processes related to beliefs.

A number of other terms are used interchangeably in the literature: *illness cognitions, illness representations, illness beliefs* and *illness schemata* but these are considered to be synonyms of illness representations (Scharloo & Kaptein, 1997). For the purposes of this work, *illness beliefs* will be used interchangeably with diabetes-related beliefs.

Figure 3.1: Leventhal et al (1984) CS-SRM of illness beliefs and behaviour



Source adapted from: Leventhal et al (1984)

Although the model assumes that people regulate their health-related behaviour according to these five dimensions, a review of 101 studies across a number of chronic conditions found that for diabetes, perceived control and consequences have been found to be the two most important factors influencing glycaemic control (Scharloo & Kaptein, 1997). Further evidence from the literature in relation CS-SRM and diabetes management will be presented later in this chapter.

3.6 Measuring illness beliefs

Earlier work in this field (Leventhal et al 1980; Bishop 1991) used semi-structured interviews to elicit illness beliefs. However, since development of the Illness Perceptions Questionnaires (IPQ) (Weinman et al, 1996) there has been an increase in the number of cross-sectional studies using the CS-SRM model to capture illness representations, adjustment and management of a wide range of chronic and acute illnesses (Hagger & Orbell, 2003). The Illness Perception Questionnaire (IPQ) is a theoretically based questionnaire, which consists of a number of subscales that address each of the five dimensions discussed above (Weinman et al, 1996). However, the revised version of the IPQ; the IPQ-R claims to have improved the original measure with the addition of two subscales assessing personal and treatment control, cognitive and emotional representations (anxiety and depression) (Moss-Morris et al, 2002). More recently Broadbent et al (2006) introduced a short version of the IPQ-R known as The Brief Illness Perceptions Questionnaire (BIPQ). This latter measure was designed to rapidly assess the cognitive and emotional response of an illness and further details of this measure can be found Chapters 5 and 6.

3.7 Empirical evidence related to illness beliefs

Research using the IPQ measures has found beliefs about diabetes to play an important role in instituting a successful self-management process (Leventhal & Crouch, 1997; Griva et al, 2000). The need to account for patients' personal and cultural beliefs about their illness was reported by Barnes et al (2004). In their study with Tongan and Europeans with T2DM, Barnes et al (2004) examined cultural differences in the way in which the two samples conceptualise their diabetes. The relationships between patients' illness and treatment perceptions and their adherence to self-care regimens were assessed using the IPQ-R and standardised measures of personal beliefs about diabetes and medication, and self-reported adherence. Findings highlighted that Tongan patients had significantly poorer control over their diabetes and HbA1c levels than did European patients. The beliefs that characterised the Tongan patients tended to be associated with poorer adherence to diet and medication taking and higher levels of emotional distress related to diabetes. Diabetes was perceived to be uncontrollable, and caused by factors such as God's will, pollution in the environment, and poor medical care in the past.

More recently, Broadbent et al (2011) investigated the relationship between illness beliefs, adherence to medication and blood glucose control in people with T1DM and T2DM. A number of significant associations were reported between beliefs about treatment for diabetes and adherence. For example, some patients rated medication more important than diet and exercise, thus reported higher adherence to medications.

Searle et al (2007) examined the influence of illness beliefs of patients with T2DM and their partners using the IPQ-R. In particular this study examined the extent of agreement between patient and partner beliefs, and whether partners' beliefs mediate the relationships between patients' beliefs and their prospective self-management behaviours. All participants completed the IPQ-R at baseline and at 12 months, and questionnaires on exercise, medication, and food frequency. Overall, similar beliefs about diabetes were found between patients and their partners and perceived control over the condition. However, some beliefs held by partners partially mediated the relationships between patients' representations and their prospective self-management behaviours. Partners who often perceived timeline of diabetes partially mediated the relationship between patients' beliefs and their self-management behaviours e.g. physical activity and dietary intake. Partners' personal control beliefs also partially mediated the relationship between patients' representations and physical activity.

3.8 Interventions

The main purpose of understanding patient's beliefs about their diabetes is to improve self-management (Cox & Gonder, 1992). A number of interventions (randomised controlled trials) have been designed in response to the difficulties in self-management that people with diabetes report to improve health outcomes (Newman et al, 2009; Winkley et al, 2006; Newman et al, 2004). Most interventions based on the Leventhal et al (1984) CS-SRM have focused on specific aspects of diabetes management, particularly glycaemic control (HbA1c) as an outcome measure (McSharry et al, 2011). These intervention trials have also measured change in illness beliefs using an IPQ measure as another outcome measure. In their trial with adults with T2DM, Davies et al, (2008) identified changes in dimensions such as the *understanding* of diabetes, *personal control* (ability to control diabetes), *timeline* (higher timeline scores) and a reduction in HbA1c in both the intervention and control groups. Positive changes in illness beliefs were also found in the Keogh et al (2011) randomised controlled trial also with adults with T2DM, for *treatment control*, *personal control*, *concern* and *identity beliefs*. In this trial participants in the intervention group had a 0.4% decrease in HbA1c (95% CI -0.90 to 0.03) and was most effective for patients with poorest metabolic control.

3.9 How useful is the Common Sense-Self Regulation Model in explaining diabetes-related beliefs of the South Asian population?

There has been limited research using this framework to explore illness beliefs of South Asians with diabetes in the UK. Rather qualitative studies from other social sciences disciplines such as medical anthropology and sociology have provided useful information and informed intervention on how beliefs may affect self-management of this population (Hawthorne, 1993; Greenhalgh, 1998). These studies, however, have not considered the influence of cognitive, emotional and behavioural responses to an illness. A recent systematic review (Appendix 2) of the literature aimed at identifying studies that have used measures such as the IPQ-R to quantitatively assess diabetes-related beliefs in the South Asian population with diabetes only found two studies which have assessed individual beliefs about diabetes using the CS-SRM and IPQ-R (Patel et al, 2012b). Kart et al (2007) used the IPQ-R and the Summary of Diabetes Self-Care Activities (SDSCA) questionnaire in an interview with 300 Nepalese patients with diabetes and found that patients attributed the cause of their diabetes to factors such as stress, worry, and lifestyle. A shared consensus was evident on beliefs about personal control, treatment effectiveness, and emotional representation as measured by the IPQ-R. More recently, Bean et al (2007) assessed the illness beliefs, self-care, and metabolic control of diabetes of three ethnic groups: South Asian, Pacific Islanders and Europeans and found that *identity, timeline, consequences and emotional representations* of diabetes differed between the groups. Compared to Caucasians and Pacific Islanders, South Asians had believed that their diabetes would last a short period of time and were less emotionally affected by their diabetes.

The application of the CS-SRM with the South Asian population has been more evident in conditions such as heart disease (Darr et al, 2008; Grewal et al, 2010) and illnesses such as cancer (Grunfield & Kohli, 2010), than diabetes. However, even in these studies, a qualitative approach has been adopted to exploring illness beliefs than using the IPQ measures.

Overall, The CS-SRM has been useful for understanding many aspects of chronic disease management in a large number of studies (Hagger & Orbell, 2003; McSharry et al, 2011). The main focus and application of the CS-SRM has been to understand how people identify and respond to the threat or onset of illness, along five key dimensions (Box 3.1). The CS-SRM enables the dynamic interaction between cognitive and emotional representations to be examined, to understand how people cope and appraise their response to an illness (Figure 3.1). Apart from being able to consider the different facets of cognitions related to chronic disease(s) and the adoption of maladaptive health behaviours, the CS-SRM has also been useful in informing intervention to either change or challenge peoples beliefs of a particular illness (Petrie et al, 2002; Hagger & Orbell, 2003).

To date, most of the research using the CS-SRM and diabetes has been conducted predominately with Caucasians and Europeans, with a limited focus on the social and cultural factors involved in illness management (Barnes et al, 2004). More work is needed to identify whether the CS-SRM is acceptable and rigorous enough to examine diabetes-related beliefs of UK South Asians. This will provide new knowledge relevant to diabetes management in this target population, with the hope to inform and design culturally sensitive interventions to modify or adapt beliefs for better self-management in this population in the future.

3.10 Fatalism and illness beliefs

There is awareness within the cross-cultural psychology literature that individuals from non-western cultures may differ in terms of their illness beliefs and illness-related behaviour (Bauman, 2003). In an attempt to understand the extent to which individuals believe they can control events that affect them, Rotter (1966) developed the theory of locus of control. This theory considered individuals to have either an internal or external locus of control. People with external locus of control believe that rewards are largely determined by external forces such as fate, luck, chance or powerful others; whereas people with an internal locus of control believe that their own responses and actions largely determine the amount and nature of the rewards they receive (Rotter, 1966). Fatalism is a term used to describe '*beliefs that the* *outcomes of situations are determined by forces external* (e.g. chance, luck, powerful other) *to the individual'* (Cockerham, 2007, p. 111). The distinction between fatalism and locus of control is complex. It is not within the remit of this thesis to deeply discuss the ample literature on this subject, but a brief overview of the two concepts and the relationship between them will be provided in this section, and again in Chapter 11.

Fatalistic beliefs are thought to transcend between generations with cross-cultural differences in how fatalism is conceived (Ruiu, 2012). The concept of fatalism is not unique to the South Asian population, but has also been studied in other ethnic groups, predominately the African-American population with diabetes in the USA. In these studies, higher fatalistic beliefs have been found to lead to poor diabetes control and poor quality of life (Lange & Piette, 2006; Walker et al, 2012) in African-American's with lower education levels, lower income and higher number of co-morbidities (Egede & Bonadonna, 2003).

3.11 Measuring Fatalism

Using the theoretical underpinnings of locus of control, Wallston et al (1978) developed a locus of control measure, specific to health beliefs and named it the Multidimensional Health Locus of Control (MHLC) scale. The aim of this measure was to identify whether individuals perceived their health to be personally controlled; controlled by powerful others; or under control by external factors such as fate and luck. Ethnicity and religiosity have been found to affect of all three subscales of the MHLC. In their study with South Asian and Afro-Caribbean women, Wrightson & Wardle (1997) compared health locus of control scores, as well as ratings of religiousness, and found South Asian women scored more highly on external locus of control and religiousness even after controlling for occupation and health status.

It can be argued that fatalism and locus of control are two related concepts since the MHLC accounts for fatalism within the external control dimension. However, MHLC has been criticised for its lack of specific relevance for people living with an illness (Luszczynska & Schwarzer, 2005). Studies that have used MHLC have found modest influence and/or predictor of health behaviour (Norman & Bennett, 1996) with recommendations for further refinement of the measure to address cultural sensitivity (Luszczynska & Schwarzer, 2005).

There are distinct variations in the way in which fatalism has been measured and conceptualised in other studies. For example, Grace et al (2008) compared South Asians with White populations using a qualitative study design (focus groups and semi-structured interviews) and found South Asians were more likely to attribute responsibility of diabetes to external factors, such as fate in comparison with internalised responsibility by White groups. Although both groups in this study believed that being diagnosed with diabetes or heart disease was part of their fate; fatalism in the South Asian group was reinforced by religious beliefs, especially among the older generations, in that God, not the individual, was ultimately responsible for health and illness. Furthermore, Farooqi et al (2000) conducted a focus group to identify key issues relating to knowledge and attitudes to lifestyle risk factors of coronary heart disease amongst South Asians in Leicester. The findings showed that ill health was believed to be God's will, an indication from God that they had not looked after their health, and a sign to take responsibility and make necessary lifestyle changes to improve their health.

Current evidence suggests that fatalism beliefs in the South Asian population, extends beyond the notion of external control. Most qualitative studies have explored fatalism independently of locus of control, with a specific focus on the relationship between causal beliefs, fatalism, religion and diabetes management (Fleming & Gillibrand, 2009; Kohli & Dalal, 1998). Nearly twenty years on, the study by Landrine & Klonoff (1994) remains one of the key studies in this field that investigated cultural diversity in beliefs about the causes of illness in a number of ethnic groups. This study found that the South Asian population were more likely to attribute the cause of an illness to supernatural and external forces than the Caucasian population. This has also been evident in other illnesses such as cancer, whereby people believe saying the word `cancer' is a way of tempting fate and may cause cancer. In their qualitative study, Bottorff et al, (1998) found that compared to the Caucasian sample, South Asian women believed that thinking or talking about illnesses such as cancer was a matter of tempting fate for the diagnosis of the illness. Thus, the evidence from these studies suggests that fatalism is distinct from locus of control in that fatalism has a ‘dual’ role in the experience and management of an illness in South Asian population. Apart from external control, fatalism also appears to be related to the cause of an illness and has specific cultural and religious differences in the meaning and understanding of an illness. In other words, fatalism is deeply rooted within the culture and religious beliefs and has an impact on to both casual and control beliefs in South Asian people with diabetes.

Although the IPQ-R (Moss-Morris et al, 2002) has one item measuring ‘chance or bad luck’, the overall control dimension of the common-sense model does not explicitly measure for external factors such as fatalism. Despite the permission for modification of the IPQ-R control scale to account for such factors; to date only one study (Barnes et al, 2004) has included a measure of fatalism to determine cultural differences in the way in which diabetes and treatment for diabetes is conceptualised. Results found that the Tongan group believed diabetes was caused by God’s will and they had poor adherence to medication and perceived diabetes to last a short period of time (Barnes et al, 2004). Therefore, the processes through which such metaphysical beliefs operate, (i.e. whether fatalism shapes causal attributions and management of diabetes in South Asians), requires further research, as most studies using the CS-SRM (Leventhal et al, 1984) have been designed in a western cultural context (Europe, New Zealand, USA) and do not account for such factors (Uskal, 2010). More work is need to explore and identify differences between fatalism beliefs when using closed questions on a survey, in comparison to using open-ended questions in a interview using qualitative methods. This will provide new knowledge on both issues related to measuring fatalism, as well as the association between fatalism, diabetes management and the role of the social, cultural and religious context in shaping these beliefs.

3.12 How useful is the Common-Sense Self-Regulatory Model in explaining the influence of the social context on illness beliefs of the South Asian population with diabetes?

The preceding section has shown that despite the usefulness of the CS-SRM, this theory has not been very successful in accounting for illness beliefs of the South Asians with diabetes. This section looks at how useful the CS-SRM has been in explaining the influence of the social context on illness beliefs in this target population.

In their early inception of the CS-SRM, Leventhal et al (1980; 1984) suggest three basic sources to be involved in the expression of an illness:

1. Cultural factors;
2. Basic information from other people both health professionals and lay persons;
3. Individual experience.

Leventhal et al (1980) aimed to understand the self-regulation process within the social and cultural context in which they occur. However, the call for the CS-SRM to consider social context dates back nearly three decades (Diefenbach & Leventhal, 1996) and to date, there is little evidence from this literature to confirm these possibilities. Despite knowledge of the illness experience and beliefs being defined by an individual's social context (and as highlighted by the earlier definition on health beliefs) (Leventhal et al, 2003; Petrie & Weinman, 2012), little is known about the relationship between illness beliefs (e.g. symptom appraisal through discussion with others and family experiences or where they come from, how they develop?) and the social context of disease representation (Bishop, 1991; Ogden, 1995). More recently, in their review of behavioural research for chronic illness management, Leventhal et al (2008) reported the need for more psychological research into the specific cultural and socioeconomic factors, the impact of religious participation, and spirituality on beliefs and behaviours and health outcomes. The aim of these additions is to inform conceptual developments of the CS-SRM (Leventhal et al, 1984) and generate more tailored, behavioural interventions that will improve quality of care. Although, some research has begun to explore the importance of religion and spirituality in coping and adjusting to an illness (Thuné-Boyle et al, 2006; 2012; Swinton et al, 2011) this has been more evident in illnesses such as cancer than diabetes *per se.* Overall, neither the CS-SRM theory nor the range of IPQ measures explicitly account for the social context in which people manage their illness and this requires further research.

3.13 Rationale and the operationalisation of the CS-SRM in this study

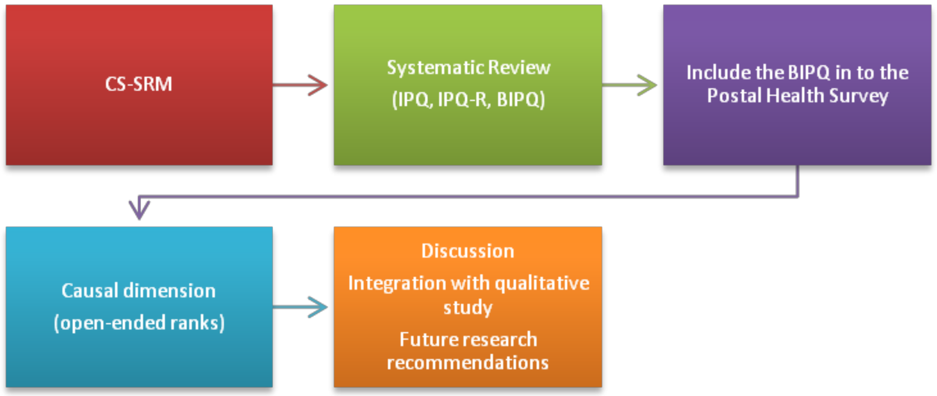
There are four main reasons for selecting to use the CS-SRM in this study.

The CS-SRM:

1. Considers the determinants of health behaviours when a person is experiencing an illness episode as opposed to when one is healthy;
2. Has been derived from empirical studies among patients with existing chronic conditions (Meyer, 1985; Lau & Hartman, 1983);
3. Acknowledges a person's emotional response to health threat as an important determinant of health behaviour;
4. Considers different facets of illness beliefs, with a specific focus on cognitions related to the cause, consequences, timeline and control of an illness – which is of interest in this study.

Taking into consideration the current gaps in knowledge, the CS-SRM will be used at different stages in this study (Figure 3.2). Firstly, the concepts and terminology related to the CS-SRM (e.g. IPQ, IPQ-R, and BIPQ) will all be included in the search strategy for the systematic review (Chapter 5), in order to identify studies which have previously used the CS-SRM and the available measures to assess diabetes-related beliefs in South Asians. The findings of the systematic review will then inform the design of the quantitative study, specifically in relation to the selection of the BIPQ to assess beliefs in this study.

Figure 3.2: The different stages at which the CS-SRM will be used in this study



Then in the quantitative study, the initial analysis will provide data on descriptive statistics in relation to the each of the BIPQ items before exploring the associations between BIPQ, demographics, health outcomes, and social networks for the management of diabetes. The open-ended causal dimension of the BIPQ will be analysed by ranking the three most common causes of diabetes stated by participants. Finally, the findings of the quantitative study will be discussed in relation to the CS-SRM and integrated with the qualitative study in Chapter 11, together with recommendations for future research and contribution to knowledge.

Before providing detail of the studies which have assessed the social context of South Asians with diabetes, it is important to provide a brief background into the research into the relationship between the social context and health, followed by the literature on social support and social networks and a rationale for exploring social networks in this thesis.

3.14 What can the studies on social support tell us about the influence of the social context on the management of diabetes in the South Asian population?

It has been well established that human attachments and relationships and the degree to which an individual is interconnected and embedded with others is vital to health and wellbeing (Sani, 2012). For example, Durkheim (1951) found that poor mental health was more prevalent among people with low *social integration* and higher rates of suicide, thus the social forces in which people live in their natural, everyday environment were stated to have an impact on health. Social integration is referred to the existence of the number and range of social ties between the individual and their social network/context (Seeman, 1996). Thereafter studies from a number of health-related disciplines began to examine the social context, in particular the relationship between strong and weak ties/relationships (Granoveter, 1973) and consideration of the types and number of ties/relationships within the network has advanced research in this area (Berkman & Glass, 2000) and will be further discussed in the next part of this chapter. Although recent psychological approaches to health and illness emphasise the importance of the individual's social context for behaviour, much of the evidence on social relationships and health comes from studies measuring social support. The concept of social support will be the focus of this part of the chapter hereafter.

3.15 Social support

There are a number of definitions of social support used interchangeably in the literature, for example Schwarzer et al (2004) have defined social support as:

> *'The function and quality of social relationships, such as perceived availability of help or support actually received (p.160)'*.

Whereas de Ridder (2004) has social support defined as:

> *'Information from others that one is loved and cared for, and part of a social network of mutual obligations' (p.218).*

The majority of the early work into social support stemmed from the stress literature and the role of social support in facilitating adaption to stressful life events (Cohen & Janicki-Deverts, 2009). House (1981) proposed four taxonomies of social support which include:

1. **Instrumental** – help, aid or assistance with tangible needs such as getting groceries, getting to appointments, phoning, cooking, cleaning;

2. **Emotional support** – the amount of love, care, sympathy, reassurance;
3. **Information support** – problem-solving and information;
4. **Appraisal support** – feedback relevant to self-evaluation.

In health psychology, social support has commonly been used to examine people's perceived and actual support. Perceived support has been found to moderate stress (Taylor et al 2004) and a better predictor of adjustment to chronic illness than actual support (de Ridder, 2004). Although there is evidence for perceived support buffering the effects of stress, longevity and chronic illness, there is no evidence to suggest that perceived support translates into actual support (Wills and Ori, 2000). Studies which have attempted to reduce the recurrence of heart attacks by increasing patients perceived social support, have been successful. For example, Wethington and Kessler (1986) found that perceived support was a stronger predictor of adjustment to stressful life events than actual support. Social support has been stated to have beneficial effects on cardiovascular disease, endocrine and immune system and the work of Uchino, (2006) provides substantial evidence for this in that people with higher levels of social support appear to have more positive 'biological profiles 'and lower rates of morbidity and mortality.

3.16 Social support in the South Asian culture

The sociological literature has examined social support using structural measures that have assessed the number of social relationships, roles and the structure of the interconnectedness among these relations (Thoitis, 2011; 1995). A number of measures have been developed to estimate network size and density. Berkman & Glass (2000) have divided the range of available measures into 3 domains:

1. Measures that assess social ties or social integration;
2. Measures that more formally assess aspects of social networks;
3. Measures assessing social support (perceived and actual).

Despite the availability of good quality measures of social support, these measures do not account for network structure in comparison to the methods that present network data graphically and visually in the form of sociograms or matrices. Furthermore, evidence is emerging to suggest that westernised views of health differ in various ways from conceptualisations of health in non-westernised countries (Chandarana & Pellizzari, 2001). Research into cross-cultural psychology has shown that there are cultural differences in social relationships. For example, within some cultures individuals prefer not to depend on other people for support, with issues of independence over interdependence. In comparison to an individualistic culture whereby behaviour is driven by individuals' needs and wants, collectivist culture places emphasis on actions motivated by the community and family. Thus, a person's culture may have implications for interventions targeted at changing behaviour, as the individual may not be solely accountable for goals or priorities related to diabetes management (Chandarana & Pellizzari, 2001).

The influence of social support has been more evident in epidemiological studies examining the risk factors associated with coronary heart disease in the South Asian population. To test the hypothesis that social isolation maybe a reason for high rates of coronary heart disease, Pollard et al (2003) compared the social networks of South Asians and European-origin participants. Using a questionnaire (from Bhopal et al's 1999 study) this study examined the relationships between social network size and coronary heart disease risk factors in both groups. The study found partial support for their hypothesis and concluded that both ethnic groups utilise their networks differently and future work needs to explore the variation in sources of support and the mechanisms which link social support and health between ethnic groups. Other studies have examined social support using a range of questionnaires (Williams et al 2009) and reported that South Asians, in comparison to Caucasians, have larger social networks independent of socioeconomic status, but often report lower social support and more negative social interactions. Research evidence on social support in the South Asian population comes mainly from coronary heart disease studies. Interventions on chronic conditions with the general population have focused on social support for cancer and coronary heart disease (Cohen & Janicki-Deverts, 2009; Berkman & Glass 2000; Cohen & Lemay, 2007). However, in the South Asian culture, the opinions and approval of lay sources such as family and friends have been found to determine the intention to attend medical appointments and/or comply with advice from educational sources in the UK (Choudhary et al, 2009a; Greenhalgh et al 1998; Hawthorne 1994). This has also been evident in other illnesses such as cancer in the South Asian population (Johnson et al 1999; Bottorff et al 1998). Furthermore strong family ties have been found to play a key role in shaping the attitudes and experience of patients from this group. In particular close family networks have been found to be an important source of information, sharing knowledge, providing emotional (Stone et al 2005) and language support (Fleming & Gillbrand 2009). Bottorff et al (1998) stated that: *'Health is not an individual matter for South Asian women' (p.9).* Results of their study found that practices are strongly influenced by family and community responsibilities, and whether South Asian women engaged in self-care activities depended on their family and social expectations. Similarly, Lawton et al (2007) found that South Asian women with T2DM often find it difficult to modify their diet because their husbands do not want to alter the taste of food through using healthier alternatives. Therefore the social networks of the South Asians may not always have a positive effect on self-care behaviours since friends and family may have their own beliefs and experiences about the healthcare system, or may believe in alternative treatment or therapy (Leventhal & Crouch, 1997), which may influence or pressure the individual to engage in these behaviours. Consequently, the use of lay referral networks can work for or against seeking health care or adherence to self-care regime and requires further investigation (Leventhal et al, 2008). Studies in the USA have found that some Asian Americans are often reluctant to ask for support from close relations, because of concerns about making inappropriate demands or undermining the harmony of the group (Taylor et al, 2004; Kim et al, 2008). It is not within the remit of this work to dispute the immeasurable contributions of the literature on social support. However, it is important to explore the precise role and/or contribution of the social networks involved in the daily management of diabetes to better understand the relationship between a person's social context and their beliefs about diabetes.

3.17 Social networks and beliefs about diabetes of the South Asian population

Most of the evidence on the role of the social environment and physical health comes from studies focusing on social integration. Social integration has been defined as the:

'structure and quantity of social relationships, for example, size, density of networks, frequency of interaction and subjective perception of embededness' (Schwarzer et al, 2004). The concept of social integration has a long-standing history in the social support literature that has stemmed from Durkheim's (1951) work on the relationship between society and health, as mentioned earlier. A review by Berkman & Glass (2000) found that those with more types of relationships, for example, being married, having close family and friends and belonging to community and religious groups improved longevity. Furthermore, longitudinal prospective studies examining the effects of diverse networks on people living with chronic conditions have found that more socially integrated individuals with risk of cardiovascular disease have a lower incidence of stroke (Rutledge et al, 2008), reduce risk of complications associated with CVD and mortality (Kop et al, 2005) in comparison to those that have less integrated networks. Thus, we have known about the importance of social integration for health and longevity for 30 years, but we still do not know why having a more diverse social relationships might have a positive influence on our health, and there are a lack of studies and interventions to explain which characteristics of the network that are beneficial to physical health (Cohen & Janicki-Deverts, 2009).

3.18 Social networks

Humans are social beings and illness beliefs are thought to be acquired through social factors (Zboroswki, 1952); therefore it is logical to suppose that people and resources within a person's social context may influence beliefs. Anthropologists Barnes (1954) and Bott (1957) developed the concept of social networks to analyse ties and view structural properties of relationships among people. Social networks have been defined as:

> *'A web of social relationships that surround an individual and the characteristics of those ties'* (Schwarzer et al 2004, p. 160).

An individual's social network details the number of people or possible support providers in their environment (Berkman & Glass, 2000). Previous research has focused on deriving network typologies on the structural aspects of social networks, for example network size and density, also known as social network analysis (Hall &

Wellman, 185, p.26). This analysis has focused on the characteristics and patterns of ties between people in a social system on behaviour, rather than on characteristics and/behaviour of the individual themselves. Central to this analysis is the assumption that network analysis enables attention to be focused on the structure, composition, content and resources of the networks (Hall & Wellman, 1985). This enables analysis of the egocentric networks by placing the individual (ego - participant) at the centre of the network map to explore the egos network ties.
Recent work in health psychology has used qualitative methods to assess social relations using the 'convey model' developed by Kahn & Antonucci, (1980), to better understand the structure and content of social networks. According to this model, a network of people surrounds individuals, and the quality of the network is shaped over time by personal and situational factors, available resources and demands (Ajrouch et al, 2001). Using this model, people are subjectively asked to identify network members on a diagram of three concentric circles in order to establish and map strong and weak ties (more information in Chapter 5). Nonetheless there are a lack of studies on the impact of social networks on self-care for diabetes, as social network studies have focused on studies of the family (Bott, 1957), ageing and friendship (Pahl & Spencer, 2004) and explored size of the network rather than the effect of being embedded in a network (Fiori et al 2006).

The influence of social networks for chronic illness management e.g. family and friends has previously been explored using focus groups among older African American and Caucasian men and women (Gallant et al 2007). Results of Gallant et al (2007) study suggested that social network members exert positive influences on a number of self-management tasks e.g. helping with diet, monitoring diet, accommodating dietary needs, offering medication reminders, exercising with playing an active role during GP appointment, providing transportation to GP appointments and sharing illness-related information. A recent review by Vassilev et al (2011) examined the types of social networks implicated in LTC management, their properties and differences. The findings revealed three types of network categories: *relationships, communities and personal communities*. Larger networks, which consisted of both family and friends, were associated with better health outcomes. However, the review criticised existing evidence on social networks for being narrowly defined with insufficient discussion in the literature on the types of networks that support or undermine self-care and called for the following shifts in research and practice to consider for: from *consultations to everyday settings, from self-management to illness work, and from individuals to networks*. Thus, shifting the focus on to the social context in which diabetes is managed, rather than focusing solely on the health behaviours of the individuals.

3.19 Types of work

To understand how different networks vary in the quality of support received, the 'illness work' typology set out by Corbin and Strauss (1985) was used. This typology distinguishes between *illness work; everyday work and biographical work* as shown by Table 3.1. The usefulness of this typology is that it provides a clear framework for exploring the range of illness-related work, which patients engage in daily, and the competing priorities of managing their health, everyday life and relationships.

Table 3.1 Types of illness work

Illness work	Has been defined as regimen work, crisis prevention and management, symptom management and diagnostic-related work.
Every day work	Refers to the essentially daily round of tasks that keep the household going, for example, cleaning, washing, repairing, and occupational work, and marital work, child rearing, practical and social activities such as eating (Corbin & Strauss, 1985).
Biographical work	Refers to the reassessment of personal expectation, capabilities and future plans (Bury, 1982).

Source adapted from: Brooks et al (2012): The illness work framework (drawn from the work of Corbin & Strauss, 1985; 1988)

Despite some of the similarities the illness work typology shares with House's (1981) social support model in terms of the different tasks and support involved in managing an illness (e.g. every day work versus. instrumental/tangible support) the advantage of using the above illness work typology is that it closely related to chronic illness management. More recently the existing illness work framework (Corbin and Strauss, 1985) has been extended to closely assess and gain an in-depth understanding in to the people and resources involved in self-care of long-term conditions and the implications for health behaviours (Vassilev et al, 2010; Rogers et al, 2011; Brooks et al, 2012). The illness work typology has been revised to include *articulation work* – the ability to 'get things back on track' in the face of the unexpected (Rogers et al, 2011; Brooks et al, 2012), and has distinguished between five types of work related to *articulation work*, including emotional work (Table 3.2).

For the purposes of this work - understanding the amount of *emotional work* undertaken in the network is important. As mentioned earlier, people with diabetes have been known to experience emotional distress (depression/anxiety) as a result of their diabetes (Roy et al, 2012). Emotional distress has been suggested to have negative effects on glycaemic control (Anderson et al, 2001) and increased complications associated with diabetes (de Groot et al, 2001). Research into social integration indicates that social relations tend to have protective effects on emotional health (Berkman & Glass, 2000), thus exploring the relationship between *emotional work* and beliefs about diabetes is of interest for the purposes of this study. Similarly as mentioned in Chapters 1 and 2, adjustment and the management of a chronic illness such as diabetes is complex due to the number of *practical* tasks ('work') involved in managing blood sugar levels, *for example eating regularly, adhering to medication, healthy diet,* to reduce the risks and complications associated with this condition (Mzbeuze, 2010). Taking into consideration the recent evidence on the importance of social networks for chronic illness management, understanding the amount of *practical and emotional work* undertaken and the implications this has for beliefs about diabetes is of particular interest in this study.

Table 3.2 Types of work – Articulation work

Contingency/Improvisation	Work that gets things back 'on track' on the face of the unexpected, and modifies action to accommodate unanticipated contingencies.
Translation mediation work (Practical work)	The translation of abstract knowledge into practical knowledge and then into practice. The difference between knowing and doing. Includes illness specific work related to diet, exercise and medication (regimen work). Symptom management and diagnostic-related work related to assessment of health status.
Coordination work	Negotiations regarding the ways in which work is done, who does what, when, how and why.
Advocacy work	The negotiation of contributions and the work done by others on one's behalf
Emotional work	Work related to comforting when worried or anxious about health related issues

Source Adapted from: Brooks et al (2012): The illness work framework (drawn from the work of Corbin & Strauss, 1985; 1988)

Rogers et al (2011) state that this approach considers: *'responses to chronic illness states as problems of action through investigating people's everyday life, identifying networks implicated in self-care and exploring the manner in which home and work impact on the management of LTC' (p.3)*. Furthermore, this approach extends beyond the traditional measures of social support and social network analysis to measures that focus on the structural and functional aspects of support (e.g. density, size of the network, frequency of contact). The importance of this approach is that it offers a wider conceptual scope to understanding illness management and the relationship between individual's sources of their social context (e.g. family, peers and health care professionals).

As mentioned earlier, the CS-SRM recognises that the social and cultural context in which individuals manage their illness is important as illness management is often a shared task involving family members and friends (Bauman, 2003) and culture provides a framework for categorising different illness experiences which can influence management behaviours (Leventhal et al, 2008; 1997).

Rogers et al (2011) define social networks as *'networks of networks'* (Rogers et al, 2011 p.2) and for consistency, this definition will be used in this work too. Although chronic illness management often relies on the support of other people, services, networks and other resources, it has also been suggested to be shaped by inequalities, psychological and emotional contexts (Sanders & Rogers, 2008). Moreover, the ‘types of relationships’ section in the social networks survey interview also accounts for religious ties people may have (Appendix 16) which offer the opportunity to understand the influence of religious networks for diabetes management. The social networks survey interview will be discussed in further detail in Chapter 6.

This study aims to explore the role of social networks on diabetes-related beliefs in the South Asian population to fill the current gap in knowledge.

3.20 Summary

This chapter presented one of the most influential theories in health psychology; the CS-SRM, which has been developed to measure beliefs in people living with an illness, along five key dimensions. Understanding people’s beliefs about their illness is important to know how people make sense and cope with their illness and the CS-SRM provides a useful framework in which to consider the cognitive and emotional responses to an illness as well. However, there has been limited research using this framework to explore illness beliefs of South Asians with diabetes in the UK. Qualitative studies from other social sciences disciplines have been at the forefront in providing information and informing intervention on beliefs related to self-management of diabetes in this target population. For example, these studies have explored the concept of fatalism in relation to cause and control of diabetes and its relationship with illness management. Although the IPQ-R has one item measuring ‘chance or bad luck’ in the IPQ-R, the overall control dimension of the CS-SRM does not explicitly account for fatalism, and this requires further research. More work is also needed to identify whether the CS-SRM is acceptable and rigorous enough to examine diabetes-related beliefs of UK South Asians. This will provide new knowledge relevant to diabetes management in this target population, to inform and design culturally sensitive interventions to modify or adapt beliefs for better self-management in this population. Whilst lay sources such as family and friends have been known to be an important for illness management in the South Asian culture, there is a lack of understanding into the precise role of such networks in helping the individual manage their diabetes. There is little known about the relationship between illness beliefs and the social context of disease representation, especially since the CS-SRM, nor IPQ measures, explicitly account for the social context in which people manage their illness. Thus, the approach undertaken to exploring the role of illness beliefs and social networks in this study, offers a novel and wider conceptual scope to understanding diabetes management in the South Asian population. This may be the first step towards extending the CS-SRM to address the relationship between the psychological, social, cultural and religious context and illness management.

The next chapter provides further information on the aims and research questions, including the use of a mixed methods design.

Chapter 4

Aims, Research Questions and Mixed Methods Design

4.1 Introduction

This chapter will provide an overview of the aims and research questions for this study. This will be followed by a justification and rationale for using a mixed methods design and the method used to answer each of the research questions.

4.2 Aims

As mentioned in Chapter 2, the overall aim of this thesis was to provide a better understanding of diabetes management in people of South Asian origin. The aims of the review were to:

- Identify and report studies which have used questionnaires to assess diabetes-related beliefs.
- Review the feasibility and acceptability of this method in people of South Asian origin, to inform development of the postal health survey and subsequent methods for this thesis.

Use a mixed-methods design to:

- Explore the role of diabetes-related beliefs (including fatalistic beliefs) and social networks in the management of diabetes in people of South Asian origin.
- Explore the personal, social, cultural and religious context in which people of South Asian origin live and manage their condition.

To address each of these aims, a number of sub questions were developed and informed by the gaps identified in the literature review in Chapters 2 and 3 (see below).

4.3 Justification for a mixed methods design

Both quantitative and qualitative methods have been criticised for the failure to incorporate a broader range of information (Tashakkar & Teddie, 1996). Although quantitative methods can be useful in developing predictive models to explain behaviour (Bauman, 2003), this method has been criticised for not including complex and situational experiences, behaviours, characteristics and beliefs. Whilst qualitative methods account for the limitations of the former method, and focus on providing richness of behaviour and experience of illness, this method has been criticised for using smaller samples, with a lack of data reduction techniques and problems of generalisation of findings (Ritchie & Lewis, 2003).

There are a number of debates in the literature over the definitions, research design and how to draw inferences from research using a mixed methods design. The mixed methods approach was initially defined as methodological triangulation to assess quality in qualitative research (Denzin, 1970). The method of triangulation is discussed in further detail in Chapter 7.

More recently mixed methods have combined quantitative and qualitative approaches within different phases of the research process (Tashakkar & Teddie, 1996) as shown by Table 4.1. The term ‘mixed model’ is often given as an alternative to mixed methods, as the latter had been criticised for not accounting for the complexity of mixed methods through different stages (i.e. theory, literature, data collection) of research (Tashakkar & Teddie, 1996). However, in this thesis the term ‘mixed methods’ will be used to remain consistent with the literature.

4.4 Paradigms in mixed methods research

Using a mixed methods approach means combining one or more paradigms (Creswell, 1995). A paradigm is the belief system that guides researchers (Guba & Lincoln 1994). The two main paradigms in this field include positivists and constructionists. The former is associated with quantitative methods and the latter with qualitative methods. The linking of the two paradigms has been called ‘pragmatism’ (Howe, 1988). The pragmatism paradigm provides the underpinning and rationale for using mixed methods or mixed models, especially with regards to the issues of epistemology and ontology (Tashakkar & Teddie, 2003; Bergman, 2008). Paradigms in relation to qualitative research will be discussed in further detail in Chapter 7 of this thesis.

4.5 Types of mixed methods designs – Sequential Embedded Design

There is a range of mixed methods design to choose from in the literature (Triangulation, Embedded, Explanatory and Exploratory). Creswell & Plano-Clark (2007) have proposed four main types of mixed methods design (Table 4.1). This study used the 'sequential embedded design'. This is a two-phase mixed design, whereby one data set provides a supportive, secondary role in a study based primarily on the other data type (Creswell & Plano-Clarke, 2007). The rationale for this design is that one single data set in not sufficient, that different questions need to be answered, and that each type of question requires different types of data. The main advantage of using this design is that it enables embedding a qualitative study within a larger quantitative design (vice versa). This design is particularly useful for studies under time and resource constraints and where one method requires less data than the other method (Creswell & Plano-Clarke, 2007). For example, in this study the data gathered using qualitative interviews, were based on relatively small number of participants, to generate in-depth information in response to the questions on the interview topic guide. In other words, the purpose of the sequential embedded design is to keep the two sets of results separate in their reports, rather than combing the two different data sets. However, Creswell (2009) suggests that the conclusions and interpretation phase of the (sequential embedded design) study should comment on how the qualitative findings have helped to elaborate on or extend the quantitative results.

Table 4.1: Four types of mixed methods designs

Type of mixed methods design	Description of the design
Explanatory	Also known as two-phase sequential study whereby the qualitative study is conducted first, followed by the quantitative study (or Vice Versa).
Triangulation	To obtain different but complimentary data on the same topic to best understand the research problem.
Embedded	One data set provides supportive, secondary role in a study based primarily on the other data type. The premise of this design is that a single data set is not sufficient.
Exploratory	A two-phase study design, whereby the results of the first study (e.g. qualitative) can help develop or inform the second method (quantitative).

Source: Adapted from: (Creswell & Plano-Clark, 2007)

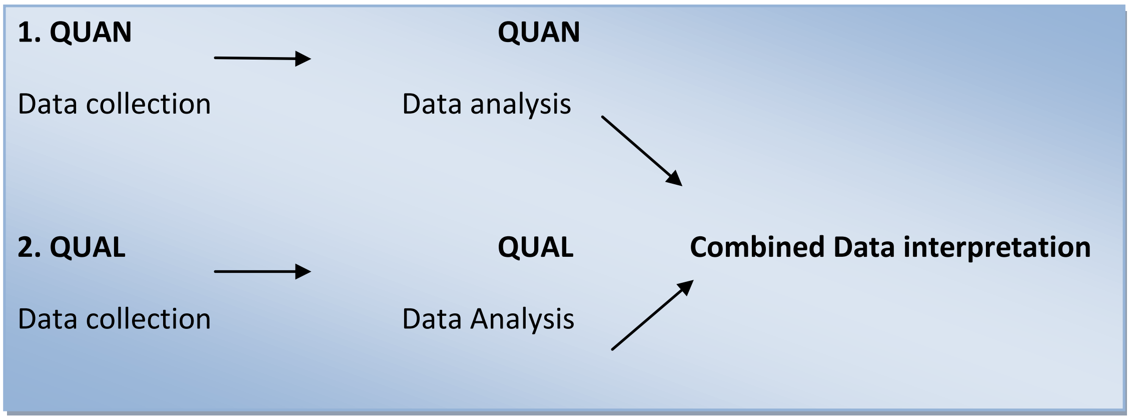
The main purpose of utilising a mixed methods design in this thesis was to gain a *complementary view, completeness and expansion* about the same phenomenon under study (Tashakkar & Teddlie, 2008). This was undertaken by:

- Drawing inferences from the two strands of methods '*to go beyond such answers by developing new understandings and new explanations for phenomena and relationships'* (Tashakkori & Teddlie 2008 p.104) (Figure 4.1).

- Identifying consistencies in findings between the two methods which also been considered to be an indicator of quality; as well as the inconsistencies which has also been considered to be meaningful and valuable (Tashakkar & Teddie 2008).

- Integrating, comparing and contrasting the findings between the two strands of methods (Tashkkori & Teddlie, 2008; Creswell et al 2008) to provide a richer understanding of the variable and their relationships (Tashakkori & Teddlie, 1996).

Figure 4.1 Visualisation of the sequential embedded mixed methods design



Source: Adapted from Creswell et al (2008) (p.68)

4.6 Research Question

The overarching research question developed for this thesis was:

What is the role of the social, cultural and religious context on beliefs about diabetes in the South Asian population in Greater Manchester, UK?

This research question was addressed using the ‘sequential embedded’ research design together with a number of sub questions outlined in Table 4.2.

Table 4.2 Sub questions

Sub question	Quan	Qual
1. Are using questionnaires a feasible and effective method for assessing beliefs about diabetes in the South Asian population?	✓	✓
2. What demographic and social network factors are associated with illness and fatalism beliefs?	✓	
3. How do illness and fatalism beliefs differ between sub-ethnic South Asian groups?	✓	✓
4. How do illness and fatalism beliefs relate to other health outcomes?	✓	
5. What social, cultural and religious beliefs influence the experience and practices of diabetes management in the South Asian population?		✓

A mixed methods design was used in this thesis to provide a better understanding into diabetes management in people from the South Asian origin. In particular it was used to overcome the strengths and weaknesses of both quantitative and qualitative research, in order to provide more comprehensive evidence for the role of illness beliefs and social networks for diabetes management in this target population.

Therefore research question(s):

- 1 was addressed by undertaking a systematic review of the literature (Chapter 5).
- 2, 3 and 4 were addressed using quantitative methods. The postal health survey and social networks survey interview were used as these materials/methods collectively offer a novel way of exploring management of long-term conditions (Rogers et al, 2011), as mentioned in Chapter 2.

- 5 was addressed using qualitative methods; in particular semi-structured interviews were conducted to explore in detail the role of social, cultural and religious beliefs which have been known to influence diabetes management. An interview topic guide with open-ended questions; independent of the CLAHRC LTC study materials was developed to answer this research question (Appendix 17).

Chapter 6 provides further details on the methods used for the quantitative study. Chapter 7 provides further details on the methodology and methods used for the qualitative study. Chapters 8, addresses the results of the quantitative study and Chapter 9 and 10 addresses the results of the qualitative results.

The next chapter describes the systematic review undertaken to identify studies using questionnaires to assess beliefs about diabetes (research question one).

Chapter 5

Systematic Review of studies using questionnaires to measure diabetes-related beliefs in South Asians

5.1 Introduction

A systematic review was chosen as the appropriate methodology to address research question one: *Are using questionnaires a feasible and effective method for assessing beliefs about diabetes in the South Asian population?* A copy of the systematic review journal paper published in *Diversity in Health and Social Care (May 2012)* can be found in Appendix 2. Therefore, the overall purpose of this chapter is to report the findings from the review as well as the methods used to conduct the review.

5.2 Aims

The review aims were to:

- Identify and report findings on studies which have used questionnaires to assess diabetes-related beliefs
- Review the feasibility and acceptability of this method in people of South Asian origin, to inform development of the postal health survey and subsequent methods for this thesis.

The main reason for undertaking this review was to find out whether studies in this field have used questionnaires such as the Illness Perceptions Questionnaire (IPQ) to assess diabetes-related beliefs in South Asians. To date most research into diabetes-related health beliefs in the South Asian population in the UK has been carried out using qualitative methods, such as focus groups, interviews (Lawton et al, 2007) and storytelling narratives (Greenhalgh et al, 1998; Greenhalgh et al, 2005a). The suitability of questionnaires as a method of data collection for measuring health beliefs is unclear. Assessing the feasibility of using questionnaires as a method of data collection was also important due to the language and literacy skills required to complete a questionnaire, especially for people whose first language is not English or who have difficulty reading any language (Lloyd et al, 2006).

5.3 Systematic review methodology

The aim of a systematic review is to:

> *'Comprehensively identify, and synthesize all the relevant studies on a given topic'.* (Petricrew & Roberts, 2008, p.19).

Systematic reviews have a long-standing history in the literature. This method enables synthesising and appraising the studies identified in order to answer a particular question (s) using a set of scientific measures that explicitly aim to limit systematic error (bias). Table 5.1 shows the key stages involved in conducting a systematic review, which was also followed in this review.

The review was conducted by the author (NP). Technical support was provided where necessary by members of the supervisory team, a senior librarian with expertise in developing search strategies and a senior academic with extensive expertise in conducting systematic reviews and who also is in the CLAHRC LTC team. Independent data extraction and appraisal was conducted by a colleague outside of the review team.

Table 5.1: The key stages in a systematic review

Identifying a suitable area for the review
The area for review was informed by the gaps in literature, described in Chapter 2 and discussions held with thesis supervisors.

Formulating a question
Rather than developing broad questions, a narrow focused enquiry was sought due to the overall aims of this thesis, population of interest to this thesis and time constraints.

Conducting searches
The aim of conducting a literature search is to identify the maximum number of studies relevant to the review. Systematic reviews on effectiveness of interventions and trials often use the Population, Intervention, Comparison, and Outcome (PICO) framework to focus question(s) to facilitate the search process. It is not essential to use every element of the PICO framework in the search strategy (Centre for Reviews and Dissemination, 2009). For this review it was preferable to search for concepts that related to the inclusion criteria and concepts that could be defined and translated into search terms (Box 4.1).

Inclusion/exclusion criteria
The inclusion and exclusion criteria describe the types of study, population, and outcomes that are eligible for in-depth review, and those that are excluded. This also reduces the chances of obtaining large amounts of irrelevant data.

Data extraction
The aim of the data extraction method is to ensure consistency and objectivity. As a procedure, data extraction forms are created to outline and describe every aspect of the title of the study, year, population and relevant methodological information and results.

Synthesis
This process of the review integrates the studies, mainly using the information gathered in the data extraction forms.

Critical appraisal
Assessing the methodological rigour of each study that meets the inclusion criteria helps to account for biases with the study and interpretation of the data.

Protocol
A protocol, which details the methods, estimated timelines and resources for the review.

Updating reviews
Due to the time it takes between conducting the search and passing through each of the key stages of the review process, the findings of a search can become out of date, especially with the number of studies published daily (Centre for Reviews and Dissemination, 2009). Subscription was made to the research database - ZETOC to keep track of new studies relevant to the review. Searches were also updated a few months after the initial search was conducted and again before submitting for publication.

Write up and dissemination
Like any other empirical study, the review should be disseminated to a relevant audience via journal publications and/or conference presentations. A copy of the peer-review publication of this review can be found in Appendix 2.

5.4 Inclusion and exclusion criteria

Box 5.1 provides details of the inclusion and exclusion criteria for the review. Initially the criteria developed for this review were set to include UK studies only. However, the initial scoping stage found no relevant studies, which fit the criteria. As a result the criteria were modified to include international studies.

Box: 5.1 Inclusion criteria

Studies *included* if:

- ✓ A study had used standardised questionnaires to assess South Asian beliefs about their diabetes.
- ✓ Participants in the study were adults aged 18 years or over.
- ✓ Participants had either T1DM or T2DM.
- ✓ Participants in the study belonged to any one of the seven South Asian ethnic groups.

Studies *excluded* if:

- ✓ Study was written in non-English and translations were unavailable for the review.
- ✓ A study used beliefs in the title, but was actually using qualitative methods to assess beliefs.

5.5 Initial scoping search

An initial scoping search allows determining what types of studies addressing the systematic review question have previously been carried out.

In the first instance, the findings of the review were used to inform the CLAHRC LTCs Health Survey which lead to inclusion of one questionnaire measuring beliefs and two validated items measuring fatalism beliefs in relation to diabetes. (See Chapter 6 for further details).

5.6 Developing the main search

A search strategy was developed using a combination of text terms and subject headings for diabetes, South Asians and illness beliefs. The full search is reproduced in Box 5.2. To minimise bias in the review process these terms are used in combination to maximize the sensitivity and specificity of the search. The search terms for diabetes were obtained from the Cochrane Metabolic and Endocrine Disorders Group, Specialised register (Richter et al, 2007).

The search strategy was systematically applied to search for studies from 1992 to 2010, across five major electronic databases: *CINAHL, EMBASE, Medline, PsychINFO and Geobase (*Box 5.3). The cut-off date chosen for the start date was 1992. This was due to the time and resource constraints of this thesis. The initial scoping of the literature showed that most of the research into health beliefs for diabetes commenced in the early 1990s.

Searches were conducted between February and March 2010 and updated in June 2010 and December 2011. Additionally, the NHS Specialist Library for ethnicity and health (NHS Evidence, 2011) was also searched.

To supplement the database search, the journals Ethnicity and Health, Diabetes Care and Diabetic Medicine were hand-searched from 1992 to 2010. Reference lists of key articles and other reviews were scanned for potentially relevant articles as was the grey literature using Google Scholar. Four authors of the papers included in the review were contacted to help identify further relevant published and unpublished papers. The search results were imported into Reference Manager 11 (2009) in order to manage the review process.

A specialist librarian and a colleague with expertise in conducting systematic reviews advised on the development of the search strategy and suitable databases to use. An external academic also an expert in systematic review, especially in the health of ethnic minority populations advised on the search terms for South Asians.

5.7 Reference Manager

All searches were imported into separate Reference Manager Databases and the complete search phase was documented and placed into a master database. The Reference Manager Databases also assisted in identifying duplicates within each database to ensure the studies were not treated as separate studies in the review.

The abstracts of these articles were initially browsed to identify suitable studies. The identified measures were appraised in relation to the inclusion and exclusion criteria of the review (Box 5.1). Additional related searches of the literature involved manually checking the reference lists of all papers that were identified through database searches (Box 5.3).

Box 5.2 Example search strategy

Diabetes

Exp Diabetes Mellitus/
Exp Diabetes Mellitus, Type 1/
Exp Diabetes Mellitus, Type 2/
Exp Diabetes complications
ExpHyperglycemia/or hyperglycaemia.mp.
expHypoglycemia/or hypoglycaemia.mp.
exp Diabetic Ketoacidosis/
Diabet$.mp
Insulin dependent diabetes mellitus.mp.
IDDM.mp
non-insulin dependent diabetes mellitus.mp.
non-insulin dependent diabetes mellitus.mp.
NIDDM.mp
diabetes mellitus type I.mp.
diabetes mellitus type II.mp.
T1DM.mp
T2DM.mp
DM1.mp.
DM2.mp.
late onset diabetes.mp.
maturity onset diabetes.mp.
mature onset diabetes.mp

South Asian

India$
Pakistan$
Bangladesh$
Nepal$
Sri Lanka$
Bhutan$
Maldives$
South Asian$
Ethnic origin
Asian

Health beliefs

Exp attitude to health/
Exp self-efficacy
Illness representation model.mp
Common sense model.mp
CSM.mp
Self-regulatory model.mp
Parallel process model.mp
Leventhal's model.mp
Leventhal.mp
Health belief model.mp
HBM.mp
Social cognitive theory.mp
Illness cognition$.mp
Illness belief$.mp
Illness perception$.mp
Illness representation$.mp
Health belief$.mp
Health cognition$.mp
Health perception$.mp
Health representation$.mp
Personal model$.mp
Self-regulation.mp
IPQ.mp
IPQ-R.mp
Personal model$ of diabete$.mp
Personal model$ of illness.mp
Diabetes illness representations questionnaire.mp
DIRQ.mp
Theory of self-regulation.mp
Parallel processing model.mp
Self-regulation model.mp
Illness perception questionnaire.mp
Illness perception questionnaire-revised.mp
The brief illness perception questionnaire.mp

Box 5.3 List and description of databases searched

http://www.library.manchester.ac.uk/eresources/databases/

CINHAL (*via OVID 1982-present*) The Cumulative Index to Nursing and Allied Health Literature (CINHAL) is a nursing and health literature database. The database includes literature from biomedicine, behaviour sciences, education, consumer health and management and health sciences.

MEDLINE (*via OVID 1966-present*) MEDLINE is a biomedical database created by the National Library of Medicine and includes over 3,000 journals.

EMBASE (*via OVID 1980-present*) Excerpta Medica includes data from over 3,500 journals related to biomedicine, biotechnology, bioengineering, health affairs and psychiatry. There is 30% duplication within the biomedical literature of MEDLINE and EMBASE databases

PsycInfo (*via OVID 1887-present*) PsycInfo is an International database produced by the American Psychological Association and covers over 1,300 journals from disciplines such as sociology, linguistics, anthropology, education, medicine, nursing, physiology, psychiatry, law and business.

GEOBASE (*via OVID 1994 to date*) GeoBase is a bibliographic database covering over 2,000 journals, plus books, monographs, conference proceedings, reports and theses. It covers all aspects of physical and human geography, geology, ecology and Third World studies.

5.8 Data extraction

All titles and abstracts identified were assessed for eligibility by the author (NP) and data were extracted. Another researcher independently checked all data extraction and any discrepancies resolved through discussion with the supervisors of the review.

5.9 Appraisal criteria

Effectiveness reviews commonly use checklists to assess the quality of studies and in some cases produce an overall score for each study. However, this review was not assessing effectiveness of interventions. Therefore, the questionnaires in each study of this review were appraised using a formal appraisal criteria designed to assess patient-reported outcomes in clinical trials (Fitzpatrick et al, 1998; Box 5.4). These criteria were most relevant for assessing the overall utility of health belief questionnaires. This criteria consists of eight dimensions but for the purpose of this review, four criteria were selected.

Box 5.4 Questionnaire Appraisal Criteria

Acceptability: how acceptable is the instrument to complete	• Time taken to complete the scales. • The number of items. • Response rate. • Missing data.
Feasibility: any effort or burden on the administrator of an instrument	• Resources to administer the questionnaire. • Ease of administering and processing information from the questionnaire. • Coding schemes required to produce questionnaire scores. • The training required for staff to use and interpret the scale.
Reliability: Internal consistency	• Estimates of Cronbach's alpha (internal reliability acceptable if the estimate was 0.70 or above). • Correlation of scores or other measures of agreement to assess test-retest reliability for repeated measures.
Validity: whether the instrument measures the underlying construct	• Translation guidelines e.g. back translation.
Construct validity	• Predicted diabetes-related variables.

5.10 Results of the search

A total of 303 abstracts were identified (Figure 5.1). Of these, 186 full text papers were obtained and checked for eligibility using the inclusion criteria. Five studies were eligible for inclusion. Each of the five studies was systematically assessed against the four appraisal criteria and the next section provides further details of that assessment.

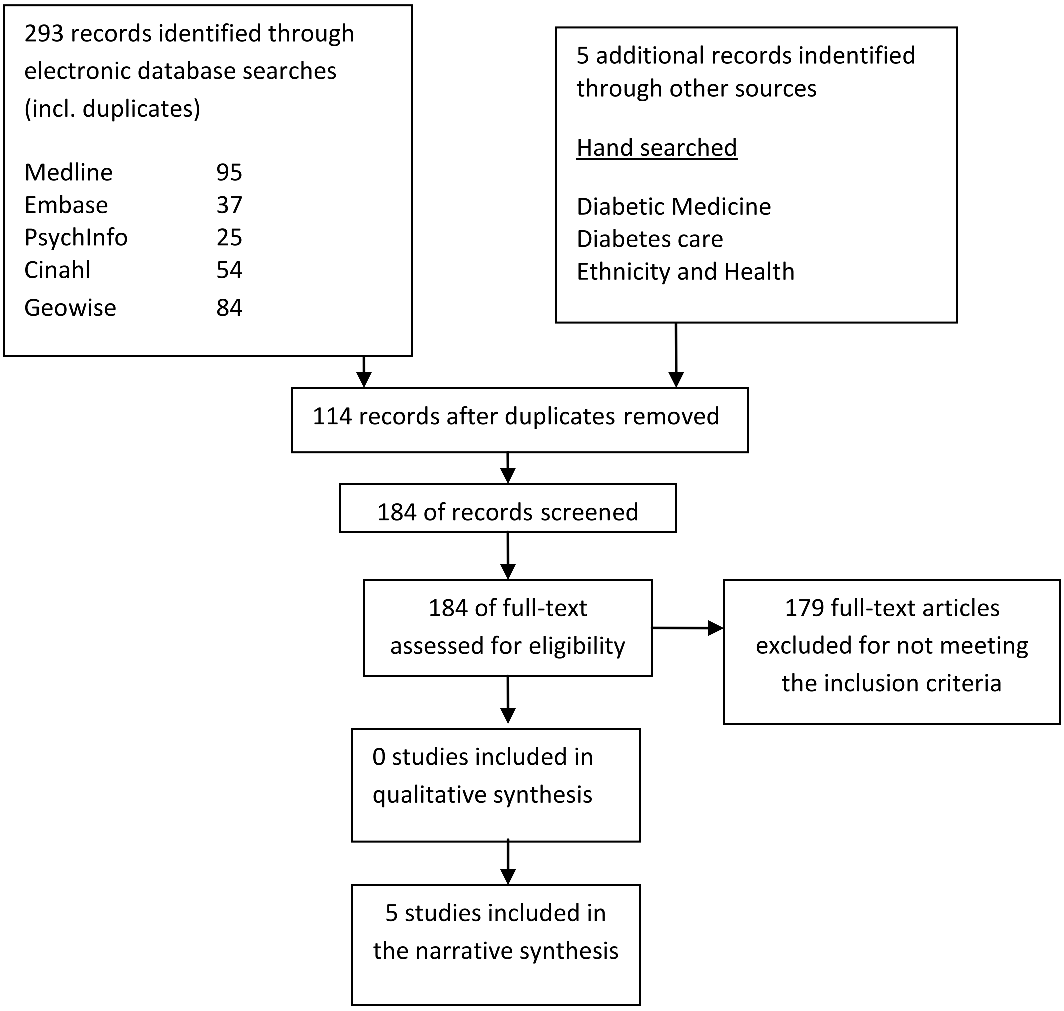
5.11 Narrative synthesis

A narrative synthesis is defined as:

> *'The process of synthesising primary studies and exploring heterogeneity descriptively, rather than statistically'.* (Petricrew & Roberts, 2008, p. 39).

This approach is to summarise findings of multiple studies using mainly text and words (Pope et al, 2007), thus this process of synthesis is descriptive, rather than statistical. Given the heterogeneity between the studies in terms of questionnaires used, research settings and ethnic groups, a narrative synthesis were deemed most appropriate.

Figure 5.1: Flow chart of progress through the systematic review



5.12 Main findings

Data on appraisal of each study in the review is reported in Table 5.2. To avoid overlap and repetition, this section will summarise the findings of the review together with a brief section on future work and conclusions. A detailed discussion of the findings can be found in the published paper in Appendix 2.

5.13 Standardised questionnaires that have been used to assess diabetes-related health beliefs

The health belief questionnaires varied between studies. Two studies used different versions of the standardised IPQ measures (Bean et al, 2007; Kart et al, 2007). One study (Bean et al, 2007) also included questionnaires about self-efficacy; metabolic rate and retinopathy to further assess the relationship between beliefs and health outcomes.

Two studies (Rafique et al, 2006; Rankin & Bhopal, 2001) adapted existing health questionnaires by adding their own questions to specifically assess diabetes-related beliefs. Rankin & Bhopal (2001) and Rafique et al (2006) developed a questionnaire based on existing health-related questionnaires. The remaining study designed and pre-tested a new health belief questionnaire with no specific justification. Therefore, it was difficult to assess this measure in any detail using our selected appraisal criteria (Sivagnanam et al, 2002) (Table 5.2).

Table 5.2 Appraisal of questionnaires

Author, year & country of origin	Questionnaire(s)	Sample, Size & Duration of diabetes	Administered	Response rate	Predicated health outcomes	Measure Translated	Process of translation	Meets translation standards	Cronbach's Alpha (CA)	Test-retest calculation
Bean et al (2007) New Zealand	The Brief Illness Perceptions Questionnaire (Broadbent et al 2006); Multi-dimensional Diabetes Questionnaire (Nouwen et al, 2003); The Summary of Diabetes Self-Care Activities (SDSCA) (Toobert et al, 2000). Metabolic rate.	Ethnicity: Indian, Fiji Indian, Bangladeshi. Opportunistic sample from: Clinic & GP appointments. n=86. Duration of diabetes: 9 years for men and women.	Self-report	82%	*Personal control* associated with: dietary self-care ($r = 0.35$, $p = <0.01$), exercise ($r = 0.27$, $p = 0.05$). *Identity* associated with medication-taking ($r = 0.28$, $p = < 0.5$). Greater perceptions of *Treatment control* predicted better glucose testing ($\beta = p=0.035$). *Emotional representation* predicted HbA1c ($\beta = 0.45$, $p = 0.013$).	English to: Hindi, Gujarati, Tongan & Samoan languages	Translated by native speakers and checked by independent person for quality.	No	BIPQ: CA = 0.58-0.70 for all items.	Not calculated.
Kart et al (2007) Nepal	Illness perceptions - Revised questions (IPQ-R); The Summary of Diabetes Self-Care Activities (SDSCA) Toobert et al, 2000.	Ethnicity: Indian Opportunistic sample from: national diabetes hospitals and diabetes club. n=300. Duration of diabetes: 11 years for men and women.	Face to face – interview format.	Not stated.	*Treatment control* correlated with exercise ($r =.18$, $p < 0.05$), complimentary alternative medicine ($r =.314$, $p < 0.05$) stress ($r =.31$, $p < 0.05$) and lower use of medication ($r = -.35$, $p < 0.05$). *Timeline* and Time cycle predicted healthy eating ($r =.16$, $p < 0.05$), adherence to medication ($r = 0.15$, $p < 0.05$). *Emotional representation* predicted foot care ($r = -.16$, $p < 0.05$).	English to Nepalese	Translated by co-author	Yes	Reported using Principle component analysis with varimax rotation for each IPQ indictor.	Not calculated.
Rafique et al (2006) Pakistan	Adapted from previous studies: Diabetes Knowledge Test (DKT) (Schoenberg et al, 1998; Fitzgerald et al, 1998). Further questions based on local beliefs and clinical observations.	Ethnicity: Pakistani Opportunistic sample: hospital outpatients n=199 Duration of diabetes: men = 7.3 yrs, women = 8.8 yrs	Face to face – interview format.	Not stated.	None reported	Not stated	Not stated	N/A	Not calculated.	Not calculated.
Rankin & Bhopal (2001) Newcastle, UK	Rose Angina Questionnaire (Rose, 1962) and questions on understanding the disease were devised by authors.	Ethnicity: Indian, Bangladeshi & Pakistani. n=16 People with diabetes no specific information on duration of diabetes or gender.	Not stated Face to face – interview format	Not stated	None reported	English to Bengali, Hindi, Punjabi and Urdu	Native speaker and back translated into English by an independent person.	Yes	Not calculated.	Not calculated.
Sivagnanam et al (2002) Sri Lanka	Designed specifically for local population.	Ethnicity: Nepalese n=243 Duration of diabetes: Not stated	Self-report	Not stated	None reported	No - designed in the local language, Tamil.	N/A	N/A	Not calculated.	Not calculated.

5.14 Appraisal of questionnaires

The next section details each stage of the appraisal process for each standardised measure included in the review.

5.15 Acceptability

Data about measures of acceptability were relatively limited. Only one study (Bean et al. 2007) stated the response rate of the number of completed questionnaires. The remaining studies only reported the achieved sample size, with no specific information on response rates or rates of missing data. The length of the questionnaires ranged from 7 to 39 questions across the five studies, of which none provided specific information on the time taken to complete them. All five studies included additional questions on self-management with the longest questionnaire totalling 53 items.

5.16 Feasibility

Measures of feasibility were very limited. Three studies (Rankin & Bhopal, 2001; Rafique et al, 2006 and Kart et al, 2007) employed a member of the research team to either distribute questionnaires or to assist respondents to complete it during an interview.

5.17 Reliability

Two studies (Bean et al, 2007 and Kart et al, 2007) stated that the questionnaires had internal consistency but Bean et al (2007) was the only study to report Cronbach's Alpha for the BIPQ (Table 5.2). None of the studies reported on test-retest reliability of the questionnaires (Table 5.2). Three studies (Bean et al*,* 2007; Kart et al, 2007 and Rafique et al, 2006) translated questionnaires but only two of these (Kart et al, 2007 and Rafique et al, 2006) met international standards for translation by adopting the method of back translation to ensure the validity and reliability of the measures. Although back translation is stated as one of the most common methods of translation in survey research (Brislin, 1970), none of the studies made reference to using any specific translation guidelines.

5.18 Validity

The studies differed in terms of how they assessed the relationship between beliefs and diabetes management. Bean et al, (2007), using the BIPQ found these health beliefs to be predictive of self-care and metabolic rate. For example, *personal control* beliefs were positively associated with dietary self-care and exercise. *Identity* beliefs were associated with medication taking for South Asians. Beliefs about *treatment control* predicted better glucose testing whereas emotional representation predicted HbA1c outcomes (Table 5.2). Kart et al, (2007) also found that *treatment control* was positively correlated with exercise, Complementary Alternative Medicine, stress and lower use of medication. Beliefs about the *chronic* and *cyclicality* elements of diabetes predicted healthy eating and adherence to medication whereas *emotional representation* was predictive of foot care (Table 5.2).

The remaining three studies were more descriptive and did not provide any additional information about the relationship between beliefs and other health outcomes associated with diabetes. These studies only stated the findings from the belief questions. For example, 85% of Sivagnanam et al (2002) respondents believed that wheat played a crucial part in the diet for people with diabetes and over half believed that diabetes only affected adults. Rankin & Bhopal (2001) reported that controlling and reducing sugar intake and eating a healthy diet were factors believed to prevent diabetes. Similarly, Rafique et al (2006) found that people with diabetes significantly held diet- related beliefs about managing their diabetes.

5.19 Summary of main findings

The aim of this review was to identify studies in which standardised (validated) questionnaires were used to assess health beliefs in South Asians with diabetes. Each questionnaire was assessed for feasibility; acceptability, reliability and validity using established appraisal criteria. Five studies were identified, of which four used pre-existing questionnaires from the literature, and one study designed a new questionnaire. Two studies showed that diabetes-related health beliefs might predict relevant health outcomes in the South Asian population. However, the studies conducted so far have been of varying quality and there is limited data on acceptability, feasibility, reliability and validity.

5.20 The utility of using questionnaires to assess diabetes-related health beliefs

The studies in this review show some utility in using questionnaires to assess beliefs in the South Asian population with diabetes. The studies varied in the types of questionnaires used and provided very limited information about acceptability and feasibility making it difficult to assess them against these two criteria. Most studies required a high level of resources because researchers provided face-to-face support for either recruitment or assisting participants to complete the questionnaire. This aligns with previous research in the literature, which has reported barriers to using questionnaires with the South Asian population (Lloyd et al, 2008a). The main issue with some of the studies in this review was the lack of information and justification for the choice of questionnaires. For instance, in Sivagnanam (2002) it is not clear why the author of this study developed a new measure when other researchers used modified or existing questionnaires.

The primary aim of this systematic review was not to explore illness perceptions in relation to self-management. However, the evidence from the two studies using illness perceptions questionnaires and additional health outcome questionnaires in this review (Bean et al, 2007; Kart et al, 2007), helps to better understand the link between beliefs and diabetes management. For example, both studies found that beliefs about *treatment control, identity, emotions and personal control* influenced specific self-management behaviours. Nonetheless more research is needed to provide a rigorous assessment of the utility of these questionnaires and to assess whether that utility is equal in other populations.

5.21 Chapter Summary

This review identified very few studies that have used questionnaires to assess diabetes-related health beliefs in the South Asian population. The usefulness of this review is the preliminary data to suggest that measuring health beliefs using questionnaires is possible, especially when language support is provided. There is some preliminary evidence, which also suggest that these beliefs may predict self-management in this target population. Therefore the lack of studies using questionnaires to assess beliefs about diabetes is a cause for concern because it may hinder the development of diabetes management strategies for this population.

5.22 Rationale for the selection of the BIPQ in this study

The BIPQ is most useful for populations who would find completion of a long questionnaire difficult or when researchers are already using multiple measures but wish to also include an assessment of illness perceptions, as well as reduce the burden on research participants (Broadbent et al, 2006). In comparison to the earlier measures of illness beliefs, for example the Illness Perceptions Questionnaire (IPQ) and Illness Perceptions Questionnaire-Revised (IPQ-R), the BIPQ is a nine-item measure, designed to rapidly assess the cognitive and emotional representations of illness along the following dimensions: identity, consequences, timeline, personal control, treatment control, concern, understanding and emotional representations using a single item scored on an 11-point Likert scale, with the exception of causal question in a wide range of research and clinical settings. The causal question is assessed by an open-ended response item adapted from the IPQ-R, which asks patients to list the three most important causal factors in their illness (Broadbent et al, 2006). Higher scores on the BIPQ indicate stronger endorsement of that item.

The narrative systematic review presented in this chapter provides some evidence and justification for using theory-based questionnaires such as the BIPQ to assess beliefs in South Asian people with diabetes. Apart from being able to gather large amounts of data from using this method, using a theory-based questionnaire, such as the BIPQ can determine whether the findings refute or support theory and which dimensions of the theory need to inform intervention. Using the findings on the feasibility of using questionnaires from this review is also important, especially since previous studies have relied solely on face-to-face qualitative methods such as interviews to explore beliefs about diabetes in this target population.

Before discussing the psychometric properties of the BIPQ and the appropriateness of this measure for South Asians, it is important to provide some detail on the development and item selection of the BIPQ.

5.23 The relationship and item selection between the BIPQ and IPQ-R

As mentioned earlier, three measures are available to assess illness beliefs are: IPQ, IPQ-R and more recently the BIPQ. The IPQ-R is commonly used in place of the IPQ as this measure offers advantages when researchers want to perform a more detailed analysis of the patient’s identity beliefs, that is, the specific symptoms the patient associates with their illness. Unlike the IPQ, the IPQ-R also provides information on cyclical timeline beliefs, which are not assessed by the BIPQ or the IPQ. The IPQ-R scale may also be more sensitive to changes in illness perceptions due to the larger score range of the subscales. Broadbent et al (2006) developed the items for the BIPQ by forming one question that best summarised the items contained within each subscale of the IPQ-R. The psychometric testing of the BIPQ has been found to have moderate to good associations between the BIPQ and the IPQ-R on all the equivalent dimensions. The discriminant validity of the BIPQ was examined by comparing mean scores on the BIPQ between five different illness groups (diabetes, asthma, colds, myocardial infarction patients prior to discharge, and pre-diagnosis chest pain patients waiting stress-exercise testing) and was able to distinguish between different illnesses. The causal question in the BIPQ identified the same top-rating causal factors, as did the IPQ-R in both asthma and renal samples. However, not all the responses to the BIPQ causal question could be categorised into the items listed in the IPQ-R, highlighting the advantage of the open-ended causal question in the BIPQ to identify causal beliefs. The test-retest reliability of the BIPQ has been assessed in renal outpatients only. The concurrent validity was assessed by comparing the BIPQ with the IPQ-R in asthma, renal and diabetes outpatients, and the predicative validity was established by examining the relationship between the BIPQ scores and outcomes in patients with myocardial infarction. Furthermore, blood glucose control for patients with diabetes was associated with the BIPQ personal control, treatment control, and identity items. Overall, the pattern between the BIPQ and the IPQ-R were found to be fairly comparable.

5.24 The psychometric properties and appropriateness of the BIPQ for South Asians

The BIPQ has been shown to be a valid and reliable measure of illness perceptions in a variety of illness groups and has demonstrated good test-retest (Cronbach’s alpha ranging from 0.42 to 0.75 over a 6 week period in a renal patient sample) concurrent, predictive and discriminant validity (Broadbent et al, 2006). In their development of the BIPQ measure, Broadbent et al (2006) state that the methods of recruitment (questionnaires vs. clinical recruitment) was unlikely to have had a major effect on beliefs and the differences between the samples were due to the different experiences inherent to each illness. Although the BIPQ has been validated in patients with T2DM using HbA1c test results, Broadbent et al (2006) have not provided information on the ethnic composition of their sample. This suggests that the ethnicity of the sample was not accounted for during the development of the BIPQ and may implications for the differences found in illness experience within the sample. Thus, it is not possible to comment on the role of ethnicity in relation to the psychometric properties of this measure.

Overall, the BIPQ is a relatively new measure that has shown good psychometric properties. This measure is claimed to be applicable in a wide range of settings and the results from the scales have been suggested to be easily scored and readily interpretable by researchers (Broadbent et al, 2006) and one of the reasons for using it in this study. Although the BIPQ has been translated into different languages (see http://www.uib.no/ipq), there has been a lack of research into validating and establishing utility of this measure, especially within the UK South Asian population. To date, one study has provided information on the utility of the BIPQ in a study of 200 patients with diabetes from three different ethnic backgrounds of which 86 were South Asian, 87 Pacific Islanders and 86 Europeans (Bean et al, 2007). All participants in the Bean et al (2007) study were recruited in New Zealand, and all the subscales of the BIPQ were added to form a summary score that demonstrated good internal reliability, with Cronbach's Alpha ranging from 0.58 to 0.70 in all three ethnic groups.

Furthermore, the use of self-completion questionnaires remains problematic in sections of the UK South Asian population where there are high levels of illiteracy or where the main language spoken has no agreed written form (Lloyd et al, 2006; Lloyd et al, 2008a). Whilst some work has been carried out in relation to validating some of the standardised depression measures (Lloyd et al, 2008b), the appropriateness of measures such as the BIPQ in the UK South Asian population is unclear and requires further research.

The next chapter describes the methodology for the quantitative study.

Chapter 6

Methods for the quantitative study

6.1 Introduction

This chapter will provide details of the methods used for the quantitative study (see Chapter 7 for details on the research design for the qualitative arm of this thesis). After an outline of ethical approval for this thesis, the reasons behind the choice of methodology, including why particular research methods were chosen and others discarded will also be outlined.

6.2 Research question related to the quantitative methods

As mentioned in Chapter 4, the aim of the quantitative study was to examine diabetes-related beliefs (including fatalistic beliefs) and the role of social networks in the management of diabetes. The methods presented in this chapter are in relation to research questions 2-4 (outlined in Chapter 4) and were addressed using a cross-sectional postal health survey and social networks survey interview.

6.3 Study procedure

There were three different stages of data collection for this thesis:

1. Postal health survey (of 67 South Asians).
2. Social networks survey – face-to-face interview using a second questionnaire to explore social networks, which also included open-ended questions and was audio-recorded (with 37 of the South Asians who had already participated in the postal survey, see Figure 8.1, Chapter 8).
3. Semi-structured interviews (with 37 participant from stages 1 and 2), with open questions, this was also audio recorded. The interview topic guide designed for this study was independent of the CLAHRC study materials, but

was incorporated into the social networks survey interview. The exact procedure for this study will be explained in further detail in the next chapter.

6.4 Ethical Approval

As this study was nested within the CLAHRC LTC programme, ethical approval for this study was obtained through this programme application. Ethics approval was obtained from the Greater Manchester Research Ethics committee in February 2010 (ref: 10/H1008/1, Appendix 4). The ethics approval covered both the quantitative and qualitative aspects of the methods used in this thesis. Therefore, it was important to adhere closely to the methods used by CLAHRC LTC study obtaining research and development approval, along with an honorary contract and Criminal Records Bureau (CRB) check was also required (Appendix 4).

The author (NP) provided assistance on the ethics application for:

- Drafting the written patient information sheet.
- Conducting pilot interviews with people from the local community to test and modify the social networks survey questions accordingly.
- Providing details of suitable measures for inclusion in the CPT survey to assess illness beliefs and fatalism for this study.

Prior to submitting the final ethics application, discussions took place concerning the need for translation of the information sheet and relevant materials into appropriate South Asian languages for the purposes of this study. However, due to CLAHRC LTC study time constraints and project deadlines, this was not feasible and the option of recruiting an interpreter was offered to overcome any language barriers during this study.

6.5 Study sample for the quantitative study

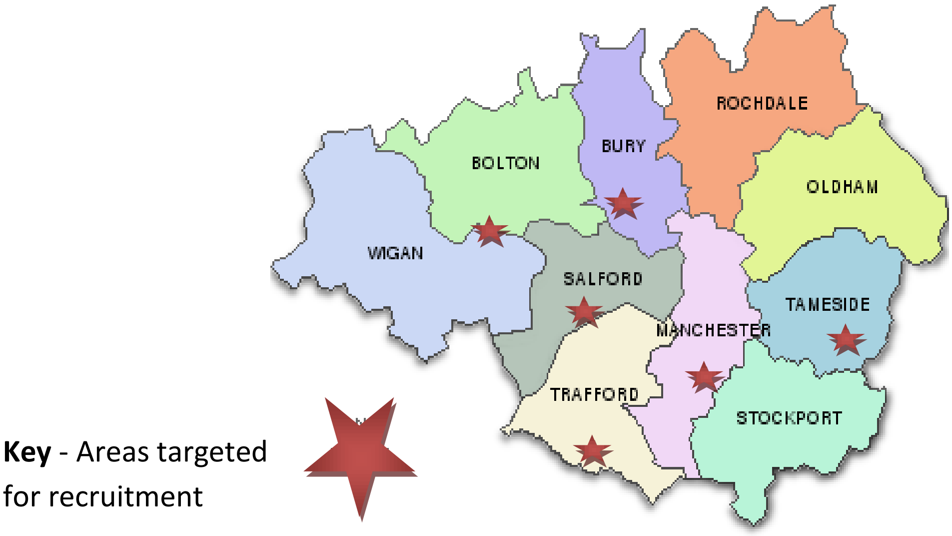
The inclusion criteria for the sample were as follows:

- South Asian men and women from one of seven sub-ethnic groups (as described in Chapter 1) who are above 25 years of age.
- Diagnosed to have T1DM or T2DM for at least 6 months with the presence or absence of diabetes related risks (e.g. cardiovascular problems and/or other co-morbidities).
- Resident in Greater Manchester (Figure 6.1)
- Literate in English or any of the three South Asian languages: Hindi, Urdu and Gujarati commonly spoken/used in this ethnic population.

Exclusion Criteria

- Those who were not mentally capable of consenting to participate.

Figure 6.1: Areas of Greater Manchester targeted for recruitment of South Asians



6.6 Power calculation for the postal health survey

A power calculation was performed to determine the sample size required for the Brief Illness Perceptions Questionnaire (BIPQ) measure (Appendix 15). Using an effect size of 0.5 (medium effect) with 80% power and a two-tailed hypothesis at the 5% level of significance, a sample of n=64 South Asians was required.

The initial research plan included an assessment of differences between the three sub-ethnic South Asian groups (Indian, Pakistani and Bangladeshi). However a power calculation indicated that a sample of n=85 per sub-ethnic group would be required to detect an effect size difference of 0.5 between any pair of groups, n=255 in total. Due to time and resource constraints, it was not feasible to recruit a sample of this size.

6.7 PHASE l: Sampling and Recruitment of GP Practices

The next section provides detail on the methods used to recruit both GP Practices and participants into this study.

6.8 Recruitment procedures

Two methods of sampling were used to recruit South Asian participants into this study: Random sampling from GP registers and purposive sampling from the community. The procedure for recruiting GP practices will be described in the next section.

6.9 Recruitment of GP Practices

Following the CLAHRC LTC Standard Operating Procedures (SOP) guidelines for recruiting GP practices into the study (Appendix 5), initial contact with GP Practices was made by telephone to the receptionist, whereby transfer to the Practice Manager (PM) was requested in order to inform them of the study. After this, a face-to-face meeting was held with either the PM or PN or both, to further explain the study procedures and answer any questions the practice had about the study. Prior to the meeting, all practices were emailed or posted a copy of the patient information sheet and a separate practice information sheet, which gave specific details about the study (Appendix 6). A total of 22 GP practices were recruited from the following areas: Bolton, Tameside, Central Manchester and Oldham (Figure 6.1).

A close working relationship was maintained with the CLAHRC LTC team to recruit GP practices in the Greater Manchester area. Recruitment of two practices in Tameside was led by the author (NP). One of the main reasons for focusing on recruiting GP practices from this area was because there are a large number of established South Asians communities living in Tameside, especially in Ashton (Tameside and Glossop NHS, 2005). Unlike other areas of Greater Manchester such as Oldham and Stockport; Tameside is often underrepresented in research, despite the poorer health and higher levels of deprivation of people in this area compared to England average (Public Health Observatories, 2011).

6.10 Randomisation of GP patient lists

Once recruited, the PM or PN was asked to email the identification (ID) numbers of the patients (Caucasians and South Asians) on their diabetes and coronary heart disease register lists using an Microsoft Excel spreadsheet to the researcher responsible for recruiting in that particular practice (Figure 6.2).

The CLAHRC LTC statistician responsible for randomising the disease registers was informed of the size of the disease registers and requested to send the random numbers to the researcher (Figure 6.2). The number of random numbers the statistician generated depended on the size of the disease registers. For example:

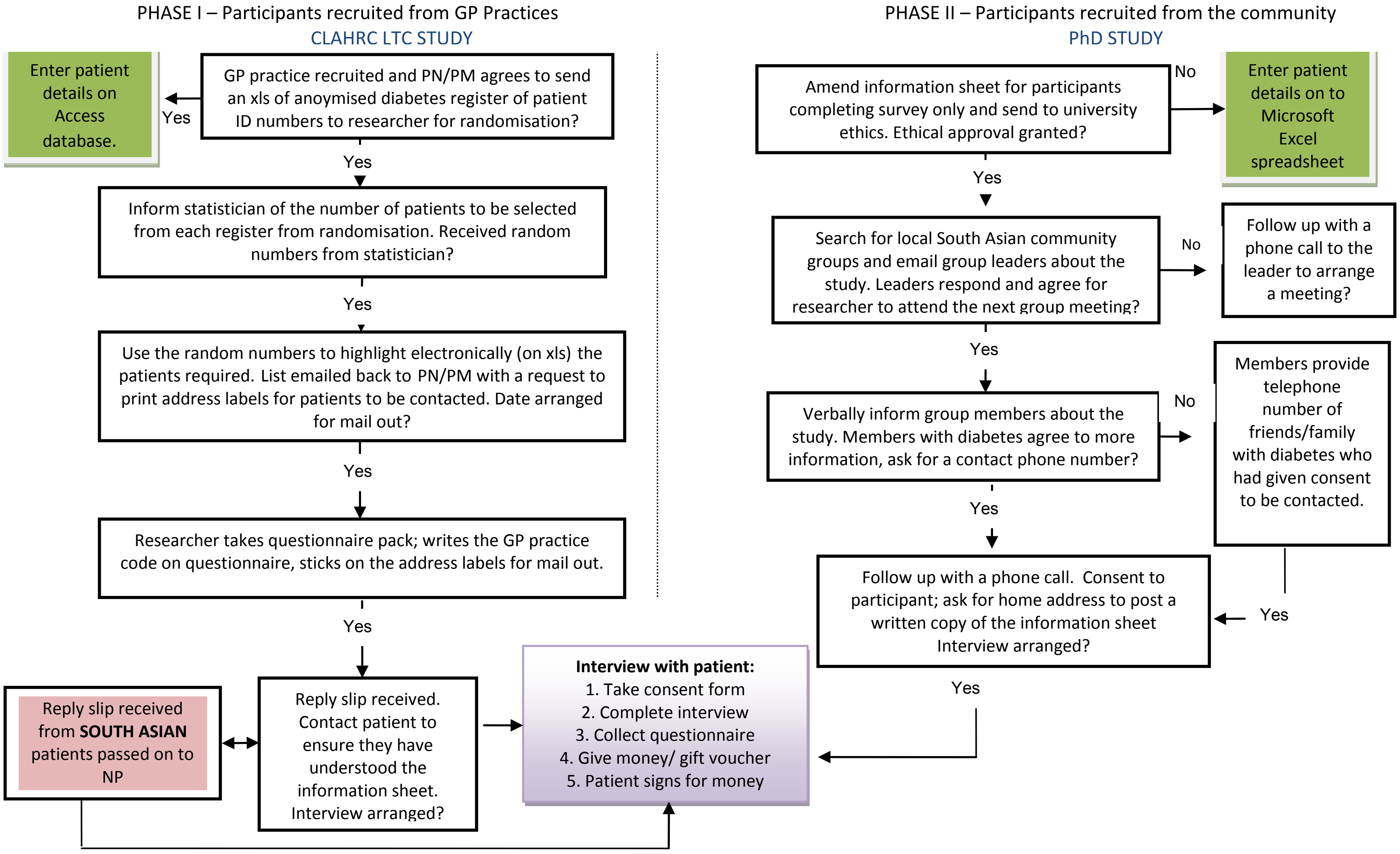
- If there were less than 50-60 patients on each list, then random numbers were not required and all patients were sent an invitation to take part in the study.

- For small practices (60-100 patients per list), the statistician was requested generate 50 random numbers. For medium practices (100-200 patients per list) the statistician was requested generate 60 random numbers.
- For larger practices (200+ per list) the statistician was requested generate 75 random numbers.

Using the random numbers, the researcher (NP) highlighted, electronically, the patient IDs chosen to approach to take part in the study. The randomised list was then sent back to the practice and the PN or PM was requested to remove any patients who were unsuitable to take part, for example, patients they knew had severe mental health problems, dementia or those who were unable to consent to take part or deceased. Invitation letters to all patients were sent from GP practices (Figure 6.2).

Reply slips sent back from all South Asian patients in the random sample were forwarded to and approached by the author (NP). The total number of South Asian people recruited for this study is detailed in Chapter 8, Figure 8.1.

Figure 6.2: Recruitment procedures



PHASE I – Participants recruited from GP Practices

CLAHRC LTC STUDY

GP practice recruited and PN/PM agrees to send an xls of anoymised diabetes register of patient ID numbers to researcher for randomisation?

Enter patient details on Access database.

Inform statistician of the number of patients to be selected from each register from randomisation. Received random numbers from statistician?

Use the random numbers to highlight electronically (on xls) the patients required. List emailed back to PN/PM with a request to print address labels for patients to be contacted. Date arranged for mail out?

Researcher takes questionnaire pack; writes the GP practice code on questionnaire, sticks on the address labels for mail out.

Reply slip received. Contact patient to ensure they have understood the information sheet. Interview arranged?

Reply slip received from **SOUTH ASIAN** patients passed on to NP

Interview with patient:
1. Take consent form
2. Complete interview
3. Collect questionnaire
4. Give money/ gift voucher
5. Patient signs for money

PHASE II – Participants recruited from the community

PhD STUDY

Amend information sheet for participants completing survey only and send to university ethics. Ethical approval granted?

Enter patient details on to Microsoft Excel spreadsheet

Search for local South Asian community groups and email group leaders about the study. Leaders respond and agree for researcher to attend the next group meeting?

Follow up with a phone call to the leader to arrange a meeting?

Verbally inform group members about the study. Members with diabetes agree to more information, ask for a contact phone number?

Members provide telephone number of friends/family with diabetes who had given consent to be contacted.

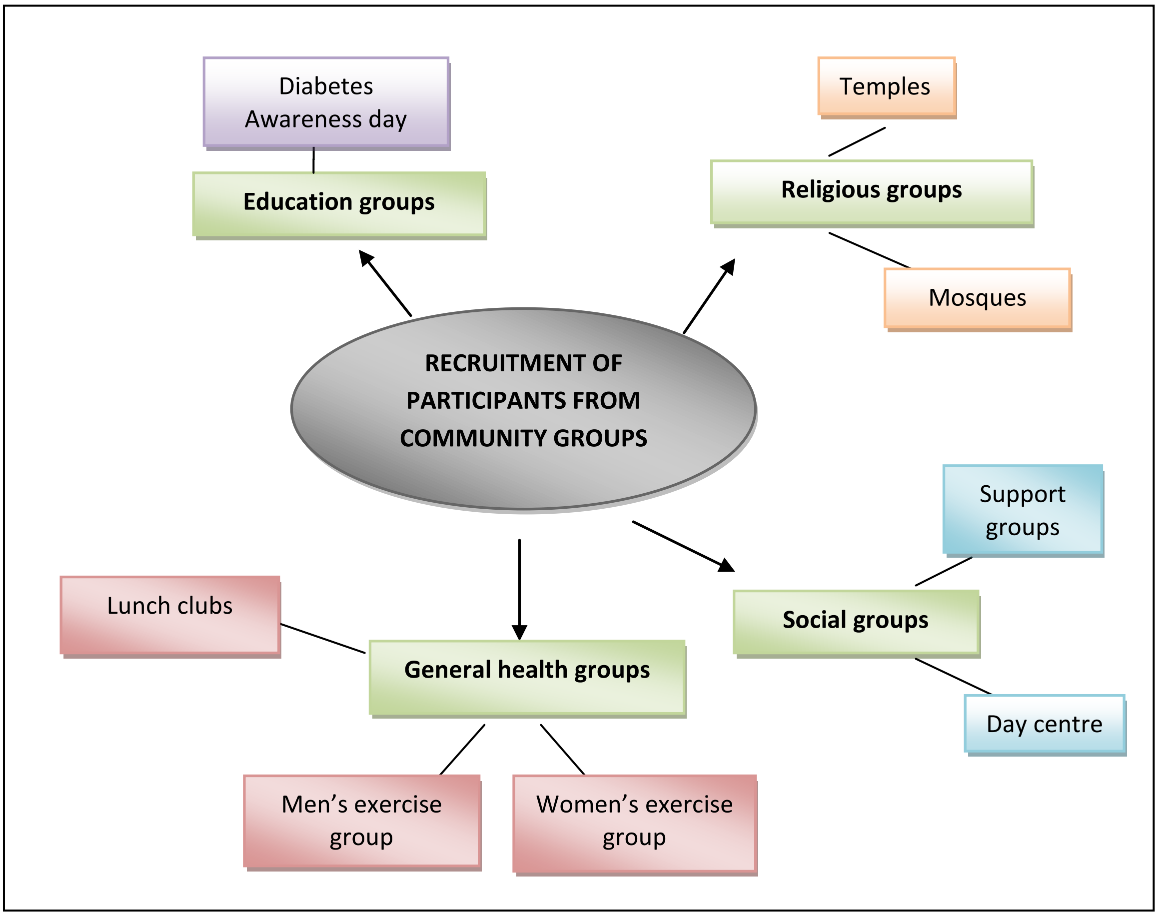
Follow up with a phone call. Consent to participant; ask for home address to post a written copy of the information sheet Interview arranged?

6.11 PHASE ll: Sampling and Recruitment for Community Groups

After reaching the target sample size of n=300, CLAHRC LTC ceased recruitment of patients in March 2011. At this point only n=30 South Asians had been recruited. Therefore, a decision was made with input from the supervisory team, to commence recruitment via community groups (Figure 6.3) to reach power and the target sample size of n=64. (See Chapter 8, Figure 8.1 for more details on the total sample recruited for this study).

It has been recommended that several methods of recruitment should be employed to maximise the chances of recruiting South Asians, (especially those who face language barriers) into research; (Lloyd et al, 2008b; Samsudeen et al, 2011).

Figure 6.3: Methods used to recruit participants from local community groups



6.12 Sampling

Purposive sampling involves selecting participants on the basis of researcher's judgement and knowledge about which population or participants will be most suitable for the phenomena under study (Ritche et al, 2003). For this study, people from the South Asian origin living in the UK with T1DM or T2DM were purposively chosen with the assumption that they were likely to have beliefs and experiences related to the research question. To ensure the data was 'rich', participants were selected from a range of South Asian sub groups (e.g. Indian, Pakistani and Bangladesh) to enhance variability.

Online search engines, for example Google were used to search for local South Asian community groups and local Primary Care Trust websites. Direct contact with local businesses run by South Asians for information on local community groups was also made. Informal contact was made with leaders of several community groups in Greater Manchester (Bury, Whalley Range, and Wilmslow) to ask if they would be willing to introduce me to their group members in order for me to inform them about the study. A copy of the participant information sheet was emailed to group leaders or personally given during the initial meeting. Once the group leader(s) agreed attendance to the next group meeting, the group members were verbally informed about the study and those interested in taking part were handed a copy of the information sheet. The groups recruited using this approach included exercise groups, day centres, a diabetes awareness day, lunch clubs and places of worship, for example, mosques and temples to recruit participants, as shown by Figure 6.3.

Preliminary analysis and discussion around the transcripts during supervision indicated that South Asian females, 40 to 60 years of age, especially from the Bangladeshi and Pakistani groups were under-represented, thus efforts were made later to specifically recruit from these groups.

6.13 Snowball sampling

A snowball technique was used whereby people, who had friends or family members with diabetes, were requested to approach them to find out if they were interested in taking part. This type of sampling strategy is appropriate when people of a particular population are often difficult to locate such as the South Asian population and other hard to reach groups (Rankin & Bhopal, 2001).

6.14 Diabetes Asian Link Workers

The Diabetes Asian Link Workers (DALW) for Tameside and Glossop Primary Care Trust were initially contacted in December 2009 to gain more information about this service. A face-to-face meeting with two of the DALWs (a Bangladeshi male, and a Hindu female) took place in mid-December 2009 to further discuss their roles and to inform them of both the CLAHRC LTC and my thesis. Thereafter, regular communication with the DALW team was maintained between January to June 2011, mainly via telephone and email, as both the DALW offered to help with recruitment. The DALWs provided information on local community groups for South Asians in Tameside and where possible introduced me to the leaders of these groups. The DALW also provided some names and contact details of participants whom they already had contacted on my behalf to inform them of this study. These participants provided consent to be contacted for more information or were interested in taking part.

6.15 Information sheet

All patients were instructed to read the information sheet (Appendix 9), particularly the procedure of the study before consenting to participate in the study. After reading the information, patients were asked to select one of the following options:

Option 1: Complete the reply slip enclosed with the information sheet and send it back to the CLAHRC LTC research team in the stamped addressed envelope provided. Once the reply slip had been received, patients were informed that a member of the research team would contact them via telephone for their home address to post the survey to and at that point arrange a suitable time and place for the interview. Once arranged, a letter with further information about the interview together with details about agreed time, date and place of the interview was sent via post to the patient's home address (Figure 6.2). The day before the interview, a telephone call was made to patients to confirm the interview, with a polite reminder to have the survey completed for collection after the interview.

Option 2: Participants who required further information or had difficulty understanding the information sheet, were instructed to telephone the CLAHRC LTC research team using the Freephone number provided on the information sheet. A member of the team provided verbal information about the study and answered any questions patients had about the study. At this point patients either agreed to take part or declined the invitation.

6.16 Reimbursement

All participants were reimbursed fifteen pounds in shopping vouchers for their time from CLAHRC LTC study: £10 for completing the postal health survey and £5 pounds for participating in the interview. The majority of patients were reimbursed face to face after the social networks interview.

6.17 Recruiting South Asian participants

Nearly all of the reply slips or telephone calls received from South Asian patients were forwarded to the author (NP) to contact and recruit for this study sample, as well as add to the recruitment figured of the wider CLAHRC LTC study (Figure 6.2).

6.18 Amendments to the Information sheet

The original participant information sheet was amended to reflect the changes to the recruitment strategy. As mentioned earlier, not all participants recruited from the community groups were required to social networks survey interview due the time and resource constraints of conducting interviews within a mixed methods design. Although it is common for the same participants to take part in both phases of a mixed methods study (Creswell, 2009), the advantage of the sequential embedded design also is that it allows for one method (e.g. qualitative) to have less data than the other (e.g. quantitative) (Creswell & Plano-Clarke, 2007), as mentioned in Chapter 4. Therefore, participants completing the postal health survey only were informed that they would receive a payment of £5 in shopping vouchers. The small number of participants required to complete both the health survey and social networks interview were paid the original amount of £15 in shopping vouchers. The amended information sheet and a letter detailing the changes were sent to the University of Manchester, chair of ethics early April 2011 (Appendix 12) and ethical approval for new recruitment strategy and information sheet was granted, via email communication at the end of April 2011 (Appendix 13).

6.19 Consent

Written informed consent was obtained from all participants taking part in the study (Appendix 13). In all cases, consent was taken prior to commencing the interview. In circumstances whereby participants were unable to read or write in English, the consent form was read aloud either in English or the preferred South Asian language by the interviewer (NP), a family member or the interpreter present at the time.

All participants were given the opportunity to ask questions about the study at the start of the interview. All participant information e.g. contact details, date of birth, condition type was stored on Microsoft Access database (password protected).

Each participant was assigned a personal identification number to ensure participant anonymity.

The already approved CLAHRC LTC informed consent was appropriate and used with community participants, as no changes were made to the actual design of this study.

6.20 Procedure for recruiting participants from the community

Participants completing the survey only were informed that they had two options in which to submit the completed survey:

Option 1: Post back the survey in the stamped address envelope provided.

Option 2: Allow me to collect the survey from a preferred location, day and time in receipt for a £5 shopping voucher and this was the option most of the participants chose.

6.21 Response rate and follow up

The response rate for the number of South Asian patients invited to take part in study from the 22 general practices (random sample) cannot be presented, as the proportion of patients that were South Asian is not known. This is because most of the practices recruited into the study did not routinely record the patient's ethnicity and it was not a specific requirement of the CLAHRC LTC to obtain this information. For this reason, no follow-up of non-respondents was possible.

6.22 The use of interpreter and family members for language support

It was anticipated that language support would need to be provided for the interviews with patients whose first language was not English, or who did not feel confident speaking English. The author (NP) whom is a fluent speaker of both Gujarati and Hindi conducted interviews with participants who requested or preferred to be interviewed in these languages. An Urdu speaking female interpreter was appointed to assist with the interviews with Urdu speaking patients and was paid £20 per hour for her time. For some interviews family members (e.g. the spouse or a dependent) were also present and provided language support during the interview. Further issues related to ethics and methodology of working with interpreters will be considered in Chapter 7.

6.23 Materials

The next section will provide information on the materials used in this study.

6.24 Postal Health Survey

The CLAHRC LTC team began the design and content of both the postal health survey and social networks interview survey prior to the planning of this study. Therefore, it was not possible to establish utility of the measures in the sample of South Asians in this study. The implications of this will be discussed in Chapter 11. The postal survey contained measures listed below (Full copy of the survey can be found in Appendix 15).

The next section will provide detail on the postal health survey, including the two measures included in the postal survey for this research, followed by the social networks survey interview.

6.25 Outcome measures added to the surveys for this thesis

After studying the draft postal health survey and the measures proposed to be included, the CLAHRC LTC team were asked to consider adding the BIPQ to enable individual’s beliefs about diabetes to be collected for this thesis. Since the BIPQ does not have any specific questions assessing fatalistic beliefs, the team were asked to also include two items measuring fatalism. Both the BIPQ and Fatalism items were used as outcome measures in the quantitative study (Figure 6.4).

The next section of this chapter will describe both these measures in detail, together with the additional measures from the postal health survey used in this thesis.

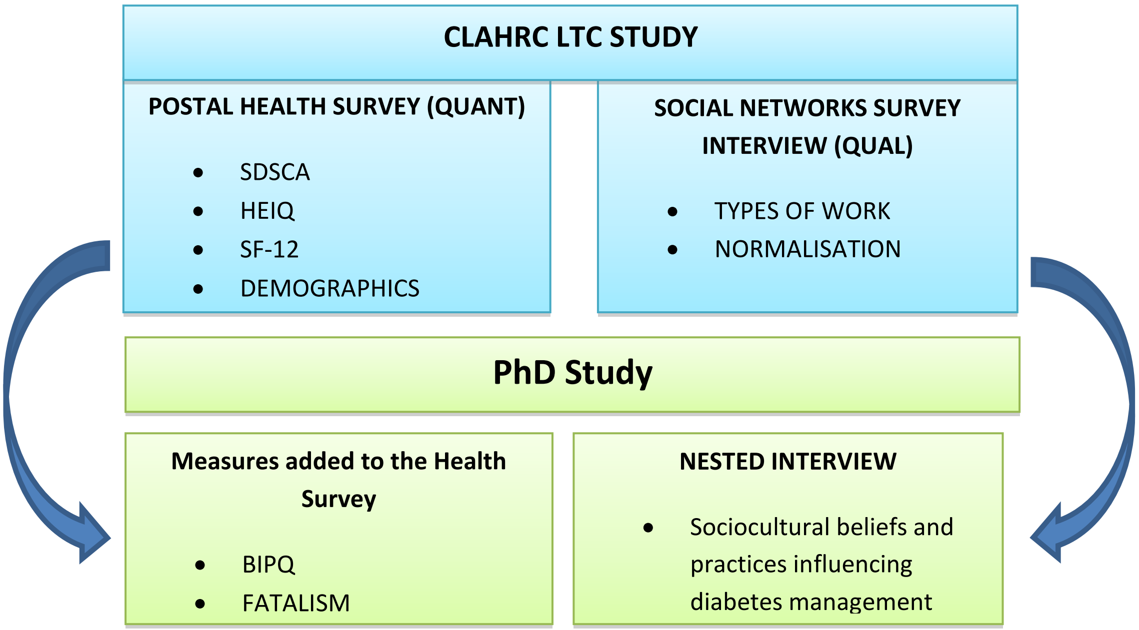
6.26 Outcome measure 1: Brief Illness Perceptions Questionnaire (BIPQ)

As mentioned in Chapter 5, the BIPQ is a 9-item measure of illness beliefs. Five items assess cognitive representations, i.e. *consequences, timeline, personal control, treatment control and identity;* two items assess emotional representation, i.e. *concerns* and *emotional response;* and one item assesses illness comprehensibility, *understanding*. All items use a zero to eleven point Likert scale. The last item on the BIPQ is an open-ended causal beliefs question on which individuals rank the three main causes of their illness. The BIPQ measure has been designed to assess individual's cognitive and emotional representation of illnesses and has proven to be a valid and reliable measure of illness perceptions in a variety of illness groups (Broadbent et al, 2006). This measure is also much shorter and quicker to complete than the original IPQ (Weinman et al, 1996), IPQ-R (Moss-Morris et al, 2002) and when administered as a part of a larger set of measures, like the CLAHRC LTC Postal Health Survey.

6.27 Outcome measure 2: Fatalism Index – items

Two items from a previous study measuring fatalistic beliefs were included alongside the BIPQ, as BIPQ itself includes no assessment of fatalistic beliefs. In their study, Lange & Petrie, (2006) used these items to explore fatalism beliefs and the diabetes illness beliefs of a multi-ethnic population in USA. Both items are rated on a scale of 1 to 5 (1: strongly disagree; 5: strongly agree). The answers to these statements in their study were averaged to create a Fatalism scale and had reliability (Cronbach's Alpha) of .77 at 6-month and .72 at 9-month measurement with a test–retest reliability of .68.

Figure 6.4: Material used from and added to the CLAHRC LTC study



6.28 Health Outcome Measures

Three health outcome measures (outlined below) and the socio-demographic variables from the CLAHRC LTC Health Survey were also used in this thesis to explore relationships between these outcome measures and beliefs about diabetes (Figure 6.4).

6.29 Health Education Impact Questionnaire (HEIQ)

The Health Education Impact Questionnaire (HEIQ) has been designed to evaluate patient education programmes (Osborne et al, 2007). This measure consists of 48 items over eight dimensions, with each dimension reflecting a different component of outcomes of health education. The authors of the HEIQ state that the items within each of the dimensions were developed and validated using a lay-centred approach to self-management as well as patient experiences of managing chronic conditions (Osborne et al, 2007). For this reason the CLAHRC LTC team, chose to use this instrument as an alternative to the traditional self-efficacy measures. Two of the eight HEIQ dimensions were selected for use in the health survey: Skill and Technique Acquisition and Self-monitoring and Insight.

6.29.1 Skill and Technique Acquisition

There are five items on this dimension which measures the knowledge-based skills and techniques (including the use of aids) that help participants manage disease-related symptoms and health problems more effectively. Each item is rated on a scale of 1 to 5 (1: strongly disagree; 5: strongly agree). High scores on this dimension indicate a high level of skills in symptom relief and techniques to manage health (Appendix 15).

6.29.2 Self-monitoring and insight

This dimension consists of seven items that measure the individuals' ability to monitor their condition, their physical and or emotional responses which lead to insight and appropriate action(s) to manage their condition. As stated above, each item is rated on a scale of 1 to 5 (1: strongly disagree; 5: strongly agree). High scores identify self-monitoring, self-management, setting reasonable limits or targets, and insight into living with a health problem (Appendix 15).

Overall, the HeiQ is a reliable measure with high construct validity, designed to evaluate outcomes from patient education and self-management interventions for people with chronic conditions (Osborne et al, 2007). The HeiQ was deemed an appropriate measure for the South Asian sample, as this measure has been designed with a range of patients with a number of chronic illnesses.

However, similar to the BIPQ, it is not clear whether any of the patients were South Asian because Osborne et al, (2007) do not refer to South Asians or have any specific information on ethnicity of the sample involved in the development of this measure. Thus, the validity of the HeiQ is yet to be established in this population.

6.30 The Summary of Diabetes Self-care activities (SDSCA)

The SDSCA (Toobert et al, 2000) is a brief questionnaire that aims to measure the frequency of diabetes-related self-management activities undertaken by patients over the preceding seven days. The measure comprises specific questions relating to general diet, exercise, foot care, smoking and blood-glucose testing and has been validated in studies with ethnic minority groups (Bean et al 2007; Sarkar et al 2006). Each item is measured by asking participants to circle how many days in the past seven days they performed a diabetes-specific behaviour. Responses range from 0 to 7, with higher scores indicating better performance of self-care activities (Appendix 15).

6.31 SF-12 Health Status

The SF-12 is a short version of the health status measure SF-36 (Ware et al, 1996) and can be used to derive two summary component scores: Physical Component Summary Score (PCS) and Mental Health Component Summary score (MCS) (Appendix 15). An analysis was undertaken within the wider CLAHRCS study of the data on SF-12 collected under the study, in part because of evidence from previous studies that PCS and MCS can be highly correlated within some patient groups. Confirmatory structural equation modelling (SEM) indicated that these two components were a good fit to the collected data, but only provided they were allowed to correlate. The correlation was high, 0.83, indicating strong colinearity between PCS and MCS. In view of this a decision was taken to include only PCS in the analysis, with patient scores on PCS being derived from the SEM analysis.

6.32 Socio-demographics

Socio-demographic data included gender, age, income, marital status, ethnicity, employment status, and highest education status. Deprived areas were identified and selected as the locations for the study. The Index of Multiple Deprivation (IMD) (based on postcodes) was then assigned to the individual participants (Appendix 15).

6.33 Measuring Social Networks

As mentioned earlier in Chapter 3, personal network mapping has been applied to studies of the family (Bott 1957), ageing (Phillipson et al, 2001), and access to services (Pescosolido, 1992; Litwin, 1997), but has not been used in relation to self-care and chronic illness (Rogers et al, 2011; Vassilev et 2011) apart from a pilot study in the Netherlands (Wensing et al, 2010). Therefore a more innovative method, developed by the CLAHRC LTC team was used to explore the role of social networks on illness and fatalistic beliefs in order to fully understand the association between the social context for diabetes management and beliefs related to diabetes.

6.34 Social networks survey interview

The second survey instrument developed by the CLAHRC LTC team included a set of questions on the participant's social network and perceived support provided by for example, relatives, and friends. As mentioned in the preceding chapters of this thesis, one of the aims of this structured survey was to find out how much diabetes-related 'work' for example, cooking healthy meals, collecting prescriptions and providing emotional support was undertaken by the support network (Rogers et al, 2011). This survey was administered face to face, using a semi-structured interview format and was audio taped. A series of questions related to management (e.g., diet, exercise, medication, emotional distress) were also included in the survey (Appendix 11 and 16). Further details about interviews will be detailed in Chapter 7.

6.35 Mapping social networks

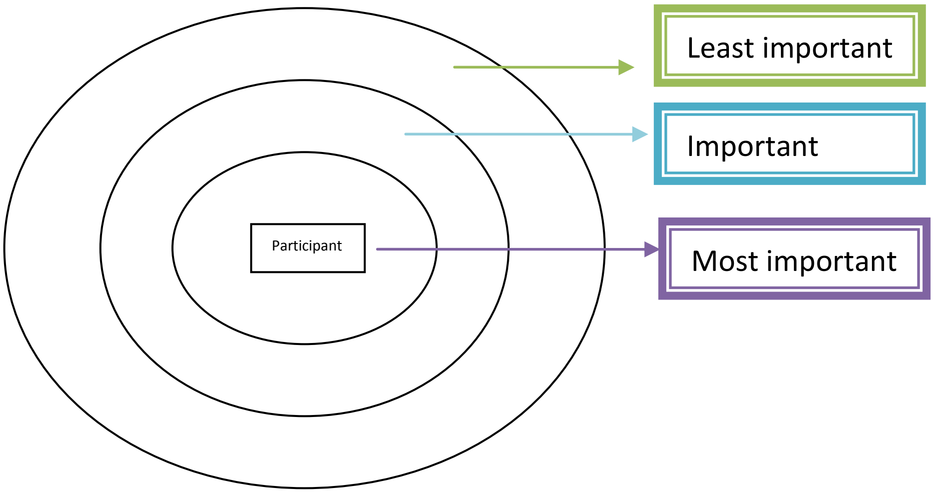
Antonucci's hierarchical approach (1986) was selected by the CLAHRC LTC to map social networks as shown by Figure 6.6. This method provides a framework for describing one's support network, whilst making no assumptions about who is or who should be a network member. This process allows people to describe their social support according to their own personal feelings of closeness (Nadoh et al, 2004).

6.36 Procedure for mapping networks

The approach to mapping network using concentric circles was developed by Antonucci (1986). The participant (also known as ego) is informed that he or she is the person in the centre of the inner circle (Figure 6.4). The inner circle symbolises those people, groups, services providers or other members (such as pets and organisations) whom the respondent considers *most important* in relation to managing their diabetes. The middle circle symbolises those they consider *less important* (compared to the first group), whilst the outer circle symbolises those who they consider *least important* (compared to the other two groups).

According to this approach, individuals are surrounded by a network of people and the network is shaped over time by personal and situational factors, available resources and demands (Ajrouch et al, 2001).

Figure 6.5: Concentric Circles (Antonucci, 1986)



6.37 Social network variables

In total there were 17 social network variables in the wider CLAHRC LTC study. However, in view of the much smaller numbers in the South Asian sample a pragmatic decision was made in discussion with the supervisory team to focus the analysis on a subset of nine social network variables. The chosen variables were deemed the best fit to answer the aims and research questions of this study.

Table 6.1 provides details of each of the nine social networks variables. (Full copy of the social network survey can be found in Appendix 16).

Table 6.1: Social network variables as defined by CLAHRC LTC

Social network variable	Description
Size of support network	A supportive network member was defined as being a member with a non-zero score on any of the work questions. The number of supportive network members was then aggregated to give a total number of supportive network members per network.
Illness work emotional	Emotional work refers to comforting when worried or anxious about everyday matters, including health, well-being. The total amount of illness specific emotional work done in a network. Scores for each network member were added up across the network to give a total illness specific emotional work score per network.
Illness work practical	Practical work refers to the work related to taking medications, regimen work, understanding symptoms, making appointments etc. Total work score summed across all network members. Practical work scores for each network member were added up across the network to give a total illness specific practical work score per network.
Frequency of contact	This variable explored the number of network members in the network who were deemed to be frequent contactors. Options for frequency of contact with support network ranged from *every day, at least once a week, once a month, every couple of months and less often.* This score was then aggregated per network to give the total number of frequent contacts in the support network.
Number of supportive females	The number of supportive females in a participant's network was calculated using gender of the network member and their work scores.
Proximate number of children	The number of children in a participant's network who were either *cohabiting with the participant, a short walk away or within a short car or bus journey* from the participant's home of residence. This variable was calculated per network and collapsed into 0,1,2,3 and 4 plus, based on total network.
Density	The extent to which network members know each other. The numbers of pairs of members who are described as not very close, close and very close.
Fragmentation	Degree to which there are distinct member subgroups within the network. To calculate measures of density and fragmentation for each network, participants were asked to rate the *perceived* strength of links between each pair of network members as either very close, close or not very close.
Mix of relationships (members in the network)	All network members identified by participants were classified as follows: *Immediate family, extended family, friend, neighbour, groups, work, medical professionals, and other professionals, pet, other*. This list was of relationship types constructed by CLAHRC LTC team. The individual types of member were then aggregated by network and re-categorised. These were then added to see the amount of different classes of network member the participant had in their network. This was based solely on the support network.

To quantify amounts of illness work undertaken by network members in individual personal networks, a 17 item questionnaire consisting of questions concerning three types of work: illness work, emotional work and everyday work was devised (Appendix 16). Participants were asked to score each member of their network according to the perceived extent to which they provided assistance with each work item, on a Likert scale ranging from 1: not at all, to 5: a lot. Details for the two 'illness work' domains used in this study (*practical and emotional work*) were presented in Chapter 3.

6.38 Normalisation

Within the social network survey interview, four items were constructed to measure normalisation; the extent to which vascular (diabetes and heart disease) conditions were disrupting everyday routines and the degree to which a patient (and their families) have adapted to living with the condition, such that its presence is accepted as a 'normal' part of their lives (Appendix 16).

6.39 Data management

All survey measure scores were analysed using the Statistical Package for Social Scientists (SPSS) version 16.0. Details of the analysis methods applied are given in Chapter 8.

Open-ended questions, for instance the causal dimension of the BIPQ was analysed using the guidelines provided by the authors of the measure (Broadbent et al, 2006). Findings of this dimension can be found in Chapter 8.

6.40 R- Statistical software

The R-Statistical software was used to calculate the measures of network density and fragmentation, as it was not possible to compute these within SPSS.

6.41 Data management for the health and social networks surveys

All scores for the social network variables were computed using the syntax devised by the CLAHRC LTC researchers responsible for analysis of the main survey. This was to ensure that all the variables derived for South Asians remained consistent with how they were calculated for the main Caucasian sample. Modifications were made to the syntax files to ensure compatibility with the SPSS data files for this study.

The next chapter provides detail on the methodology and methods for the qualitative study.

Chapter 7

Qualitative Study Methodology and Methods

7.1 Introduction

This chapter begins by detailing the aims of the qualitative study, the justification for the methodology and the theoretical stance drawn upon. This will be followed by an outline of the methods used to collect and analyse the data. The chapter briefly discusses quality in qualitative research and relates issues of quality to the methods and methodology for this study.

7.2 Research aims

The aim of the qualitative study was to explore the role of social, cultural and religious beliefs for the experience and practices of diabetes management in the South Asian population. As mentioned earlier in Chapter 4, the ‘sequential embedded design’ was used in this study. Therefore this qualitative study was embedded within the larger quantitative study, and the integration of the findings from both phases can be found in Chapter 11.

7.3 Justification for qualitative research methods

Qualitative research involves the collection, analysis and interpretation of data that are not easily reduced to numbers. The overall purpose of qualitative research is to explore and describe participants understanding and interpretation of the social phenomena under research (Richie & Lewis, 2003). Qualitative research addresses the ‘who, how, when and where’ questions; focusing on exploration and understanding of areas that are not always possible through quantitative research

(Barbour, 2008). This method of research has been commonly used to understand health behaviours of the South Asian population in the UK, as mentioned in Chapters 2 and 3.

As mentioned in Chapter 4, using qualitative methods to complement quantitative methods are emerging as a powerful approach to inform research (Bergman, 2008; Richie & Lewis, 2003; Teddlie & Tashakkori, 2003). This is particularly important in a population like South Asians whereby some people who have difficulty comprehending and communicating in English may struggle to complete a questionnaire in English (Lloyd et al, 2006). The feasibility and acceptability of using quantitative methods, such as questionnaires to explore beliefs about diabetes in the South Asian population was reviewed in Chapter 5. However, due to a small number of studies (n=5) identified, only tentative conclusions were made about the feasibility of using this method, with recommendations for future research to consider establishing utility of measures such as the BIPQ to understand beliefs about their diabetes in wider ethnic groups.

Although the social network survey interview (described in Chapter 6) contained a number of open-ended questions relevant to self-management of diabetes (and other vascular conditions), these were not specific or sensitive to the aim of this PhD. Therefore developing a separate topic guide was essential to explore the personal, social, cultural and religious context which may underpin particular beliefs about diabetes.

7.4 Theoretical stance

Qualitative research enables exploration of social phenomena, as described in the preceding section. There are a number of different theoretical strands that can be drawn on to explore social processes in qualitative research (Patton, 2002). These philosophical perspectives are ontology, epistemology, logic and teleology (Maykut & Morehouse, 1994). The two that are most relevant for this study are ontology and epistemology and these will be briefly discussed in the next section.

7.5 Ontology and Epistemology

Ontology is concerned with the nature of social reality in the world and questions *'What is there to know?'* (Guba & Lincoln, 1994). As mentioned in Chapter 5, epistemology is a branch in philosophy that is concerned with the origins and the nature of knowing and asks the question *'how can we know?'* in order to derive knowledge (Maykut & Morehouse, 1994).

The primary aim of research entails producing knowledge about the world. There are a number of different epistemological strands in social sciences research and each epistemological position has its own assumptions about knowledge. The epistemological position researchers draw on, to come to know the world, and the truth or validity of that knowledge is important. There is a long-standing history in debates over which epistemology provides 'reality' and knowledge (Patton, 2002). Many of these assumptions arise from a critique of the epistemology relevant to quantitative research: 'positivism' in favour of interpretative and social constructionist approaches to research (Green & Thorogood, 2004). For example, positivism is concerned with describing phenomena that can be observed and measured. Whereas the social constructionist perspective is interested in how people construct a meaningful reality, the reported 'truths', beliefs and explanations about the world and the consequences of these constructions for behaviour and interaction with others (Patton, 2002). In comparison, the phenomenological perspective '*is concerned with the phenomena that appear in our consciousness as we engage with the world around us*' (Willig, 2008, p.52). This approach accounts for the context in which the individual perceives phenomena at particular times. This is also known as *intentionality*, in that the self-perception is assumed to be intentional and constitutive of experience itself (Patton, 2002). Using a phenomenological approach also allows for patterns and/or categories to emerge from the interview transcripts in the study. One of the major assumptions of this stance is that *'different people can and do perceive and experience the same environment in radically different ways'* (Willig, 2008, p.53). The social constructionist approach focuses on *how* factors such as social networks, culture and religion influence beliefs about diabetes. Thus, the *meaning* and *understanding* participants attribute to managing diabetes was of most interest in this part of the study.

In contrast to the qualitative approaches concerned with making sense of the world, grounded theory is one approach which focuses on: '*the process of generating theory rather than a particular theoretical content*' (Patton, 2002, p.125) The emphasis is on the importance of generating theory grounded in the data with no prior assumptions to influence theory development (Glaser & Strauss, 1967; Strauss & Corbin, 1998). However, the grounded theory approach is not appropriate to this study, as this research had *a priori* assumptions about the study and sample that were influenced by theoretical assumptions and ideas from the literature. The *a priori* assumptions were used to develop the research questions and interview topic guide for this study, which will be discussed later in the chapter. It was not the intension of this analysis to produce a 'once-and-for-all-time' singular truth, but rather to encourage a dialogue among perspectives of the participants, to contribute towards the 'truth' (Patton, 2002).

7.6 Pragmatism

As mentioned in Chapter 4, there are a number of debates and arguments surrounding mixed methods research design. These controversies have seen the introduction of the pragmatism paradigm, which provides a plurality and justification for mixing the qualitative and quantitative paradigms and philosophies (Maxcy, 2002). Pragmatism has been defined as:

> *'A philosophy rooted in the common sense and dedicated to the transformation of culture, to the resolution of the conflicts that divides us'* (Sleeper, 1986, p.8-9).

However, Patton (2002) states:

> *'Being pragmatic allows one to eschew methodological orthodoxy in favour of methodological appropriateness as the primary criterion for judging methodological quality, recognising that different methods are appropriate for different situations'* (Patton 2002, p.72).

Both definitions inform the importance of using methods and doing ‘what works’ as the truth for the research question under investigation.

7.7 Epistemological position of this study

As mentioned above, combining different research paradigms is inevitable when using a mixed methods approach. Although the phenomenological and social constructionist approaches are both relevant to the aims of this qualitative study, it can be argued that mixing such paradigms goes against the laws for epistemology, lending further support for a ‘pragmatic’ approach.

Nonetheless, a specific qualitative methodological approach has not been used in this study; rather a more ‘generic’ approach to using qualitative methods has been taken. This is because this study was embedded within a mixed methods (sequential embedded) design in which the findings were compared against those of the quantitative study to provide a clear synthesis and completeness of results (Creswell & Plano-Clark, 2007). In other words, a part from providing a rich insight into the experiences of managing diabetes in the South Asian population, the overall purpose of the qualitative study was to also assist in explaining and interpreting the findings of the quantitative study which is deemed acceptable in a mixed methods research.

7.8 Research design

In qualitative research, there are a number of methods that can be used, for instance, observation, focus groups, case study and interviews. Observation involves systematically watching behaviour and talk in naturally occurring settings (Pope & Mays, 1995), but at a distance to avoid influencing behaviour (Flick, 2009). This method was unsuitable for the aim of this qualitative study, which was to engage in conversation with participants to explore and understand their beliefs and experiences of managing diabetes. In comparison, focus groups are becoming a popular method of data collection in qualitative research. Focus groups target specific topics with a small group of people to generate data (Flick, 2009). Unlike a semi-structured interview, listening to and engaging in conversation with a group of participants' means that the number of questions on the topic guide for a focus group may need to be limited, depending on the duration of the focus group (Flick, 2009).

Case studies are often used to explore complex issues in-depth with a small sample of participants (Pope & Mays, 1995). A case can be a situation, organisation, an incident or experience. Although this method may have addressed a range of experiences and behaviours related to diabetes management in South Asian people, it would have involved identifying a case that would be significant for the research question and studying a series of cases in order to overcome the problems related to generalisation in qualitative research.

Interviews have commonly been used to explore a wide range of illnesses in health research (Arksey & Knight, 1999). The focus is on conversation to enable participants to describe 'what it is like' to live with, experience and manage a particular condition in the community and in the context of their everyday lives (Willig, 2008).

There are three main types of interviews that can be used in qualitative research; structured, semi-structured and in-depth (Patton, 2002). Structured interviews are similar to that of a survey design, whereby the interview format follows a specified set of questions, in a specific order for each interview to generate comparable answers from each respondent. In-depth interviews are less structured, covering one or two issues in depth at the most. Semi-structured interviews are widely used to uncover and explore the meanings that underpin people's lives, routines, behaviours and feelings in relation to health (Rubin & Rubin, 1995; Arksey & Knight, 1999). Open-ended questions in semi-structured interviews are used and these questions can be defined *a priori* using the literature, documents and other interviews. In this study, one-to-one semi-structured interviews were chosen to obtain data; the reasons for selecting this method of interviewing will be discussed next. Unlike structured interviews, a semi-structured interview is more informal and allows for a topic guide with key questions and probes to guide the interview. Semi-structured interviews also help to uncover the ‘insiders’ perspective (Jensen, 1989) and enable the interviewee’s to define social phenomena from their own perspective and experiences, and the relative importance of each of them. However, semi-structured interview also requires sensitive and ethical negotiation of rapport between the interviewer and interviewee (Willig, 2008). This method of interviewing closely aligned with the social network survey interview, in which this study was embedded (Chapter 6, Figures 6.1 and 6.2). Conducting semi-structured interviews, like all interview methods, requires careful planning of the sample to recruit, sampling strategy, interview topic guide, recording and transcribing of the interviews, all of which will be discussed in the next section.

7.9 Sampling strategies in qualitative methods

There are a number of different types of sampling strategy in qualitative research. Unlike random (probability) sampling which aims to produce a statistically representative sample, a non-probability sample is the preferred method of sampling in qualitative research (Ritchie et al, 2003). However, sampling depends on the phenomena under investigation, as well as the aims and objectives of the research (Maykut & Morehouse, 1994). For example, ‘maximum variation sampling’ involves selecting persons or settings known to represent the range of phenomenon under investigation. Similarly, ‘snowball sampling’, as mentioned in Chapter 6, is where the recruitment of one or a few participants of the target population leads to a recommendation of others whom participants happen to know would be suitable for the study (Maykut & Morehouse, 1994). This type of sampling strategy is appropriate when people of a particular population are often difficult to locate, such as the South Asian population and other hard to reach groups (Rooney et al, 2011). In comparison, ‘purposive sampling’ involves selecting participants on the basis of researcher’s judgement and knowledge about which population or participants will be most suitable for the phenomena under study. This type of sampling is also known as 'judgement sampling' (Ritchie et al, 2003). A 'convenience sampling' is precisely what the name suggests. Participants are chosen according to the ease of access and lack any clear sampling strategy or criteria (Ritchie et al, 2003).

7.10 Sampling and recruitment for this study

This qualitative study used the same sampling and recruitment strategy (random and purposive/snowballing) as the one outlined for the quantitative study in Chapter 6. In a mixed methods (sequential embedded) design, it is common for the same participants to take part in both phases of the study (Creswell, 2009). Furthermore, the topic guide for this qualitative study was nested within the social networks interview survey described in Chapter 6. Therefore, the participants (n=37) who participated in the social networks interview; also participated and answered the questions on the topic guide for this study as well (see Figure 8.1, Chapter 8). Nonetheless, there are still some additional methods that are pertinent and unique to this qualitative study and will be described below.

7.11 Sample size

In qualitative research, sample size is usually small, due the intensity and richness of information obtained from interviews. A sample size over 50 is thought to be difficult to manage (Ritchie et al, 2003). The interviews in this study continued until category saturation was achieved in that interviews continued until no new themes emerged from the data (Strauss & Corbin, 1998). The notion of saturation stems from grounded theory as opposed to more general qualitative research. As mentioned earlier, this study had *a priori* ideas and did not qualify for a full-grounded theory approach.

7.12 Place of interview

Efforts were made to hold interviews at times and places convenient to the participant. The majority of interviews were conducted in participants' homes, with the exception of two participants who requested the interview to be carried out in a room of a nearby community centre. The security measures on the 'University of Manchester Lone Working Policy for students' (University of Manchester, 2007) were closely adhered to for all interviews.

7.13 Conduct of interviews

The social network survey interviews in which this qualitative study was nested were conducted from September 2010 to July 2011.

7.14 Ethical issues

As mentioned in the preceding chapter, ethical approval for this study was obtained through the CLAHRC LTC programme application (ref: 10/H1008/1, Appendix 4). The ethics covered both the quantitative and qualitative aspects of the methods used in this thesis. Research governance was obtained from Salford Primary Care Trust. The overall aim of research ethics is to protect the welfare of research participants. This section outlines the ethical considerations undertaken in this study.

7.15 Obtaining consent

It is the duty of the researcher to protect their participants from any harm or loss (Willig, 2008). A crucial part of any study is to inform participants about the purpose of the study, so that they understand the nature of the research and its likely impact on them, before consenting to take part (Willig, 2008). All participants were informed about the study in writing, and verbally both when arranging the interview date over the telephone and in person before the start of the interview. All participants were given an information sheet about the research. Participants contacted by their GP Practice were given an information sheet once they gave initial consent to be contacted (Appendix 9). Participants contacted through community groups were given an information sheet at the point of contact (Appendix 13). All participants were given a full explanation of the study and the level of commitment involved from completing the postal questionnaire to taking part in an interview. Before the start of the interview, participants were given the opportunity to ask any questions before providing them a consent form. Written consent in this study was obtained using the same consent form for the social networks survey interview, described in Chapter 6. Each point of the consent form was read and discussed with participants. It was at this point that some participants, especially the elderly or those who had difficulty with the English language revealed their concerns and suspicions about the audio file being shared with their GP and the negative impact taking part in this research could have on their diabetes care.

It is common for participants to be uncomfortable and tense in the presence of a tape recorder during a research interview (Willig, 2008). Therefore, all participants were informed of the rationale for recording and how it was going to be used, for example for transcription and analysis. It was also important to reassure and inform participants about the procedures taken to ensure anonymity and confidentiality. Ensuring that participants fully understood the research process and felt comfortable taking part was important in gaining their trust and establishing rapport (Green & Thorogood, 2004). It is not uncommon for South Asians, especially the non-English speaking and elderly, to be suspicious of researchers asking them personal questions about themselves. This can also be due to the lack of knowledge about the research process or participating in research studies (Choudhary et al, 2008; Lloyd et al, 2008b). All participants were given a copy of the consent form that was signed by the researcher, and were informed that they could withdraw or stop the interview at anytime should they wish to do so.

7.16 Confidentiality and anonymity

Distinguishing accurately between confidentiality and anonymity is important part of a research interview (Patton, 2002). Confidentiality involves not disclosing any confidential material related to the participants, whereas anonymity involves ensuring that the participant cannot be personally identified for anything he or she says in the interview without altering the meaning or value of what is being researched (Willig, 2008). This is to ensure that the participant does not endure any physical or emotional hard as a result of participation. The interview began with informal chat about the author's journey to the participant's house and the weather, which helped to establish rapport. As mentioned above, participants were anxious about the negative effects taking part in this study would have on their relationship with their GP and it was important to stress anonymity of the interview and reassure them from the outset that it would not affect their care and that no information would be disclosed to their GP. As mentioned in Chapter 6, all information regarding the participant's personal information, (e.g. contact details, date of birth, condition type) and field notes were stored on a Microsoft Access database (password protected). Each participant was also informed that they would be assigned a personal identification number to protect their identity and ensure anonymity. Confidentiality was assured at the start and the end of each interview (Appendix 10). Furthermore, all electronic copies of the interview transcripts (including those uploaded on to Atlas.ti computer software) and network diagrams were annoymised, stored and encrypted on a password protected computer and hard copies were kept in a locked filing cabinet.

7.17 The use of interpreters – family and professional

As mentioned in Chapter 1, there is a general paucity of research with South Asian people in health psychology. Equally there has been little attention and guidance given to working with an interpreter in interviews, and the influence of an interpreter on the research process in qualitative research (Vara & Patel, 2012). It is important for researchers to be aware of participant's linguistic variability (Willig,

2008) and to include non-English speakers in research to ensure the generalisability of findings and health inequalities (Plumridge et al, 2012). The level of English literacy varies considerably within the UK South Asian population. People from the South Asian women are also less likely than South Asian men to be able to communicate in English, and this is particularly true among the elderly and migrant South Asian population (Gerrish, 2008).

Some of the Pakistani and Bangladeshi participants in this study were not able to speak, read or write English very well. It was anticipated that obtaining written consent would be difficult. All Urdu speaking participants were offered the option of having a professional interpreter to be present to help overcome any language barriers during the interview, and assist with obtaining informed consent. Most of the participants welcomed and were grateful of being offered language support from a professional interpreter and also described having this facility available to them during routine GP and hospital appointments. Some participants stated that they would prefer to have a family member present to provide language support rather than an interpreter. However, involving an interpreter (hired or family member) presents methodological and ethical challenges in the conduct of research interviews (Plumridge et al, 2012). The next section describes some of the methodological challenges of working with interpreters in qualitative research.

7.18 Methodological challenges of working with interpreters

Using an interpreter in qualitative research presents the risk of not being able to capture the interviewee’s responses accurately (Vara & Patel, 2012). Methodologically, the difficulty of using interpreters in qualitative interviews is that some interpreters may find it easier to summarise the participant’s answers to the questions asked, rather than interpret each answer in verbatim. It was anticipated that the interpreters might also offer advice on alternative choice of words, which may detract from the meaning of the original question. To avoid this from happening, all interpreters were briefed by the author about the aims of the study in advance of the first interview. They were also given the opportunity to familiarise themselves with vocabulary and grammatical structure of the words used in the topic guide, and offer advice on alternative choice of words where they saw fit and without altering the meaning of the question. This approach was used with all interviews that were conducted with non-English speaking participants in this study (n=9). All interpreters were bilingual in Urdu and English. The interpreter translated each question from English to Urdu, and then translated the participant's answers for the tape. The interpreter established rapport with participants by introducing herself at the start of the interview and asked warm up questions from the topic guide. However, after the first interview with the professional interpreter and participant, the similarity between the Urdu and Hindi language (the latter spoken fluently by the author) became apparent to the author. However, for consistency and accuracy, all interviews with non-English speaking participants continued to be carried out with the presence of an interpreter. After each interview, the researcher and professional interpreter reflected on the interview (through conversation), in order to identify any problems and strategies to employ to overcome them in the subsequent interviews. Both parties also reflected on the interviewee's responses to some of the more difficult questions and the interpreter clarified any uncertainties in responses noted by the author.

7.19 Ethical issues of using interpreters

Working with interpreters raises a number of ethical issues in terms of confidentiality and anonymity. Anonymity of the participant can be difficult to ensure when working with interpreters (Edwards, 1998). An interpreter drawn from the community of the interviewees without any experience of interviewing has been suggested to impact on the ethics of the study, specifically in terms of confidentiality (Jentsch, 1998). However, the hired, professional interpreter used in this study was known to The University of Manchester, and has had vast amount of experience in undertaking interviews, both in a research and social care settings. The professional interpreter was made aware of the ethical guidelines and was given a copy of the consent form to inform and request her to adhere to the ethical issues, especially in relation to participant confidentiality and anonymity after the interview was over. It was anticipated that interviewing with an interpreter could cause fatigue for all parties, especially because of the time taken in having a triangular conversation (Hennings et al, 1996). Paying close attention to the interviewee's body language was essential to ensure they were not feeling distressed or uncomfortable.

The interpreter, in the same way as the researcher, has the potential to influence the research. In particular, it was important that the professional interpreter did not abuse the interview to encourage the interviewee to reveal more than they may be comfortable with. Interpreters may have their own interests and perspectives which they may want to explore, and the more autonomy they have, the greater the effect on the validity of the data (Vara & Patel, 2012). Establishing a trusting relationship between the three parties was fundamental to ensure credibility of the data gathered.

7.20 Development of the interview topic guide - Pilot study

The gaps identified in the initial scope of the literature informed the development of the interview guide and prompts for the pilot study that took place from April 2010 to June 2010. The aim of the pilot study was to network with people and key stakeholders in the local South Asian community, assess the feasibility of recruiting participants, and practice of conducting semi-structured interviews, both in English and Gujarati. The topic guide underwent an iterative process with modification of the questions, as interviews progressed on the pilot study.

7.21 Topic guide

For the purposes of the pilot study, demographic information on age, gender, and marital status were collected. For the main study participant's socio-demographics were derived from the postal health survey.

To ease any anxiety and make the participant feel comfortable, general questions about migration, employment and general wellbeing were asked at the start of the interview (Appendix 17 for a copy of the interview guide). The aim of the interview guide is to provide a framework for the main body of the semi-structured interview; based on the key research questions of the study (Willig, 2008). For the purposes of this study, a number of open-ended questions were derived in relation to the aims of the study. The questions were grouped into a range of relevant categories, together with probes for further elaboration or clarification where necessary.

7.22 Adaptations to the topic guide

The following changes were also made as a result of the pilot study:

1. Transcription and analysis of the pilot interviews showed that more probing was needed to go into depth on the issues raised by participants during the interview. To ensure this happened in future interviews, more prompts were included into the section on probes on the interview topic guide and key prompts were highlighted in different colours for reminders during the interview.
2. The pilot study highlighted the number of Pakistani and Bangladeshi participants who had difficulty speaking and understanding English. For the pilot study, ad hoc arrangements being made, whereby informal interpreters such as family members provided language support and the Diabetes Asian Link Workers (DALW) provided language support for the participants they helped to recruit.
3. For the main study, a professional Urdu speaking interpreter was appointed to provide language support for interviews with Pakistani or Bangladeshi participants with English language difficulties. For further details about translation and the translator see Chapter 11.

7.23 Using the interview topic guide

As mentioned earlier, initially this interview topic guide was embedded within the social networks survey interview. However, after the first three interviews it became apparent that this was not feasible due to the difficulty of distinguishing between the narratives which related to the CLAHRC LTC study and those narratives which related to the study for this thesis. Therefore, after discussing these issues with the supervisory team, it was agreed that the interview guide for this study would be best placed at the end of the social networks interview. This meant that a new audio file could be created specifically for this interview, by a clicking the 'new file' button on the digital voice recorder; making it easier to identify the interviews which were related to this study. Asking the questions at the end of the social network interview also provided more opportunity to develop further rapport with participants and probe new areas or ideas. A few warm up questions were asked at the start of the interview to establish rapport with participants. It was vital to move on to the main questions before participants became tired and reluctant to discuss deeper issues (Holloway & Wheeler, 2009). However, separate interviews using this interview topic guide were conducted with participants, who required an interpreter to help with translation during the interview. This was also due to ethical reasons such as considering for research fatigue and burden on the participant (Clark, 2008). Asking too many questions in one interview may also put burden on the interviewee, the researcher and in this case the interpreter too (Patton, 2002). The time and concentration involved in a qualitative interview has been suggested to be demanding and at times inconvenient for both the participant and interviewer (Holloway & Wheleer, 2009).

7.24 Digital voice recorder

The interviews were audio taped using the hand held Olympus dictation recorder (DS-2400). All recordings were stored and archived on a secure computer at the university and individual recordings were saved using the participant's identification number, so that they could be easily identified and linked to the transcripts. Confidential demographic information was not audio taped, but kept as paper records separately in a secure, locked, filing cabinet.

7.25 Field notes and initial analysis

Interviews have been criticised for the lack of information about the contextual factors surrounding the participant (Green & Thorogood, 2004). To overcome this, detailed field notes were recorded immediately after the interview using the digital voice recorder that was used to tape the interview, as this was a quicker way of documenting any personal reflections and impressions about the interview. This also formed a record of emerging themes and explanations used during analysis to demonstrate intellectual integrity and credibility of findings (Patton, 2002).

7.26 Transcription

Eight of the interview recordings were emailed to an external transcription service; however, the author transcribed the remaining 38 interview recordings and audio field notes verbatim. This was vital in order to immerse, and become familiar, with the contents of the interview transcripts and reflexive notes.

Interviews were transcribed as soon as possible after each interview, to highlight the issues of interest within each transcript and to enable issues to be followed up with the next participants, as part of the constant comparison approach. All transcripts were annotated by NP; together with any emotional moments during the interview (e.g. participants start to cry, or utterances) to inform the nature of the interview.

7.27 Data analysis

The search for themes is an important part of all qualitative data analysis. Some qualitative studies use deductive data analysis and have *a priori* themes based on a theory. This study used an inductive approach to data analysis to enable findings to emerge out of the data (Maykut & Morehouse, 1994). The most appropriate method of analysis for the qualitative data was considered to be thematic analysis. Thematic analysis is the foundation and widely used method for most qualitative analysis (Braun & Clarke, 2006). Thematic analysis is recursive, and involves constantly moving back and forward between the data set in order to highlight the similarities and differences across the data set (Braun & Clarke, 2006). This approach is more aligned to identifying and categorising the common themes and key accounts from the data and think about the meaning of the data in relation to research question(s) (Green & Thorogood, 2004). Furthermore, it has been deemed more acceptable to use thematic analysis in mixed methods research (Teddlie & Tashakkori, 2009) due to its flexibility and applicability to a range of epistemologies and research questions (Braun & Clarke, 2006). As mentioned earlier, in addition to identifying common themes, the purpose of the qualitative study was also to assist in explaining and interpreting the findings of the quantitative study.

7.28 Coding process and generating of themes

Reading and re-reading the transcripts many times to ensure intellectual rigour, and selecting and coding pieces of texts, led to the development of themes (Patton, 2002). Coding is a process of analysing data (Strauss & Corbin, 1990); a code being a word or a short phrase that captures a proportion of data in a transcript. All transcripts were coded and transformed into themes (Saldańa, 2009). Reflecting on how the themes interrelate and connect together was also part of the reflexive process. Codes were developed both from *a priori* deductive themes from the literature and from analysis of the data and discussion of coding. Codes were re-categorised into major themes, in relation to the aims of the qualitative research study. Memos in the form of written records, and diagrams (see thematic map, Chapter 9) were used to illustrate the relationships between themes, as well as identify any gaps in the data and points where comparisons could be made (Saldańa, 2009).

7.29 Constant comparison approach

The constant comparative approach of analysing data was formulated by Glaser & Strauss (1967) and later refined by Lincoln & Guba, (1985). This approach is commonly used in grounded theory. This technique allows for comparing different codes across transcripts, developing categorises, refining categories and exploring patterns across categories simultaneously (Lincoln & Guba, 1985). As mentioned earlier, thematic analysis uses a comparative process in which accounts from the data gathered are compared with each other to classify reoccurring or common themes in the data set. Therefore, the constant comparative approach of analysing data was also used in this study.

7.30 Deviant cases

Deviant or disconfirming cases, which did not appear to follow the emerging themes, were sought through careful analysis of the data. Some of the deviant cases emerged as a result of the differences in beliefs and management practices between migrant South Asians and UK born South Asians. These cases were further considered in the analysis, particularly for the themes – alternative medicines and travelling back home (Chapter 10). The importance of identifying deviant cases is to ensure credibility and validity of the findings (Green & Thorogood, 2005). Further details on steps taken to ensure credibility in this study will be discussed later in this chapter.

7.31 Role of supervisors

Meetings were regularly held with supervisors throughout the period of data collection and analysis to discuss the interviews and transcripts. The interview transcripts were seen by a multi-disciplinary team of supervisors with extensive experience of qualitative research (two senior female academics; one with a background in general practice, and one with a background in health services research). Supervisors were not directly involved in the analysis. The author carried out all coding. However, codes were compared with both supervisors to triangulate perspectives and to ensure that the analysis was not confined to one perspective to increase validity of the findings (Yardley, 2008). All analysis was based on the interpretation of the author. Therefore, discussing the data with supervisors was useful in verifying the revised topic guides, emerging themes, and deviant cases to ensure trustworthiness of the analysis (Henwood & Pidgeon, 1992).

7.32 Use of Atlas.ti software

All transcripts and field notes were uploaded on the computer software, Atlas.ti (2012), as mentioned earlier. The main advantage of using this software is that it enabled records to be kept of the coding. It also enabled keeping memos attached to each coded category, and then to any categories (also known as 'families' in Atlas.ti), which help to collate all re-occurring codes to show how the themes emerged from the raw data.

7.33 Quality in qualitative methods

In qualitative research there is no single set of criteria to assess the quality of research data. Rather there are a number of criteria developed by a number of different authors for judging quality (Patton, 2002). In relation to the social construction paradigm; *credibility, transferability, dependability and confirmability* are considered as markers of quality. In combination these criteria are known as 'trustworthiness' and an indication of 'rigour' (Lincoln & Guba, 1989).

7.34 Credibility

Credibility (internal validity) refers to how much the data collected accurately reflects reality of the phenomena from the perspective of the participant in the research (Lincoln & Guba, 1985). There is debate in the literature as to whether there can be one unified method of assessing quality due to the difference paradigms in qualitative research (Madill, 2000; Silverman, 2002).

It can be argued that all qualitative data analysis is based upon interpretation of the researcher (Dey, 1993). It is the researcher's responsibility to develop a meaningful and adequate account of the data (Dey, 1993). However, to ensure credibility and trustworthiness of the data, it was important to that all methodological decisions made were transparent (Dures et al, 2010). Some of these processes have already been discussed in the earlier sections of this chapter but what is remaining is the way in which, the author, her background and assumptions may have influenced this study. This is important, especially because of the author's South Asian decedent, her experience of working with people with diabetes, and pre-existing knowledge of the Indian culture, Hindu religion and beliefs surrounding diabetes in this population. In qualitative research it is not possible to exclude the researcher from data collection, interpretation and analysis, especially since qualitative research is a reflexive process (Willig, 2008). The sections on 'Credibility of the researcher' and 'Reflexivity' both provide further detail on how the author has taken into account her own assumptions and background in this study to ensure credibility of the data.

7.35 Credibility of the researcher

As mentioned in the preceding section, the credibility of the researcher is especially important in qualitative research, as it is the researcher who is the major instrument of data collection, analysis and interpretation (Patton, 2002). The possible affects the researchers own social identity (e.g. gender, ethnicity, and age) was considered on the interviewee (Willig, 2008). For example, being mindful of wearing smart but casual attire was essential in order not to be perceived as a figure of authority that was there to test them about whether or not they were managing their diabetes properly. Extreme caution with regards to the attire worn for interview was also given to ensure both arms and legs were fully covered, as in some South Asian groups, it is forbidden for women of any age to exposure these parts of the body. Although the author does not follow this tradition, it was important not to create an unsettling environment for participants or to let inappropriate attire affect rapport.

7.36 Reflexivity

Reflexivity is the process of 'reflecting critically on the self as researcher', the 'human instrument' in terms of their biases, values and personal background such as gender, culture, and socioeconomic status (Denzin & Lincoln, 1994). The literature suggests that these factors related to the researcher can shape data collection, analysis and interpretation during a study (Coffey & Atkinson, 1996). To account for this process, the researcher was aware that the social setting in which the interview took place may have an impact on the interview data. For example, some of the participants may perceive her as a member of their community, especially the Indian participants and may wish to divert conversation from the interview topic guide to a more general and social conversation about herself e.g. her place of residence, marital status, education, country of origin and so forth. Green & Thorogood (2004) state: *'The more social and cultural similarities there are between interviewer and interviewee, the more likely to assume shared meaning'* (p.86). It was important to be aware of the wider contextual issues which could impact on the interview (Green & Thorogood, 2004) in that some participants may assume the author had knowledge of the social, cultural, political and historical values related to health behaviours in the South Asian community, which may hinder them from giving more in depth answers to the questions asked during the interview. Thus, taking account of the authors 'subconscious' assumptions of how her background may shape the interview data was important in ensuring that each part of the methods in this study was rigorous, especially data collection and analysis. (See Appendix 24 for an example of the author's reflexive notes).

7.37 Triangulation

Triangulation provides a diverse way of looking at the same phenomena and adds credibility to the findings drawn from the data (Patton, 2002). There are four methods of triangulation used to validate qualitative analysis; methods triangulation; trust of sources; analyst triangulation and theory triangulation (Patton, 2002). In this qualitative study, analyst triangulation was used, through discussion of transcripts with supervisors in order to test for consistency, reduce bias and compare findings.

7.38 Dependability

Dependability is another approach to assessing the ‘reliability’ of findings through a process of auditing. Ideally, once data has been analysed, the interpretations and findings of the study could be returned to the participants to determine accuracy of the data. However, due to time constraints and language issues this was not feasible. To ensure dependability, all stages of the study, from recruitment to data collection to analysis of transcripts were carried out through the process of ‘peer debriefing’ (Lincoln & Guba, 1985). In peer debriefing the researcher and an impartial peer(s), discuss the data, highlight any personal biases the researcher may have in order to minimise bias within the data and increase the trustworthiness of the data (Guba & Lincoln, 1989). Guba and Lincoln (1989) suggest that this process: ‘provides an opportunity to search out and try the next methodological steps in an emergent design within a confidential and professional relationship’ (p.237). In this study, peer debriefing was achieved through regular meetings with supervisors in this study.

Providing plausible and coherent explanations of the phenomena under investigation to ensure reliability is most often encouraged in qualitative research (Mays & Pope, 1995). Rogers et al (1997) dispute the idea of replicating a qualitative study, as doing so would go against the aims of this methodology, which as outlined earlier is to respond to social phenomena. They argue that qualitative research should be flexible not standardised.

7.39 Confirmability

Confirmability refers to the degree to which results could be confirmed or corroborated by others (Patton, 2002). There are a number of strategies for enhancing confirmability for example; the research can document the procedures for checking and rechecking the data throughout the study. In this study this was addressed through adopting an iterative process to data collection analysis, peer-debriefing and identifying deviant cases, as mentioned earlier. Despite these strategies, the researcher ultimately influences the data collected. Data collected by someone else may be different because the researcher through personal reflexivity has the advantage of examining their role in the research to promote 'validity' (Willig, 2008).

7.40 Transferability

Transferability refers to the extent to which the findings are transferable to other settings and populations (Green and Thorogood, 2004). It is well known that the findings of a qualitative study cannot be generalised to the wider population (Patton, 2004). However, the findings from this study may assist to better the experience, understanding and beliefs (e.g. culture and/or religion) in South Asian people with diabetes. The findings may also be of relevance to better understanding illness beliefs in other conditions such as heart or kidney disease in the South Asians. In addition, the method of recruitment described in this study certainly may also be useful in future research undertaken with South Asians. For example, purposive and snowball sampling appear to be more effective, efficient and acceptable within the community compared to invitation letters from general practices (random sampling). The differences in ethnicity within the sample may also be useful in future health research exploring the similarities and differences of

South Asian population, as well as contribute to the debate on the heterogeneity of this target population.

7.41 Chapter Summary

This chapter has outlined and justified the reasons for using a qualitative approach to meet the research aim to further explore beliefs about diabetes in the South Asian population. The methods used to collect and analyse data were also described. The findings of the qualitative study will be presented in Chapters 9 and 10.

Chapter 8

Results of the quantitative study

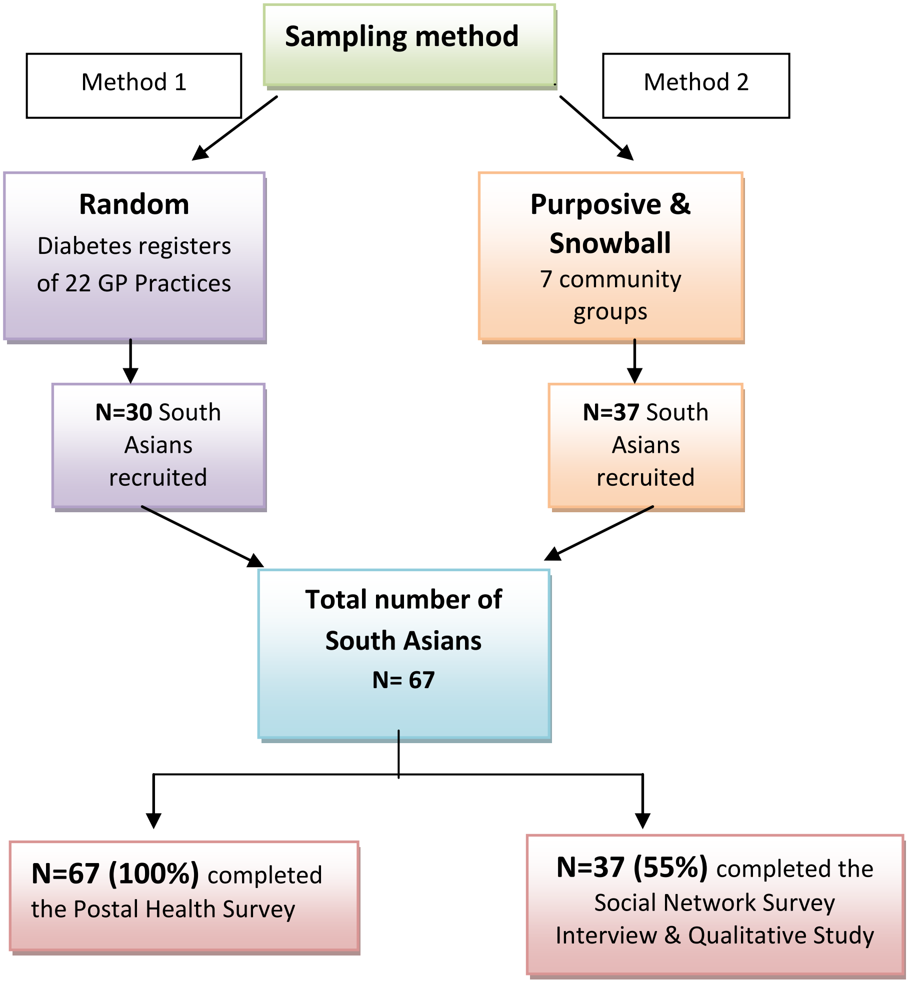
8.1 Introduction

This chapter will begin by giving an overview of the sample recruited using both random and purposive strategies. It will outline how missing data values on the variables were handled, together with the tests of normal distribution for the BIPQ and fatalism items. This will be followed by a description of the demographic characteristics of the South Asian participants. Before providing sub-ethnic group comparisons, the analysis will investigate the social network (independent) variables significantly associated with illness and fatalistic beliefs (dependent variables). The analysis will also explore which of the social network variables predict diabetes-related illness and fatalistic beliefs in the South Asian population.

8.2 Sampling and sample size

As mentioned in Chapter 6, two methods of sampling were used to recruit participants into the quantitative and qualitative studies. Figure 8.1 shows the results of the sampling strategies used and the flow of participants in the study. In total, 30 South Asians were recruited through GP practices (random sampling) and 37 South Asians were recruited through accessing local community groups, using both purposive and snowball sampling. A total of 67 South Asian participants were recruited and completed the postal health survey. Ideally all 67 participants should have also completed the social networks interview. However, due to time and resource constraints, only 37 participants (30 from the random sample and 7 from the community sample) completed the social networks interview. Participants who completed the social networks survey interview also participated in the qualitative study.

Figure 8.1: Sampling method and size



8.3 Analysis plan

Before commencing the analysis of the postal health survey and social networks survey interview, a pre-specified plan was written to guide the analysis of the quantitative study. Due to the small sample size of participants completing the social networks survey interview, it was important to pre-plan and restrict the number of analyses conducted.

The analysis conducted was:

- Examination of missing data;
- Normality of distributions;
- Outlier detection and management
- Descriptive statistics for South Asians and comparison of random and community samples;
- Social networks and health outcome factors associated with illness and fatalistic beliefs for South Asians;

A 5% alpha level was used throughout for assessing the significance of statistical inference tests. No adjustment, such as the Bonferroni method, was used to adjust for the application of multiple significance tests. This study was exploratory in nature and did not have a pre-specified set of key hypotheses for final decision-making and the recommendations of Bender and Lange (2001) of not adjusting in this type of study were followed. For example, the large number of tests undertaken and the lack of a clear structure to the multiple testing would make it difficult, if not impossible, to select an appropriate method of multiple test adjustment. The detrimental consequences of the increased risk of making Type 2 errors (of failing to detect a true effect) would arguable cancel out any benefits from reduced numbers of Type 1 errors. Thus, all the significant results in this thesis have to be treated as exploratory or provisional results, requiring validation in further confirmatory studies.

8.4 Data cleaning

A substantial amount of time was spent screening and cleaning the dataset for data-entry errors. This was particularly important as the majority of data for the random South Asian sample (n=30) was entered by an external agency; hired as part of the wider project. The data were then screened and cleaned for accuracy by two research staff working on the main study. All the data for the South Asian sample recruited through the community were entered on to the existing data entry templates for the postal health survey and social networks survey by the author. All variables were screened for errors using frequency analysis to identify out-of-range and missing data values. These were checked, and corrected where appropriate, by referring back to the original questionnaires.

8.5 Treatment of missing data for the dependant variables (BIPQ and Fatalism)

The BIPQ and Fatalism items were main outcome measures in this study. Only very small numbers of participants from either ethnic group had data missing on any of the items: the highest rate of missing data was three cases, and for eight of the ten items data was missing for no more than one case. Several simulation studies investigating the impact of both random and non-random patterns of missing data show that for a sample size (n=50) similar to the present study and 10% missing data, simple deletion of cases with missing values provides estimates of regression coefficients and power to detect a significance association close to that of any method for imputing missing values (Kromrey & Hine, 1994; Pastor, 2003 & Brockmeier et al, 2003). In this study, the rates of missing data for these items were so low that imputation would not gain appreciable precision or power, however it would artificially inflate numbers of degrees of freedom thus increasing the Type 1 error risk, and for these reasons it was not applied and instead cases with missing values were excluded (on a per item basis) from analysis. However, imputation was used with independent variables with small numbers of missing values, for reasons explained below. Details on the methods used to detect and address outliers are given later in this chapter.

Table 8.1: Percentages of missing data on the BIPQ and Fatalism items

BIPQ dimensions	Items	South Asians % Missing
Consequences	How much does your illness affect your life?	1
Timeline	How long do you think your illness will continue?	2
Personal control	How much control do you feel you have over your illness?	0
Treatment control	How much do you think your treatment can help your illness?	1
Identity	How much do you experience symptoms from your illness?	1
Concern	How concerned are you about your illness?	1
Understanding	How well do you feel you understand your illness?	0
Emotional response	How much does your illness affect you emotionally?	0
Fatalism items		
Chance or fate	My illness is largely dependent on chance or fate?	3
Little personally do to improve health status	There is very little I can do to personally improve my health status?	1

8.6 Treatment of missing data for the independent variables

Rates of missing data varied considerably across the independent variables (Table 8.2). The largest rate was 24% for highest qualification, although rates for most variables were much lower than this. Missing values were imputed for all independent variables, even those with low rates. The independent variables could potentially (depending upon strength of associations with each dependent variable) be used in combination as predictors in multiple regression analysis, where the accumulated number of cases with missing values might be great enough to substantially reduce precision. To avoid this risk, missing values were imputed for all independent variables.

For consistency with the broader CLAHRC LTC study, the same approach was adopted to imputation with the South Asian sample. Imputation of missing data was undertaken using a combination of item mean/mode imputation and regression imputation. To be conservative, a 5% threshold was adopted (Tabachnick & Fidell, 2007), whereby for simplicity mean imputation was used where data was missing for <5% of cases and regression imputation was used if missing data was >5%.

All variable imputation was carried out after seeking guidance and syntax from the research staff on the main CLAHRC study, in order to maintain consistency of methods between the two studies.

Table 8.2 Percentages of missing data on the independent variables

Independent Variables	Missing data N (%) South Asians	Method used to impute missing data
Rent or own	4 (3)	Imputed mode
Income	27 (14)	Regression predictions *(variables for regression imputation)* • Ethnicity • Accommodation status • Age • Highest qualification • IMD • Employee or self-employed • Employment status • Partners employment status
Age	2 (1)	Imputed means
Married	2 (1)	Imputed mode
Highest Qualification	16 (24)	Regression predictions *(variables for regression imputation)* • Ethnicity • Gender • IMD • Age • Accommodation status • Employment status • Partners employment status
HEIQ	4(3)	Imputed means
COPE	0	
SDSCA	13(19)	Missing Value Analysis, regression imputation
SF-12	12 (18)	Missing Value Analysis, regression imputation

Table 8.3 provides a brief description of the social network variables included in the analysis for the quantitative study. A full version of this table was presented earlier and can be found in the quantitative methods Chapter 6 (Table 6.1).

Table 8.3: A brief description of the social network variables

Social network variable	Brief Description
Size of support network	The total number of network members.
Illness work emotional	Refers to the work related to taking medications, regimen work, understanding symptoms, making appointments and so forth.
Illness work practical	Refers to the work related to comforting when worried or anxious about everyday matters, including health, well-being.
Frequency of contact	Options for frequency of contact with support network ranged from every day to less often.
Number of females	The number of females in a participant's network.
Proximate number of children	The number of children in a network who were either cohabiting with the participant, a short walk away or within a short car or bus journey from where the participant's home of residence.
Density	The extent to which network members know each other.
Fragmentation	Degree of overlap between member subgroups within networks.
Types of relationships	Selected and derived from a wide list of relationships types constructed by the CLAHRC LTC study.

8.7 Treatment of missing data for emotional and practical work items

To generate a score for each type of work (i.e. emotional and practical work), scores were summed across participant ratings of each member of their network on the items within each work domain (emotional 4 items; practical 12 items). This produced a set of work domain scores for each network member. Because the number of items differed between domains, to be comparable these scores were then all rescaled to a range of 0 to 10. For each participant, a total work score for each of the three domains was then computed by adding the scores across all the members of their network.

8.8 Tests for Normality

The fit of the BIPQ and fatalism scores to a normal distribution was assessed using the Kolmogorov-Smirnov statistic. A non-significant result ($p > 0.05$) indicates that the distribution of data values does not significantly deviate from that expected if the underlying population has a normal distribution (Pallant, 2010). This is quite common in smaller samples. However, all the items in this study were significant ($p < 0.05$), therefore the scores of the BIPQ and fatalism items could not be assumed to be normally distributed, as shown by Table 8.4 and example Figures 8.1 and 8.2.

For ease of comparison with previous studies in the literature using the BIPQ and fatalism items, both the mean and median scores were reported. Although both the mean and the median have been suggested to be good measures of central tendency, the mean is a popular figure and commonly used for describing the characteristics of central tendency (Gibbons & Chakraborti, 2011). However, the median has been suggested to be a better indicator of central tendency in studies with small sample sizes using non-parametric tests (Friedlin & Gastwirth, 2000). The median is also less sensitive than the mean to extreme scores. Following on from the previous studies in the literature (e.g. Bean et al, 2007; Kart et al, 2007) means will be reported rather than the median in the text, as means are more sensitive to group differences when scales have a limited number of possible responses.

Table 8.4: Tests of Normality for BIPQ and Fatalism Score

BIPQ dimensions	**N**	**MEAN (SD)**	**Skewness**	**Kurtosis**	**Kolmorgorov-Smirnov TEST OF NORMALITY**		
					Statistic	**df**	**p-value**
Consequences	66	4.87 (3.07)	-.212	-.922	.124	61	.021
Timeline	65	8.87 (2.24)	-2.16	4.30	.398	61	.000
Personal control	67	4.14 (2.72)	.192	-.583	.131	61	.011
Treatment control	66	2.85 (2.42)	.608	-.060	.127	61	.016
Identity	66	5.43 (2.87)	-.392	-.610	.118	61	.035
Concern	66	6.98 (1.47)	-1.03	.115	.203	61	.000
Understanding	67	1.98 (2.01)	1.11	1.12	.196	61	.000
Emotional response	67	5.95 (3.04)	-.577	-.628	.146	61	.003
Fatalism items							
Chance or fate	64	3.43 (1.47)	-.493	-1.12	.192	61	.000
Little personally do to improve health status	66	3.00 (1.47)	-.097	-1.38	.178	61	.000

Figure 8.2: Tests of Normality for BIPQ Consequences dimension

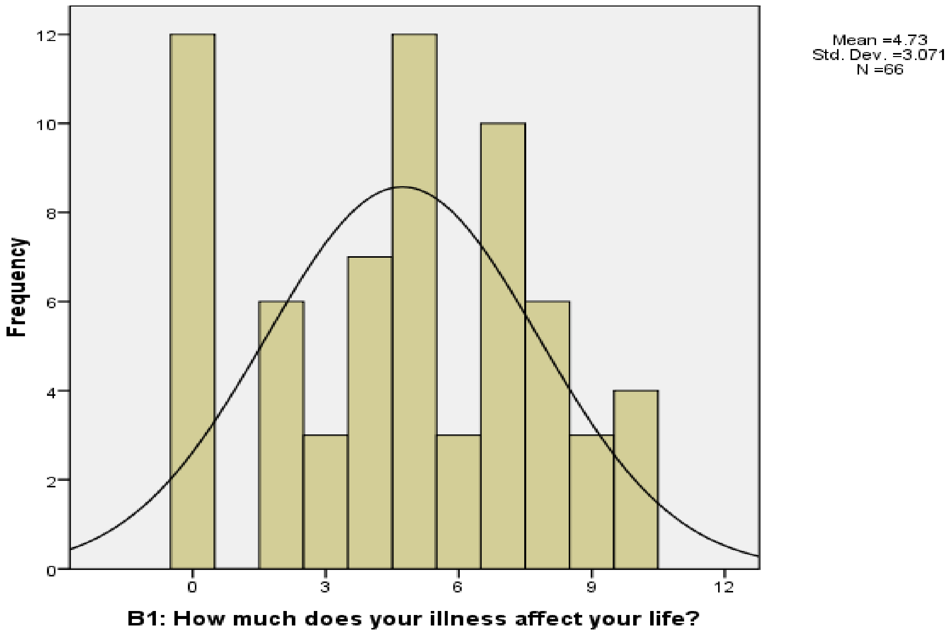


Figure 8.3: Test of Normality for Fatalism

8.9 Statistical Analysis

Due to the non-normal distributions of BIPQ and fatalism scores and the small sample size (n=67), statistical significance was based on use of non-parametric tests. Spearman correlations were used to obtain estimates of the strength of relationships between the dependent variables (BIPQ and fatalism items) and continuous or ordinal independent variables; Kruskal-Wallis non-parametric analysis of variance to examine relationships with categorical independent variables; and Mann-Whitney U-tests to compare between sub-groups (e.g. Indian and Pakistani). In one case where a non-parametric equivalent was not available, parametric tests were used (e.g. multiple regressions).

8.10 Outlier detection and management

Outliers are the presence of data points that deviate markedly from others (Aguinis et al, 2013). Outliers can represent an error in the dataset and it is possible for outliers to arise from the population being sample through random chance. There is as much controversy over what constitutes an outlier as whether to remove them or not. There are a number of tests that can be used to detect outliers; however Aguinis et al (2013) argue that there are no clear guidelines or techniques about how to deal with outliers once they have been found. In their recent review of the literature on outliers, Aguinis et al (2013) found 14 outlier definitions, 39 identification techniques and 20 different ways of handling outliers. There is also a debate over whether or not outliers should be removed or not. The removal of extreme scores has been suggested to distort the data in that data are more likely to be representative of the population as a whole if outliers are not removed (Orr et al, 1991). However, conceptually there is a strong argument for screening and removal of outliers in order to reduce errors of inference and conclusions. As mentioned earlier, the data in this study was not normally distributed, therefore non-parametric tests were used to analyse the data. It is important to note that non-parametric tests use a ranking procedure to derive parameter estimates from the data, as opposed to the raw values of the observations, thus this procedure has been known to reduce the influence of outliers (Gideon & Lewis, 1993). Furthermore, the aim of this analysis was to depict associations between data, not to imply causality between the variables. Thus, the significant associations between the variables have to be treated with caution. For this reason, outliers were checked for using bivariate Mahalanobis distance for variable pairs where p value score was .1 or less to allow for the relationship becoming significant after removal of outliers (Tabachnick & Fidell, 2007). It is important to point out that this was a test of the sensitivity of the results to outliers. To be conservative, rather than using .001 as recommended by Tabachnick & Fidell (2007) (p.68), .01 levels was used with the appropriate critical value used was 9.21 with 2 degree of freedom (for Tables 8.8 and 8.10). It was not possible to use multivariate Mahalanobis distance to check for outliers as this study used bivariate correlations to explore the relationship between the BIPQ, fatalism, social network and demographics variables.

8.11 Descriptive Statistics for South Asians - Demographic Characteristics

A total of 67 South Asian participants completed the postal health survey and 37 of these completed the social networks survey interview. The demographics data presented in Table 8.5 overleaf shows that 43 of the participants were Indian (64%), 21 (31%) were Pakistani, two were Bangladeshi (3%) and 1 was Nepalese (2%). The sample was comprised of 36 males (54%) and 31 females (46%). The age of participants ranged from 32 to 84 years old, with a mean age of 61 years (SD=12.5). Fifty-nine participants had T2DM (88%); 56 (84%) had additional conditions. Twenty-eight (42%) of the participants were retired, and 19 had no qualifications (28%). Household income ranged between £5000 and over £50,000 but the most common income was in the range £10,400-£15,599 per annum. Fifty four were married or in a civil partnership (81%), and 61 owned the property they lived in (91%), and 35 (95%) of the 37 participants who completed the social networks survey were cohabiting with one or more persons. The average Index of Multiple Deprivation (IMD) score was 35.

Despite the heterogeneity of the sample in terms of the demographic characteristics, the sample size was too small to explore whether the relationship between social networks and illness beliefs differed between the sub-ethnic South Asian groups. For the purposes of exploring the relationship between the BIPQ, fatalism and social networks variables, all the sub-ethnic groups (Indian n=43; Pakistani, n=21; Bangladeshi, n=2; Nepalese, n=1) were combined. However, differences between the two larger ethnic groups (Indian and Pakistani) in the sample are explored towards the end of this chapter.

The overall sample also combines people from the random and the community samples. The community sample was specifically targeted to increase the overall representativeness of the total sample (for example with respect to area deprivation) and was successful in this respect. As mentioned earlier in Chapter 6, it is common to use a combination of methods to recruit South Asians, (especially those who face language barriers) into research (Lloyd et al, 2008b; Samsudeen et al, 2011). Pooling the two groups thus improves the sample's coverage of the full population and can be expected to thereby improve estimates of overall relationships between measured factors.

Table 8.5 Demographic characteristics for South Asians

Demographic Characteristics		**South Asians (n)**	**%**
Total sample		**67**	**100**
Gender	Male	36	54
	Female	31	46
Age (mean = 61.0, SD= 12.5)			
	32-40	6	9
	41-60	22	33
	61-80	37	55
	80-84	2	3
Employment	In paid work	18	27
	Retired	28	42
	Other	21	31
Marital status	Married or in civil partnership	54	81
	Other	13	19
South Asian ethnic groups	Indian	43	64
	Pakistani	21	31
	Bangladeshi	2	3
	Other (Nepalese)	1	2
Accommodation	Own	61	91
	Rent	6	9
Index of Multiple Deprivation (M=35, SD=17.0)			
Number of cohabitants *	No cohabitants	2	5
	One of more cohabitant	35	95
Highest Qualification	No qualifications	19	28
	1 to 4 0 Levels	7	10
	5 or more O Levels	6	9
	A Levels	2	3
	Other qualifications	5	8
	NVQ	6	9
	Professional Qualifications	7	10
	First degree	10	15
	Higher Degree	5	8
Income groups (M=3.69, SD = 1.68)	£5,199	3	5
	£5,200-£10,399	12	18
	£10,400-£15,599	22	33
	£15,600-£20,799	15	22
	£20,800-£25,999	5	8
	£26,000-£31,999	4	6
	£32,000-£51,999	3	5
	£52,000 or more	3	5
Total no of conditions	One or more condition	11	16
	Two or more conditions	56	84
Duration of diabetes	0 to 5 years	14	21
	5 to 10 year	19	28
	10 years +	34	51
Diabetes Type	T1DM	8	12
	T2DM	59	88

***Social networks survey only**

8.12 Social Networks

The means and standard deviations of the social network interview survey and postal health survey variables are presented in Table 8.6.

On average each participant had 7 to 8 members in their network (mean=7.59, SD=2.73), of which three were females (mean=3.11, SD=1.71). The 'average' network consisted of:

- Four different types of relationships (mix of agents) (mean=3.78, SD=1.10);
- Two children (mean=2.08, SD=1.38) per network;
- Regular frequent contact with five members of their network (mean=5.16, SD= 2.47).

In comparison to practical work (mean=16.6, SD=9.8), a higher amount of emotional work (mean=30.0, SD=14.4) was undertaken by network members. (See Appendix 19 for an example of a completed social network diagram).

8.13 Health outcomes

On average South Asians reported being able to cope and normalise diabetes as part of their life (mean =72.9, SD= 16.1). They reported high levels of self-efficacy (mean-=5.80, SD=. 855), health status (mean = 50.1, SD=9.5) and self-care of diabetes (mean=28.2, SD=9.19).

Table 8.6 Mean and median Social Network and Health Outcomes Measure scores for South Asians

Social Network Factors	N	MEAN (SD)	MIN	25th Percentile	Med	75th Percentile	MAX
Types of relationships (mix of agents)	37	3.78 (1.10)	2	3	4	4.5	7
Size of network	37	7.59 (2.73)	3	5	7	9.5	14
Fragmentation	37	.44 (.38)	.85	.05	.40	.81	9
Density	37	.68 (.22)	.22	.5	.66	.9	1
Proximate children	37	2.08 (1.38)	0	.50	2	3	4
Number of frequent contacts	37	5.16 (2.47)	1	3	5	6.5	11
Number of females in network	37	3.11 (1.71)	0	2	3	4.5	6
Illness work							
Practical work	37	16.6 (9.8)	2.78	10	15	20.9	43.3
Emotional work	37	30.0 (14.4)	1.67	18	29	39	65.0
Health outcome variables							
Normalisation (COPE)	67	72.9 (16.1)	18.7	62	93	999	93.7
SDSCA (scaled)	67	28.2 (9.19)	9	20	29	35	45
SF-12 (physical scale)	67	50.1 (9.5)	32.4	42	50	58	68.4
HEIQ (self-efficacy, scaled)	67	5.80 (.855)	2	5.8	6	6	7.60

8.14 Descriptive statistics for BIPQ and Fatalism items for South Asians

As mentioned in the preceding chapter, beliefs about diabetes were assessed using the BIPQ (Broadbent et al, 2006) and the fatalism Index (Lange & Petite, 2006). Table 8.7 presents the data on these measures. All the BIPQ items are scored out of a maximum of 10.

Participants reported a mean score of 4.73 (SD=3.07) for the consequences of their diabetes, most believed that their diabetes would last forever, (mean = 8.91, SD=2.19), but many reported low levels of personal control (mean=4.44, SD=2.75) or treatment control (mean=2.89, SD=2.43), and poor understanding of their diabetes (mean =2.12, SD=2.21).

Furthermore, participants were relatively concerned about their diabetes (mean=6.77, SD=2.92), and experienced some emotional distress (mean =5.73, SD=3.09).

The fatalism scores ranged from 1 indicating least fatalistic beliefs to 5, indicating most fatalistic beliefs. Participants tended to believe that their diabetes was largely dependent on chance or fate, mean = 3.36 (SD=1.48), with a lack of personal control to improve their diabetes, mean = 2.98 (SD=1.45).

8.15 Floor and ceiling effects

Floor effects occur when participants' score at the bottom of the possible range of scores on a questionnaire, while ceiling effects occur when participants perform at the top of the possible range of scores on a questionnaire (Russo, 2003). Floor or ceiling effects are considered to be present if more than 15% of respondents achieved the lowest or highest possible score on a scale (Terwee, 2007). Table 8.7 shows that 30% of participants scored at the very bottom end of the BIPQ scale for *understanding* of diabetes, while some participants scored at the top end of the scale for *concern (24%)* and *timeline (68.7%)*. The presence of floor or ceiling effects may reduce the reliability of the score because participants with the lowest or highest possible score cannot be distinguished from each other (Terwee, 2007). The tests for normality also showed that all the items scores of the BIPQ were not assumed to be normally distributed and were skewed. Thus, the recommendations for using nonparametric tests for data analysis (that are less sensitive to skewed or ceiling or floor effects) were used to detect statistical significance (Rorden et al, 2007).

The implications of floor and ceiling effects on the BIPQ items will be discussed in Chapter 11.

Table 8.7 Mean and median BIPQ and Fatalism scores for South Asians

BIPQ	Item	N	MEAN (SD)	MIN	% Scoring MIN	25th Percentile	Med	75th Percentile	MAX	% Scoring MAX
Consequences	How much does your illness affect your life?	66	4.73 (3.07)	0	18	2	5	7	10	6
Timeline	How long do you think your illness will continue?	65	8.91 (2.19)	0	1.5	9	10	10	10	68.7
Personal control	How much control do you feel you have over your illness?	67	4.22 (2.75)	0	13.4	2	5	6	10	4.5
Treatment control	How much do you think your treatment can help your illness?	66	2.89 (2.43)	0	24	.75	3	5	10	1.5
Identity	How much do you experience symptoms from your illness?	66	5.35 (2.92)	0	10.4	3.75	5	8.00	10	6
Concern	How concerned are you about your illness?	66	6.77 (3.12)	0	9	5	8	9.25	10	24
Understanding	How well do you feel you understand your illness?	67	2.12 (2.21)	0	30	0	2	3	9	3
Emotional response	How much does your illness affect you emotionally?	67	5.73 (3.09)	0	10.4	3	6	8	10	10.4
Fatalism items										
Fatalism 1	My illness is largely dependent on chance or fate?	64	3.36 (1.48)	1	18	2	4	5	5	30
Fatalism 2	There is very little I can do to personally improve my health status?	66	2.98 (1.45)	1	24	1.75	3	4.00	5	18

8.16 Causal dimension of the BIPQ

The authors of the BIPQ measure (Broadbent et al 2006) suggest that the analysis of the causal dimension of the BIPQ depends on the aims of one's study and provide various options for analysing this dimension as listed below:

1. Analysis of first-rank only;
2. Analysis of all three ranks;
3. Categorise answers into groups that fit the particular illness, using either risk factors that cannot change (e.g. hereditary) or risk factors that can be changed (e.g. diet, lack of exercise);
4. For large sample data use the appropriate range of causal categories. Data can be coded in these categories and collapsed into smaller clusters of causal beliefs.

All three ranks of the open-ended question of the causal dimensions on the BIPQ were analysed using option 2 from the above list. The most commonly stated causes ranked first were: Genetics, Diet and Stress. A table detailing the results of all three ranks of the causal dimension can be found in Appendix 18.

8.17 Comparison of BIPQ and Fatalism items between the random and community samples

The community sample of South Asians was purposely selected to increase the representativeness of the overall sample with respect to the local South Asian community. For this reason some demographic differences between this subgroup and South Asians from the random sample are to be expected. These are not examined here but a subgroup breakdown is given in Appendix 20. Overall, the demographic comparisons showed that, in comparison to the random sample, the community sample of South Asian participants tended to be older, retired, living in more deprived areas of Greater Manchester and to have had diabetes for 10 years or more.

There is also the possibility that the different method of data collection used for the community sample (i.e. face-to-face interviews) could have influenced how people responded to the BIPQ and Fatalism items; for example, the method may have led to people being more likely to give what they perceived to be more ‘socially desirable’ responses. Mann-Whitney U tests were performed to compare how the community and random sub-samples of South Asians scored on the BIPQ and Fatalism items. The results showed that the two sub-samples did not differ significantly on mean scores except on one BIPQ item: personal control (p<0.05), whereby the random sample reported overall greater personal control of their diabetes (a mean of 4.96 compared to 3.62 for the community sample -see Appendix 20).

In summary: This section has presented the descriptive statistics for the South Asian sample. This comprised demographic characteristics, means and standard deviations for both the postal health survey and social networks survey interview including the descriptive statistics for the BIPQ and Fatalism items. The causal dimension of the BIPQ consisted of three open-ended ranks, and the first rank presented in this chapter found that, genetics, diet and stress were most commonly stated as causes of diabetes. Finally comparison of the analysis of the two samples, random and community, on the BIPQ and fatalism items found that the two samples scored very similarly on all items accept for personal control of their diabetes.

The next section addresses research question two and examines the association between the demographic variables, BIPQ and fatalism items.

8.18 Demographic and social network factors associated with BIPQ and Fatalism

The following analysis is in relation to research question two:

What demographic and social network factors are associated with illness and fatalism beliefs in the South Asian sample?

8.19 BIPQ, Fatalism, Social Networks and Demographics – continuous variables

To begin, a Spearman’s correlation was conducted to test for significant associations between the dependent variables (BIPQ and fatalism items), and continuous demographic and social network variables. Table 8.8 summarises the associations and shows that beliefs in relation to *consequences* of diabetes, was significantly associated with total number of conditions (*p*=. 005). The more conditions a participant had the more *consequences* they believed this had for their diabetes. There was also a significant association between the second fatalism item and index of multiple deprivation (*p*=. 035). Participants living in deprived areas were more likely to attribute diabetes control to external factors such as God.

From the bivariate checks for outliers, using the Mahalanobis distance, one outlier was found for one variable pair (understanding and income), which was close to reaching significance in the initial analysis. After removing the outlier, the association remained non-significant (*p*=.110) (Appendix 21, Table 8.8a).

No other significant associations were found in this analysis.

Table 8.8 Spearman's correlation for demographic characteristics (continuous variables), BIPQ and fatalism items

Demographic variables	Consequences (N =36)	Timeline (N=35)	Personal control (N=37)	Treatment beliefs (N=36)	Identity (N=36)	Concern (N=36)	Understanding (N=37)	Emotional response (N=37)	Chance or fate (N=34)	Little I can do to improve my health status (N=36)
Total N, Spearman correlation co-efficient, non-parametric, p-value (Spearman Correlation)										
Age	N =66 -.022 *p*=.863	N=65 .049 *p*=.745	N=67 -.245 *p*=.046	N=66 -.146 *p*=.243	N=66 -.103 *p*=.413	N=66 .047 *p*=.710	N=67 -.162 *p*=.189	N=67 .050 *p*=.688	N=64 -.147 *p*=.245	N=66 .065 *p*=.603
Total number of conditions	**N =65** **.341** ***p*= .005****	N=64 .126 *p*=.201	N=66 .017 *p*=.893	N=65 .066 *p*=.597	N=65 .122 *p*=.328	N=65 .010 *p*=.934	N=66 -.030 *p*=.811	N=66 .076 *p*=.539	N=63 -.009 *P*=.946	N=65 .143 *p*=.252
Index of Multiple deprivation	N= 66 .019 *p*=.879	N=65 .068 *p*=.481	N=67 .023 *p*=.854	N=66 -.038 *p*=.764	N=66 .180 *p*=.148	N=66 .149 *p*=.232	N=67 -.080 *p*=.522	N=67 .109 *p*=.380	N=64 .029 P=.946	**N=66** **.260** ***p*=.035***
Education (highest)	N=66 -.154 *p*=.218	N=65 .062 *p*=.622	N=67 -.068 *p*=.582	N=66 .056 *p*=.655	N=66 .133 *p*=.368	N=66 .082 *p*=.514	N=67 -.154 *p*=.224	N=67 .063 *p*=.612	N=64 -.174 *p*=.169	N=66 -.119 *p*=.341
Income	N=66 -.042 *p*=.741	N=65 .089 *p*=.451	N=67 -.213 *p*=.083	N=66 -.092 *p*=.462	N=66 .128 *p*=.304	N=66 .085 *P*=.496	N=67 -.210 *p*=.087 **(p=0.11)#**	N=67 -.033 *p*=.788	N=64 -.108 P=.395	N=66 -.167 *p*=.181

*** Significant at the 0.05 level (two-tailed)**

****Significant at 0.01 level (two-tailed)**

 # P-value after removal of outlier(s)

8.20 BIPQ, Fatalism, Social Networks and Demographics – categorical variables

A Kruskal Wallis non-parametric test was performed to test the associations between the categorical independent variables (social networks), demographic and the dependant variables (BIPQ and fatalism items).

There were no significant associations (*p*>0.05) between any of the independent social network variables and the BIPQ and fatalism items, as shown in Table 8.9. However, the second fatalism item was significantly associated with home ownership (*p*=.037), as shown in Table 8.9. Participants who were renting their accommodation were more likely to hold fatalistic beliefs about their diabetes (external control).

From the bivariate checks for outliers, using the Mahalanobis distance, one outlier was found for one variable pair (treatment beliefs and number of cohabitants), which was close to reaching significance in the initial analysis. After removing the outlier, the association remained non-significant (*p*=.061) (Appendix 21, Table 8.9a).

Table 8.9 Kruskal Wallis test for BIPQ, Fatalism and demographics (categorical variables)

Independent variables	Consequences (n =36)	Timeline (n=35)	Personal control (n=37)	Treatment beliefs (n=36)	Identity (n=36)	Concern (n=36)	Understanding (n=37)	Emotional response (n=37)	Chance or fate (n=34)	Little I can do to improve my health status (n=36)
Employment	P =.108	P=.865	P=.144	P=.776	P=.059	P=.096	P=.632	P=.759	P=.192	P=.132
Paid work	3.41	9.06	4.94	3.38	4.33	6.29	2.72	5.28	3.29	2.44
Retired	5.32	8.67	3.57	2.59	5.21	7.57	1.96	5.93	3.07	3.07
Other	5.00	9.10	4.47	2.85	6.45	6.10	1.80	5.86	3.84	3.35
Gender	P = .259	P=.462	P=.130	P=.272	P=.100	P=.825	P=.590	P=.215	P=.462	P=.064
Male	4.31	8.62	3.72	2.60	4.83	6.66	2.16	5.25	3.23	3.28
Female	5.19	9.23	4.80	3.22	5.97	6.90	2.06	6.29	3.52	2.63
Accommodation	P = .974	P=.703	P=.139	P=.946	P=.266	P=.588	P=.358	P=.125	P=.375	**P=.037***
**Rent	5.00	8.50	5.66	2.83	6.67	6.67	2.66	7.67	4.00	**4.17**
Own	4.70	8.95	4.08	2.90	5.22	5.22	2.05	5.54	3.31	**2.87**
No of cohabitants	P=.531	P=.490	P=.246	**P=.059**	P=.697	P=.530	P=.973	P=.919	P=.881	P=.548
None	3.50	7.50	2.50	**(p=.061)#** **.000**	5.00	8.00	2.50	5.00	3.00	3.50
One or more cohabitant	4.79	8.79	5.08	3.18	5.54	6.56	2.37	5.26	3.31	2.88
Marital status	P =.111	P=.752	P=.810	P=.671	P=.151	P = .369	P=.114	P=.780	P=.777	P=.414
Married or in civil partnership	4.45	8.87	4.26	2.85	5.58	6.60	1.96	5.69	3.37	2.91
Other	5.85	9.08	4.08	3.08	4.38	7.46	2.77	5.92	3.33	3.33

*** Significant at the 0.05 level (two-tailed)**
****Significant at 0.01 level (two-tailed)**
 # P-value after removal of outlier(s)

8.21 Social network variables, BIPQ and Fatalism

The previous analysis examined the associations between social network, BIPQ and fatalistic items and categorical demographics and social network factors.

The next analysis examined the associations between illness and fatalistic beliefs with all continuous factors only (all social network) using Spearman’s correlation (Table 8.10).

Table 8.10 Spearman’s Correlation for Social Network Variables BIPQ and Fatalism

BIPQ items	**Consequences (n =36)**	**Timeline (n=35)**	**Personal control (n=37)**	**Treatment beliefs (n=36)**	**Identity (n=36)**	**Concern (n=36)**	**Understanding (n=37)**	**Emotional response (n=37)**	**Chance or Fate (n=34)**	**Little I can do to improve my health status (n=36)**
Social network variables	**Spearman’s Correlation Coefficient, Non-Parametric p-value**									
No of supportive females	-.005 *p*=.978	-.080 *p*=.647	.066 *p*=.699	.249 *p*=.143	-.057 *p*=.739	**-.366** **P=.028***	-.047 *p*=.784	-.183 *p*=.278	.002 *p*=.991	-.259 *p*=.126
Frequency of contact	-.193 *p*=.260	-.146 *p*=.403	.066 *p*=.380	.220 *p*=.197	-.264 *p*=.120	**-.437** ***p*=.008****	-.009 *p*=.958	**-.352** ***p*=.004**** **(p=.032)#**	-.212 *p*=.229	-.309 *p*=.067
Emotional work	-.171 *p*=.318	.153 *p*=.381	-.241 *p*=.151	-.051 *p*=.767	-.107 *p*=.536	**-.599** ***p*=.000**** **(p=.005)#**	-.306 *p*=.065 **(p=.027)#**	**-.465** ***p*=.005****	-.022 *p*=.902	-.166 *p*=.334
Practical work	.002 *p*=.992	.238 *p*=.168	.183 *p*=.279	.209 *p*=.222	-.010 *p*=.955	**-.358*** ***p*=.032**	-.146 *p*=.389	-.195 *p*=.247	-.278 *p*=.111	-.300 *p*=.075
Size of support network	-.276 *p*=.103	-.088 *p*=.615	-.165 *p*=.329	.139 *p*=.419	-.239 *p*=.160	**-.470** ***p*=.004****	-.060 *p*=.723	**-.373** ***p*=.023*** **(p=.023)#**	-.258 *p*=.140	-.298 *p*=.078
Proximate children	.311 *p*=.065	.232 *p*=.181	-.002 *p*=.991	.249 *p*=.144	.099 *p*=.567	-.055 *p*=.749	.006 *p*=.971	.212 *p*=.208	-.205 *p*=.246	-.193 *p*=.260
Mix of agents	-.150 *p*=.383	-.215 *p*=.215	-.035 *p*=.839	.232 *p*=.174	-.195 *p*=.255	-.022 *p*=.901	-.128 *p*=.450	-.198 *p*=.239	-.133 *p*=.453	-.294 *p*=.082 **(p=.035)#**
Density	.254 *p*=.135	.139 *p*=.426	.135 *p*=.427	.219 *p*=.200	.099 *p*=.565	-.096 *p*=.576	-.018 *p*=.916	.017 *p*=.920	.067 *p*=.707	-.001 *p*=.994
Fragmentation	.041 *p*=.792	.186 *p*=.232	.048 *p=.777*	-.153 *p*=.327	-.084 *p*=.969	-.052 *p*=.740	-.091 *p*=.564	.182 *p*=.242	.061 *p*=.176	.207 *p*=.514

*** Significant at the 0.05 level (two-tailed)**

****Significant at 0.01 level (two-tailed)**

 # P-value after removal of outlier(s)

A number of significant relationships were found between BIPQ, fatalism and social networks and each will be described in turn by indicating whether the relationship was positive or negative. A positive association (an upward line) is when a high score on the dependant variable is associated with high score on the independent variable. A negative association (a downward line) is when low scores on the dependant variable follow a high score on the independent variable (Pallant, 2010).

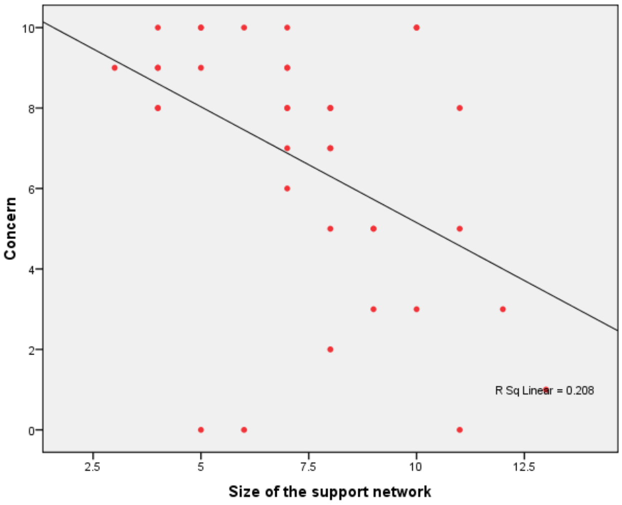
As mentioned earlier, this was an exploratory study with a small sample and it is important to point out that the overall aim of the analysis was to depict and describe associations between data, not to imply causality between the variables. Thus, the significant associations between the variables found in this analysis have to be treated with caution, and it is important to check whether the significant association are a result of outliers.

From the bivariate checks for outliers using the Mahalanobis distance, two variable pairs (concern beliefs and emotional work; emotional representations and frequency of contact) contained one outlier. The third variable pair (emotional representations and size of the support network) had two outliers. After removing the outliers, the association remained significant in three variable pairs (concern beliefs and emotional work (p=.005); emotional representations and size of the support network (p=0.23); emotional representations, frequency of contact (p=.032) (Table 8.10 and Appendix 8.10a). However, the fourth variable pair (understanding and emotional work) which was non-significant in the initial analysis, after removal of outlier became significant (p=.027) (Table 8.10 and Appendix 21, Table 8.10a).

The scatter plots on the next page describes some of the relationships between the variables using scatter plots, but it is important to point out that the analysis and scatter plots includes the outliers, as the analysis without the outliers was a test of the sensitivity to them. The implications of this will be discussed in Chapter 11.

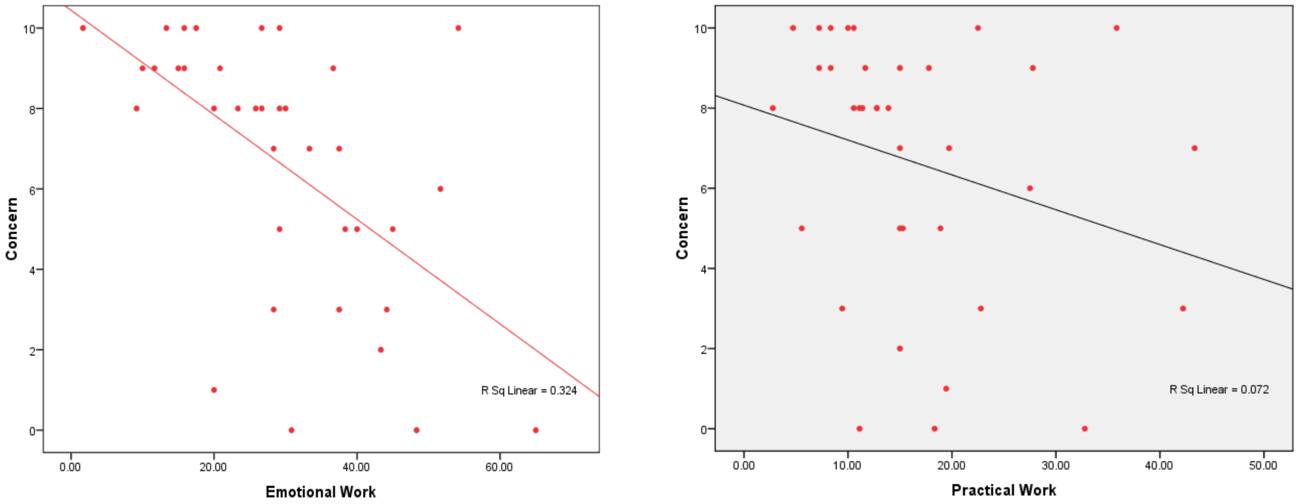
There was a negative relationship between *concern* over diabetes and the size of the support network ($p<0.05$), as shown by Figure 8.4 below.

Figure 8.4 Size of the support network and concern beliefs



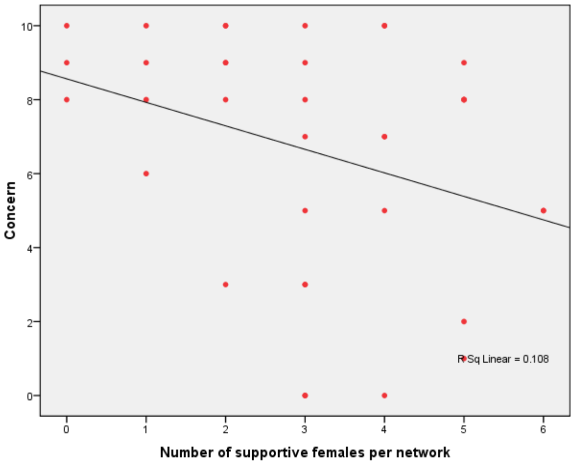
Concern over diabetes was negatively associated with total amount of practical (p<0.05) and *emotional work* carried out (p<0.05) in the network.

Figure 8.5 Emotional work, practical work and concern beliefs



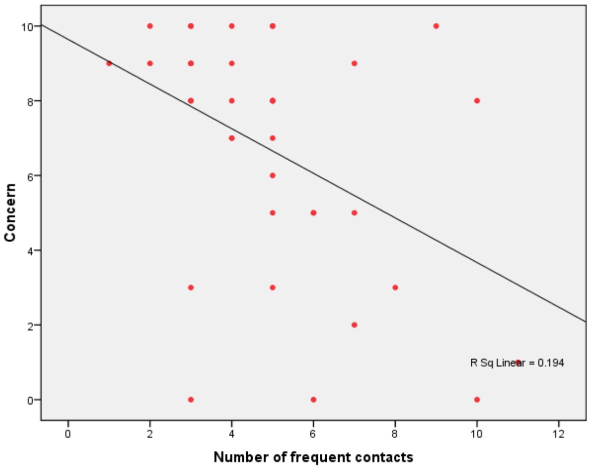
There was a negative relationship between *concern* over diabetes and the *number of supportive females* (p<0.05) in the network.

Figure 8.6 Number of supportive females and concern beliefs



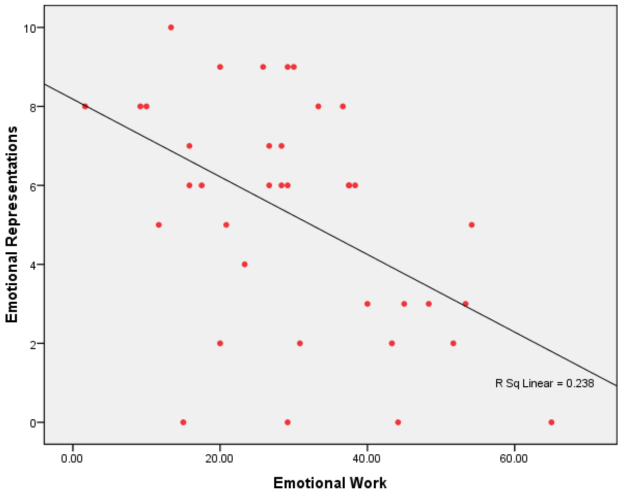
There was a negative relationship between *concern* over diabetes and *frequency of contact* (*p*<0.05).

Figure 8.7 Number of frequent contacts and concern beliefs



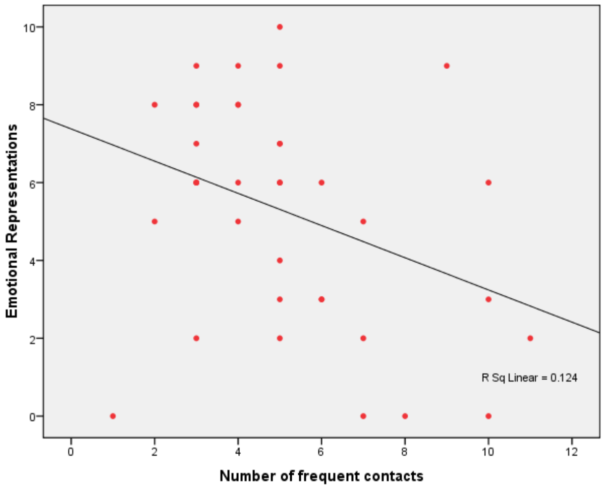
There was a negative relationship between how much diabetes affected participants *emotionally* and total amount of *emotional support* (*p*<0.05) received from the network.

Figure 8.8 Emotional work and emotional representations



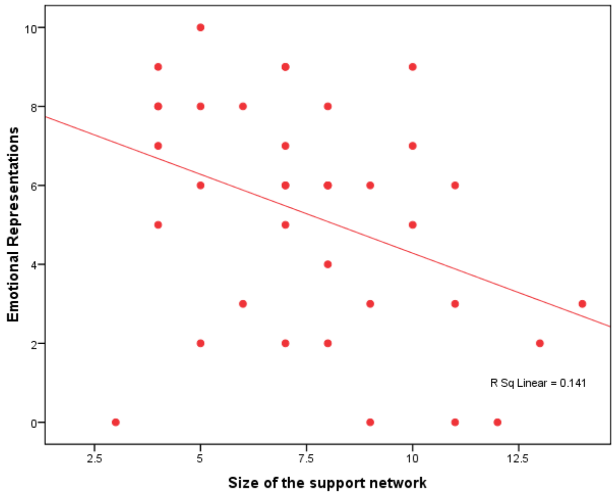
There was a negative relationship between how much diabetes affected participants *emotionally* and the number of *frequent contacts* in a network (*p*<0.05).

Figure 8.9 Number of frequent contacts and emotional representations



There was a negative relationship between how much diabetes affected participants *emotionally* and the *size of the support network* (*p*<0.05).

Figure 8.10 Size of the support network and emotional representations



8.22 Fatalism and social networks

There were no significant relationships between fatalistic beliefs about diabetes (*p*>0.05) and any of the social network variables. However, one variable pair (fate 2 and mix of agents) that was non-significant in the initial analysis, after removal of outlier became significant (p=.035) (See Table 8.10 and Appendix 21, Table 8.10a).

In summary: Two items of the BIPQ (concern and emotional representations) were significantly associated with a number of social network variables indicating that certain social network variables have an impact on beliefs about diabetes. Understanding was significantly associated with one social network variable (emotional work) after removal of an outlier. Similarly, the second fatalism item was significantly associated with one social network variable (mix of agents) after removal of an outlier.

The next analysis used multiple regressions to examine which of the social network variables were most predictive of *concern* and *emotional representations*.

8.23 Multiple Regressions

Most of the social network variables are correlated with one-another, principally by being in the form of totals across network members (e.g. size of network, number of females, number of proximate children, number having frequent contact, total emotional support and total practical support). Consequently the relationships of each of these with the dependent variables will be confounded with one-another. In order to account for this and identify the social network factors that are most predictive, forward stepwise regressions were performed for the two BIPQ items that showed significant relationships with more than one social network factor: *Concern, and Emotional Response*. Since there were no significant univariate relationships between demographic factors and illness beliefs, none of these variables were used in the stepwise regressions.

Before performing the multiple regressions, outliers were checked for using 6 degrees of freedom at .1, critical value – 16.81 for stepwise 1 and 4 degrees of freedom at .1, critical value -13.28 for stepwise 2, (Table 8.11). No outliers were found for either of the variable pairs (Appendix 21, Table 8.11a).

8.24 Stepwise multiple regressions 1: Concern beliefs

The social network variables (*number of supportive females, frequency of contact, emotional work and size of the support network*) that were significantly associated with concern beliefs (Table 8.10) were entered into the regression for this variable. In the forward stepwise analysis, emotional work (*p*=.001) was the first variable to enter the regression, after which none of the remaining three variables reached the significant level for entry (*p*=0.05).

8.25 Stepwise multiple regressions 2: Emotional representations

Using the same stepwise method, a second multiple regression was performed to explore the predictive ability of the social network variables (*frequency of contact,* *size of the support network and emotional work*) on emotional representations of diabetes. Of the three variables, emotional work was again the only variable to enter the model as a significant predictor (*p*=.002) of emotional representations. (See Appendix 22 for full table of results).

In summary: No outliers were detected for either of the variable pairs. The stepwise multiple regressions indicate that of all the social network variables entered into the regression analysis; *emotional work* was the strongest predictor of beliefs related to *concern* and *emotional* representation of diabetes. The association with *emotional work* could account for the observed relationships with other social network factors.

The next section addresses research question three and examines the association between BIPQ, fatalism and the health outcome measures.

8.26 BIPQ, Fatalism and Health Outcomes

The following analysis is in relation to research question three: *How do illness and fatalistic beliefs relate to other health outcomes in South Asians?*

8.27 Correlation Analysis

Spearman's correlation co-efficient was used to investigate associations between BIPQ, Fatalism, and the health outcome measures:

- Health status (SF-12, physical)
- Health Education Impact Questionnaire (HEIQ)
- Summary of Diabetes Self-Care Activities (SDSCA)
- Normalisation (COPE)

The next section and Table 8.11 provides details the results this analysis. From the bivariate checks for outliers using the Mahalanobis distance, three variable pairs (treatment control and SF-12; identity and HeiQ; concern and SF-12) contained one outlier. After removing the outliers, the associations in all cases remained significant (Appendix 21, Table 8.11a). Furthermore, one variable (emotional response and HeiQ) that was non-significant in the initial analysis, after removal of outlier became significant (p=.036) (See Table 8.10 and Appendix 21, Table 8.10a).

8.28 Health Status SF-12

There were no significant relationships between health status and understanding, timeline of diabetes, or either fatalism item, but there were significant negative correlations with *consequences* r = -.526, *p*<0.01), *personal control* (r = -.363, *p*<0.01), *treatment control* (r = -.378, *p*<0.01), *identity* (r = -.469, *p*<0.01), and *emotional representations* (r=-.336, *p*<0.01). That is, people in better health scored lower (i.e. were less troubled) on all these illness belief dimensions.

8.29 Health Education Impact Questionnaire (HEiQ)

HEIQ was negatively correlated with *consequences* (r=-.302, *p*<0.05), and *identity* (r =-.249, *p*<0.05).

8.30 Summary of Diabetes Self-Care Activities (SDSCA)

SDSCA was negatively correlated with *consequences* (r=-.309, *p*<0.05), and *treatment control* (r=-.270, *p*<0.05).

8.31 Normalisation (COPE)

Normalisation was negatively correlated with *personal control* (r = -.301, *p*<0.05).

Table 8.11 Spearman correlations between illness and fatalistic beliefs and other health outcomes in South Asians

BIPQ	SF-12 (PNS)	HEiQ	SDSCA	NORMALISATION
Consequences	-.526** **(*p*=.000)**	-.302* **(*p*=.014)**	-.309* **(*p*=.012)**	-.007 (*p*=.955)
Timeline	-.124 (*p*=.326)	-.201 (*p*=.109)	.005 (*p*=.967)	.094 (*p*=.454)
Personal control	-.363** **(*p*=.003)**	-.159 (*p*=.200)	-.138 (*p*=.267)	-.301* **(*p*=.013)**
Treatment control	-.378** **(*p*=.002)** **(p=.000)#**	-.108 (*p*=.388)	-.270* **(*p*=.028)**	-.054 (*p*=.667)
Identity	-.469** **(*p*=.000)**	-.249* **(*p*=.044)** **(p=.038)#**	-.137 (*p*=.272)	-.074 (*p*=.553)
Concern	-.278* **(*p*=.024)** **(p=.002)#**	-.151 (*p*=.227)	-.080 (*p*=.521)	.044 (*p*=.723)
Understanding	-.090 (*p*=.470)	-.163 (*p*=.187)	-.231 (*p*=.060)	-.135 (*p*=.277)
Emotional response	-.336** **(*p*=.005)**	-209 (*p*=.089) **(p=.036)#**	-.103 (*p*=.408)	.170 (*p*=.169)
Fatalism items				
Chance or fate	-.114 (*p*=.371)	-.060 (*p*=.636)	.100 (*p*=.434)	.048 (*p*=.708)
Little personally do to improve health status	-.176 (*p*=.164)	-.138 (*p*=.276)	-.002 (*p*=.986)	.067 (*p*=.600)

*** Significant at the 0.05 level (two-tailed)**
****Significant at 0.01 level (two-tailed)**
 # P-value after removal of outlier(s)

In summary: The two fatalism items had no significant associations with any of the health outcome measures. However, with the exception of *timeline* and *understanding,* all the BIPQ items were positively associated with at least one of the health outcome measures. The implications of these findings will be discussed in Chapter 11.

8.32 Comparison of BIPQ and Fatalism scores between the sub-ethnic South Asian groups

The following analysis is in relation to research question four: *How do illness and fatalistic beliefs differ between Indian and Pakistani South Asians?*

As mentioned earlier, due to the small sample of Bangladeshi (n=2), and Nepalese participants (n=1), these sub-ethnic groups were excluded from this analysis. Table 8.12 reports the demographic characteristics for the two sub-ethnic groups: Indian and Pakistani.

The Indian sample was a larger sample (n=43) than the Pakistani (n=21) with both groups comprising of similar percentages of males and females. However, compared to the Pakistani group more Indians were retired (51% v 24%), married or in civil partnership (84% v 71%), owned the accommodation they lived in (98% v 81%), and were older in age (mean age = 64 v 55).

Table 8.12 Demographics characteristics for Indians and Pakistanis

Sub-ethnic group	Indian	Pakistani
	N (%)	N (%)
Total N	**43**	**21**
Gender		
Male	23 (54)	10 (48)
Female	20(46)	11 (52)
Employment		
In paid work	12 (28)	5 (24)
Retired	22 (51)	5 (24)
Other	9 (21)	11 (52)
Marital status		
Married or in civil partnership	36 (84)	15 (71)
Other	7 (16)	6 (29)
Accommodation		
Own	42 (98)	17 (81)
Rent	1 (2)	4 (19)
Number of cohabitants*		
No cohabitants	1 (5)	1 (6)
One of more cohabitants	17 (95)	15 (94)
Duration of diabetes		
0 to 5 years	8 (19)	5 (24)
5 to 10 years	12 (28)	7 (33)
10 years or more	23 (54)	9 (43)
	Mean (SD)	**Mean (SD)**
Total number of conditions	2.24 (.95)	2.28 (.845)
Age	65 (11)	55 (13)
Education (highest)	4.39 (3.0)	4.71 (2.87)
Income	3.60 (1.4)	4.10 (2.1)
IMD	30.7 (16.0)	41.7 (17)

***Completed social networks survey (n=37)**

The Mann Whitney U non-parametric test was used to investigate the differences in the mean BIPQ and fatalism scores between the sub-ethnic South Asian groups.

The BIPQ and fatalism items were used as the dependant variables and a separate analysis was performed for each BIPQ and fatalism item. Results of the Mann Whitney U test found significant differences in *symptom* beliefs and *fatalistic* beliefs between the two groups. Pakistanis experienced more symptoms related to diabetes (mean score 6.29 versus 4.71, $p<0.05$) and held stronger fatalistic beliefs about their diabetes (3.5 versus 2.67, $p<0.05$) compared to the Indian group (also shown by Table 8.13).

Table 8.13 Mann Whitney U test for BIPQ and Fatalism in Indians and Pakistani

BIPQ ITEM	INDIAN N, Mean (SD)	PAKISTANI N, Mean (SD)	Mann-Whitney U
Consequences	N=42 4.36 (3.05)	N= 21 5.19 (3.09)	.299
Timeline	N=41 9.02(2.10)	N=21 8.86 (2.28)	.828
Personal control	N=43 3.67(2.52)	N=21 4.95 (2.92)	.080
Treatment control	N=42 2.59 (2.19)	N=21 3.47 (2.80)	.272
Identity	N=42 4.71 (3.00)	N=21 6.29 (2.45)	**.031***
Concern	N=42 6.40 (3.10)	N=21 7.19 (3.23)	.250
Understanding	N=43 2.00 (2.16)	N=21 2.04 (2.29)	.994
Emotional response	N=43 5.56 (3.23)	N=21 5.86 (2.92)	.774
Fatalism			
Chance or fate	N=42 3.50 (1.48)	N=19 3.16 (1.42)	.336
Little personally do to improve health status	N=43 2.67 (1.44)	N=20 3.50 (1.35)	**.036***

*** Significant at the 0.05 level (two-tailed)**
****Significant at 0.01 level (two-tailed)**

In summary: This analysis reported that the Indian sample was larger than the Pakistani sample. The differences in the mean BIPQ and fatalism scores were investigated using a Mann Whitney U test between groups. Pakistanis experienced more symptoms related to diabetes and held stronger fatalistic beliefs about their diabetes compared to the Indian group, indicating sub-ethnic group differences in beliefs about diabetes.

8.33 Chapter Summary

A total of 67 South Asians completed the postal health survey and 37 of these participants completed the social networks survey interview. Participants were recruited using a combination of random and purposive sampling. Comparison of the two samples (random and community) on the BIPQ and fatalism items found only one significant difference (the random sample reported greater personal control of their diabetes), indicating that the samples differed very little in how they scored on the items. A comparison of the demographic characteristics between the two samples can be found in Appendix 22.

The sample consisted of 36 males and 31 females, with an average age of 61 years. Most (79%) had T2DM for five years or more and 84% had at least two chronic conditions. The majority were married, retired, and owned their home, and the most common income was in the range of £10,400-£15,999 per annum. Nearly all (95%) participants who completed the social networks survey were cohabiting with one or more persons. The causal dimension of the BIPQ found that, genetics, diet and stress were stated as the main causes of diabetes.

Analysis of relationships between the BIPQ, fatalism items and demographic characteristics (research question one) found few associations, excepting that participants living in rented accommodation and areas of higher deprivation were more likely to believe there was little they could do to improve their condition.

Analysis of relationships between the BIPQ, fatalism items and social network factors (research question two) found that two items of the BIPQ (concern and emotional representations) were significantly associated with a number of social network variables indicating that certain social network variables have an impact on beliefs about diabetes. However, neither of the fatalism items was associated with any of the social network variables.

After multiple regression analysis however, (research question three) only the amount of emotional work done by network members remained a significant predictor of illness beliefs about diabetes, specifically *concern* and *emotional representations*. This suggests that the more *emotional support* received within the network, the less concerned and less emotional South Asians were about their diabetes.

Correlation analysis between the BIPQ and fatalism items and the health outcome measures found significant associations between: *consequences, concern, treatment control, identity and emotional representations* with *health status (SF-12).* South Asians with higher levels of *self-efficacy* (HEiQ) reported fewer *consequences* and *identity* of symptoms related to diabetes. Significant associations were also found between *self-care* (SDSCA) and *consequences* and *treatment control* beliefs (research question three).

Finally, the sub-ethnic group analysis (research question four) further revealed that *identity* of symptoms and *fatalistic* beliefs related to diabetes was greater in the Pakistani group than the Indian group.

The interpretation of these findings will be discussed in Chapter 11. The next chapter moves on to present the results of the qualitative study

Chapter 9

Results of the Qualitative Study

9.1 Introduction

The aim of this qualitative study was to explore the influence of social and cultural factors on the management of diabetes in the South Asian population. The thematic map (Figure 9.1) in this chapter illustrates the six main themes of this study together with the sub-themes. Three of these themes: *Fatalism, normalising diabetes and social networks* will be discussed in this chapter and the remaining three themes: *Alternative food therapies, travel back home, diabetes and religion* will be discussed in the next chapter. The reasons for the division of themes are two-fold. Firstly, the themes discussed in this chapter complement the findings of the quantitative studies, and illustrate the value of using a mixed methods study design. Secondly the themes presented in Chapter 10 will examine how specific cultural and religious beliefs influence diabetes management, with a specific focus on treatment and dietary behaviours for diabetes management in this target population and implications for clinical care.

The chapter begins by describing the characteristics of the participants who were interviewed.

9.2 Sample characteristics

The participants were recruited into this study using a combination of random, purposive and snowball sampling method, as described in Chapter 6. Thirty participants were from the random sample (GP practices) and seven from the purposive and snowball sample (community). In addition, the data of the seven participants who took part in the pilot qualitative study (described in Chapter 7) were also included into the final data set for this study only.

Thus, a total of 44 participants participated (see Chapter 8, Figure 8.1) in this qualitative study. Interviews were conducted with participants in a location of their choice; mainly their own homes, apart from two who requested to be interviewed at the local community centre. Table 9.1 show the demographic characteristics of the sample. The majority of participants in the sample were older (mean 61 years); belonged to either the Indian (49%) or Pakistani sub-ethnic group (43%); and were married (87%); and homeowners (89%). Over half the sample were not in paid work, with a household income of £5,200 to £15,999 (mean = 3.49).

Table 9.1 presents the type and the number of other conditions self-reported by participants. Table 9.2 presents the type of diabetes and other conditions interviewees had. Most of the participants had T2DM (87%); with three or more conditions (41%).

Table 9.1: Demographic characteristics of participants

Demographic Characteristics	**Random and community sample n (%)**	**Community pilot sample n (%)**
Total sample n	**37**	**7**
Gender		
Male	18 (49)	5(61)
Female	19 (51)	2(29)
Age (mean = 61.0, SD= 12.5)		
32-40	6 (16)	1(14)
41-60	15 (40)	4(57)
61-80	14 (38)	2(29)
80-84	2 (5)	0(0)
Employment		
In paid work	12(32)	*
Retired	12 (33)	*
Other	13 (35)	*
Marital status		
Married or in civil partnership	35 (87)	6(86)
Other	5 (13)	1(14)
Sub-ethnic groups		
Indian	18 (49)	4(57)
Pakistani	16 (43)	2(29)
Bangladeshi	2 (5)	1(14)
Other (Nepalese)	1(3)	0(0)
Born in the UK or Migrated to UK		
British Born South Asians	4 (12)	0(0)
British Migrant South Asians	33(88)	7 (100)
Accommodation		
Own	33 (89)	5
Rent	4 (11)	2
IMD *(M=38.1 SD=13.6)*		
Highest Qualification (M = 4.62, SD =3.10)		*
No qualifications	12	*
1 to 4 0 Levels	3	*
A Levels	1	*
Other qualifications	4	*
NVQ	3	*
Professional Qualifications	5	*
First degree	5	*
Higher Degree	4	*
Income *(M=3.49, SD = 1.93)*		*
Income groups		
Up to £5,199	3 (8)	*
£5,200-£10,399	11 (30)	*
£10,400-£15,599	10 (27)	*
£15,600-£20,799	4 (11)	*
£20,800-£25,999	2 (5)	*
£26,000-£31,999	3 (8)	*
£32,000-£51,999	2 (5)	*
£52,000 or more	2 (5)	*

***not collected for the pilot study**

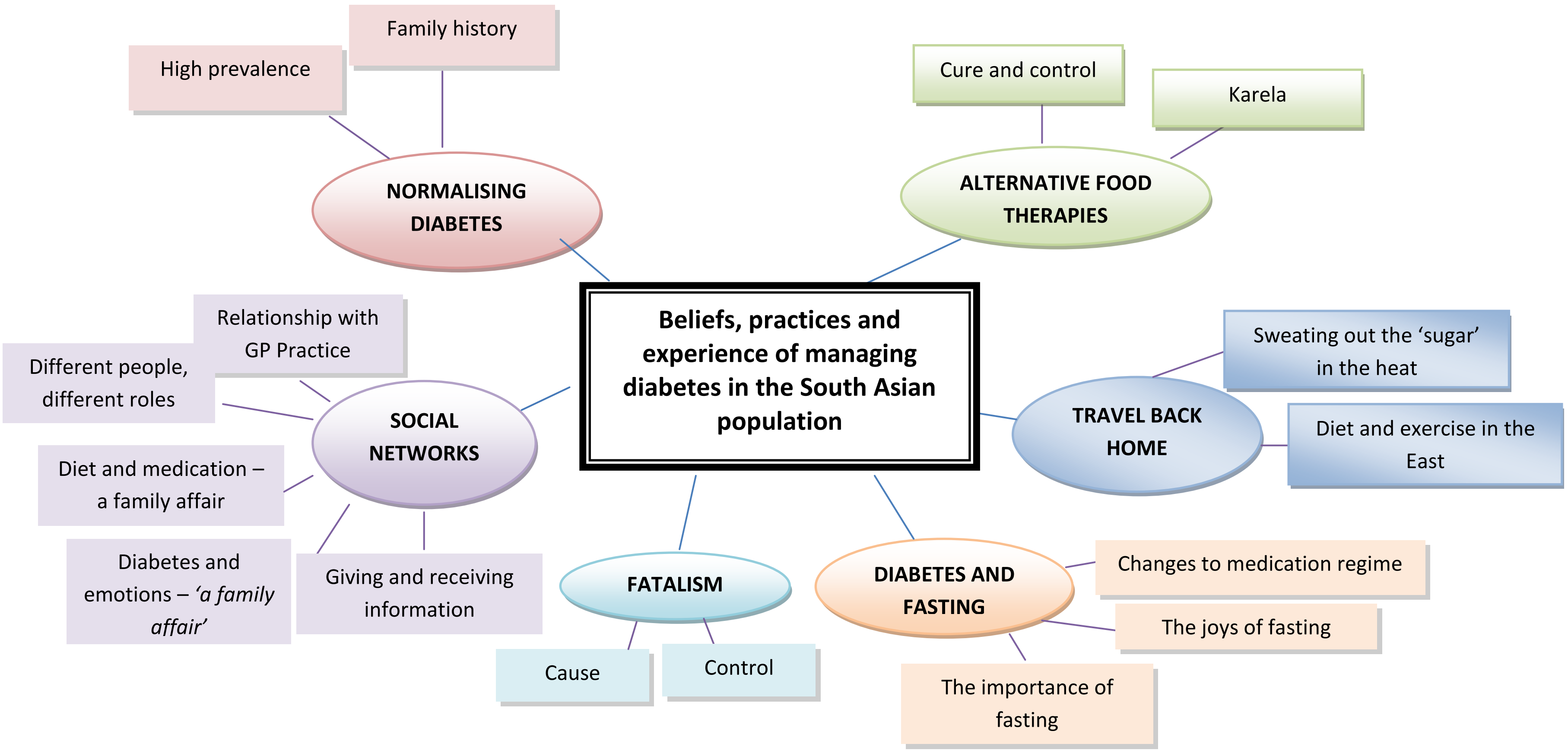
Table 9.2 Diabetes and other conditions

	Random and community sample n (%)	Community pilot sample n (%)
Diabetes		
T1DM	5 (13)	0(0)
T2DM	32 (87)	7(100)
Total number of conditions		
One or more	10 (27)	*
Two or more	27 (73)	*
Duration of diabetes		
0 to 5 years	10 (27)	1(14)
5 to 10 years	13 (35)	3(43)
10 years +	14 (38)	3(43)

***Not collected for the pilot study**

Interviews lasted between 45 minutes and 1 hour 30 minutes, (shortest 40 minutes, longest 90 minutes, mean = 68 minutes). Duration of interviews also varied according to whether they were conducted in English or in one of the preferred South Asian languages (Hindu or Gujarati with the author or in Urdu with the interpreter), as chosen by the participant.

Figure 9.1: A Thematic map showing the six main themes and sub-themes within them – Qualitative study



9.3 Fatalism : Cause

Some participants in this study described the cause of their diabetes in fatalistic terms suggesting they developed diabetes because it was part of their fate.

> *P: "Everything that happens is written in your fate" [Participant 304, Pakistani, female]*

The belief that more powerful and unpredictable forces determine health and control lives is a common feature of the South Asian culture (Landrine & Klonoff, 1994). As mentioned in Chapter 3, fatalism is a term used to describe '*beliefs that the outcomes of situations are determined by forces external* (*e.g. chance, luck, powerful other) to the individual'* (Cockerham, 2007, p.111). However, there were tensions between relating the cause of diabetes to fatalism and more medical/scientific causes. Some participants had awareness and were familiar with diabetes being caused by lifestyle factors such as diet and that diabetes was a hereditary condition. These causal beliefs were also evident in the results of the BIPQ causal dimension of the quantitative study (Chapter 8).

> *P: "To me I've not eaten sweet foods or fatty foods because I have been fighting with my weight and still I've got it that means it were genetic because both my brother's got it. I think that's what caused mine". [Participant 79, Indian, female]*

> *P: "I think stress…when I look back in my life I think I had a lot of stress, money wise and stress I think they were the main two problems…stress of trying to make ends meet and running around after the children all the time and you have husband and his family on top of that you have your own family. It's a combination of things that's the main thing. I think it could have been better controlled but at that time you don't think of this when you're young; you think you're full of energy. You are full of energy, you can do 500 things and err…but when I think about it now, I think it was mostly the stress that caused it…there was an underlying condition but it wouldn't have affected me if I didn't have that stress and worries and things". [Community participants 21, Pakistani, female]*

Participants referred to genetics, diet and stress as causes of their diabetes. Some participants also reflected back explicitly on their dietary behaviours such as 'eating too many sugary foods' and the stress of 'everyday work' in order to identify further possible cause of their diabetes.

9.4 Fatalism: Control

South Asians, particularly the elderly Indian and Pakistani participants, with one or more conditions held fatalistic beliefs about diabetes in relation to *control* of the condition, than the British born South Asians. It has been suggested that fatalism can be viewed as part of *control* or *cure* if events believed to be determined by fate are seen as unalterable (Hampson, 1997). Consequently, some participants seemed to believe that external forces such as God were more powerful in controlling their diabetes than they were alone.

> *"P: If something is going to happen, it's going to happen, it doesn't matter what the damn well you do….whether you control it, whether you don't control it's going to come" [Participant 332, Indian, male]*

Some participants also believed that taking personal control of their diabetes was not going to improve their diabetes control because God had more control over their diabetes.

> *"P: I am old now so there is no point worrying because nothing is going to happen by worrying. Whatever will happen God will decide, he sat here, the one who gave us life and he is the one that will decide. We have not come in this life with anything and nor are we going to be able to take anything with us, we will leave everything behind". [Community participant 2, Indian, female]*

This older participant with T2DM and a number of other conditions strongly believed that God had the ultimate control over the future of her health and life. She believed that it would make no difference what she or her family did to try to control her diabetes, because eventually she was going to die anyway.

Several participants across the South Asian ethnic groups (e.g. Pakistani and Indian) attributed the future of their diabetes, health and life to the time given by God.

> *P: "It's up to Allah, whenever I am going to die, I will die, and it's when Allah decides my time is up. Even if I didn't have all these illnesses I am going to*

> *die one day and even the youngsters die and the older ones stay behind. If death has to come it will come whether it's a heart attack or an accident". [Participant 393, Pakistani, female]*

In addition to fatalism, some of the Indian participants in this study also believed that *Karma* had an effect on how God determined one's fate. The prominence of *Karma* constitutes an important way of thinking about life in different groups of people (Keyes & Daniel, 1983). In the Indian culture, Karma is not believed to be a punishment nor fate, but the consequence of natural acts since humans act with free will, thereby creating their own destiny (Bhagavad-Gita, 2010). Some of the Indian participants also believed that doing a good thing in life, such as helping other people would result in good deeds from God.

> *P: "If you work for God and you do good things…then god will give you strength. Do something good and God will do something good for you. We all have a certain lifespan and then your time ends that's your time, its fate". [Participant 96, Indian, male]*

Similar tensions that were described earlier with regards to fatalism and causal beliefs were also present for fatalistic beliefs about diabetes control. Some participants did not attribute their ability to control their diabetes to God. In particular, the British born South Asians attributed diabetes *control* to lifestyle factors such as exercise and diet rather than external factors such as God. These participants described taking more control of their diabetes by modifying their lifestyle and eating healthy and exercising.

> *P: "We've changed the way we cook, and everything…The type of things we cook as well. So, less red meat and eat sensibly, loads of chicken, more vegetables and everything. I was…I've always been a bit chubby but not, you know, massive but it's probably more diet than anything else...I exercise so… At the end of the day, you have to look after yourself" [Participant 398, Pakistani, male]*

This resonates with the notion of '*practical work*', but also indicates that participants engaged in practical work for their diabetes both independently (e.g. taking part in physical activity) and/or with the help and support from the family (e.g. managing diet and cooking).

9.5 Summary

Fatalistic beliefs participants held about diabetes, specifically in relation to cause and control were evident in this study. However, there were tensions between believing that the cause of diabetes was part of fate and yet being aware of the scientific and medical facts about the cause of diabetes. Similar tensions were also found for beliefs in relation to control of diabetes, with British South Asians being less likely to attribute diabetes control to external factors such as God and more likely to take personal control and receive help from family members to control their diabetes. Accepting that God has control of their diabetes seemed to be a common way of coping with the condition, especially the older British migrant South Asian people.

9.6 Normalising diabetes

As mentioned in the preceding section of this chapter some participants had pre-existing knowledge about diabetes. This was either due to living with family members with the condition or being aware of extended family members living with the condition. The majority of participants also had knowledge of diabetes being more prevalent in the South Asian population. Consequently, it was common for these participants to ‘normalise’ diabetes and believe that it was a part of life.

> *P: “Well I don’t think they are too concerned about it really, not so shocked or anything like that, people just accept it these days because it is a common thing now isn’t it? I know quite a few people with diabetes so when they do find out nobody is really shocked about it”. [Community participant 7, pilot study, Indian, male].*
>
> *P: “We just put it down to being in the family because my Dad had it” [Community participant, 26, Indian, female]*

Being aware of the high prevalence of diabetes in the community seemed to lead participants to not only normalise the condition, but also downplay the seriousness of the condition and the importance of self-management. Having family members with diabetes also seemed to provide a platform on which they were able to map their diabetes on to. Witnessing family members, first hand, managing their diabetes also seemed to reduce the emotional distress of their own diagnosis.

> *P: "I've had it around me it wasn't that much of a shock, if you know what I mean. If it was, like, I'd never heard of it, I'd think, oh, s**t what's happened, am I going to die, this, that…but because my immediate family had it, it wasn't that much of a surprise….obviously, having an Asian diet, you know, because Asian and Afro Caribbean people are, like, prone, aren't they". [Participant 398, Pakistani, male]*

Participants who had pre-existing knowledge about diabetes described the association between the South Asian diet and the high prevalence of the condition in the South Asian population. This further led to participants normalising diabetes and expecting/anticipating to get diagnosed with the condition because of their diet.

> *P: "Diabetes is in the family, my sister had it, my parents didn't have it but other people in the extended family had it and I knew somewhere along the line it's going to happen [Community participant 34, Indian, male]*

The anticipation and expectation of diabetes seemed to mentally prepare participants for the diagnosis of diabetes and very few participants mentioned taking any sort of preventative actions to prevent or delay the onset of diabetes, even for those at high risk of diagnosis. On reflection, methods of preventing diabetes or the specific knowledge participants had about diabetes were not part of the research question for this study; therefore this was not explored in any specific detail. However, through conversation on the topics of diagnosis and management, it appeared that despite having knowledge about diabetes, participants made changes to their lifestyle habits only after diagnosis, with some attributing cause and control of diabetes to fatalism.

9.7 Summary

Normalising the diagnosis of diabetes was common in participants; they seemed to expect and anticipate the diagnosis of diabetes if they had family members already living with the condition or had pre-existing knowledge of diabetes being a hereditary condition within the South Asian population. These beliefs and knowledge reduced the emotional distress of diagnosis. Specific knowledge on the association between the South Asian diet, and the cause of diabetes also contributed to the expectation and anticipation of diabetes and further reinforced normalisation of the condition.

9.8 Social networks

As mentioned earlier in Chapter 4, one of the main aims of this thesis was to explore the role of social networks in relation to the ‘work’ undertaken within the networks in relation to diabetes and their influence on beliefs about diabetes. The findings of the quantitative study on the association between social networks, health outcomes and beliefs were presented in Chapters 8. The qualitative themes presented here also complement some of the findings from the quantitative data on social networks, but these findings provide specific insight into the ‘work’ and support (*e.g. emotional and practical)* provided by the networks for diabetes from the participant’s own personal perspective.

The thematic map (Figure 9.1) provides detail for specific themes. This section will begin by describing the different roles the people in the network play, the relationship with general practice, before moving on to family and friends.

9.9 Relationship with general practice

Participants described the support they were likely to receive from their network, with reports of receiving very little information and support about diabetes from their GP or Practice Nurse (PN).

> *P: “GP doesn’t explain anything they just give medicine, my brother tells me not drink and don’t do this and that” [Participant 364, Nepalese, Male]*
>
> *P: “She’s helpful (Practice Nurse) she checks my feet and gets this thing and taps my feet. The doctor just prescribes my medicines” [Participant 95, Indian, Female]*

Support from general practice was not explored in any great detail in the quantitative study. However in this qualitative study most of the participants described the role of the GP as prescribing medication only and attending the GP only in response to invitation from the practice for routine check-ups and vaccinations.

> *P: "GP doesn't do anything just prescribes medication that's it. In all these years I hardly go to the doctors…I am on repeat prescription and my daughter rings the surgery and she just picks up the prescription. I just go for my vitamin or flu injections when they write to me". [Participant 393, Pakistani, male]*

There was a tension between participants suggesting that the GP was the best person to seek information from for diabetes, but also knowing that he/she was pressured for time.

> *P: "I don't get much advice from my GP, I just get my tablets and that's it (big laugh)…you can't blame them because they are seeing so many patients a day, they haven't got the time to spend 20 minutes or half an hour to talk and tell you things. [Community participant pilot study 5, Indian, male]*

Overall, there seemed to be some disappointment and dissatisfaction expressed by some of the participants with regards to the care they received from their GP for their diabetes. Although some participants expressed satisfaction about the care they received from the PN, it seemed that participants wanted more information and support from their GP for their diabetes.

9.10 Different people, different roles

The limited access to information and support from formal routes such as the health services (or health charities) resulted in GPs being labelled as providing 'technical' support only. Family and friends were described as providing both practical and emotional support and guidance on managing diabetes.

> *P: "GP can support me technically because she has experience in every problem of my disease. My family and friends can support me when there are new developments, like my cousin called me last week to inform me about new insulin which you only have to take once and told me to ask my GP. I am still thinking about it and not spoken to my GP yet…I am going to*

> *make an appointment and then speak to her…I had a hypo once and somebody told me it's best to have lucozade so I asked my GP".*
>
> *I: "Were you given any information on hypos before that?"*
>
> *P: "No. The nurse gave me some information in detail after I experienced a hypo". [Participant 313, Pakistani, male]*

Family and friends were not only important sources of information about diabetes but were also sources for 'work' related medication, diet (practical work) and managing emotions (emotional work) which will be discussed in the next section.

9.11 Diet and medication- a family affair

Participants who lived with immediate family or had close family members live nearby, were predominantly at the centre of diabetes management. This was particularly the case for *practical work* related to managing their diet and cooking.

> *P: "They (mother and sisters) make sure that they give me the right diet as well….They don't give me much anything to do with sugars and things like that, so they make what I think is right" [Participant 255, Pakistani, male]*

Some of the men who were married described providing their wife with relevant information on diet for people with diabetes, as their wife were responsible for *everyday practical work* such as cooking for the family. Information on diet given to their wife was either from written leaflets, or magazines taken from GP waiting rooms, or passed on from family and friends through conversation about diabetes. This seemed to be to ensure their wife knew what ingredients to buy and what foods to make to ensure they were eating the right foods for their diabetes. Despite holding fatalistic beliefs about diabetes control and the cause of diabetes, attempts were still made to control their diet and involve family members to help effect change.

> *P: "I think my wife knows about diets, and…she knows what affects me and what has not affected me. And I think when she does the cooking, plans the cooking, the meal for the day, she always thinks about it. For example, one thing is cooking oil, we don't use cooking oil, and we use olive oil".*

> *I: "How did your wife know about that? You know, like to change the oils and the diet and things?"*
>
> *P: "It's me, my influence, because I read a lot at the beginning….*
> *And I told her what affects me from the beginning, and she became my wife…because I think I was…no I wasn't actually, in fact I became diabetic when she was here. And then we talked about it, at the beginning, how we control it and…she's got better, she likes cooking, and she likes looking in to cooking, and she just uses her own ways of doing it nice and tasty". [Participant 134, Pakistani, male]*

Most of the married men explained how their wives have played a significant role in helping to change their diet for their diabetes. However, some participants did not want changes to their diet to affect the rest of the family who did not have diabetes.

> *I: "So who decides what to cook/eat every day in your household?*
> *P: "Laugh - my wife knows my condition so she prepares the food accordingly really. Still could be modified but err…it would have an absolute impact on the whole family just because of me". [Community participant 34, Indian, male]*

Some participants assumed certain members of the family to be 'experts' in specific *every day practical work* related to diabetes management. Some men believed that their wives had the appropriate skills and expertise in cooking and managing their diet for diabetes because cooking was part of their wife's responsibility.

> *P: "She does the cooking - she is an expert cook…She plans everything, I just leave it to her, it's her department and I don't interfere....When I come downstairs in the morning the breakfast is ready...Its good tuning you know…when I want to eat something I just request her to make it and she cooks for me as well" [laugh] [Participant 96, Indian, male]*

In addition to managing their diet and cooking, some men also described how their wife or other females in their network, for instance their mother or sisters, provided *practical work* in terms of reminding them to take their medication(s) on time.

> *P: "Wife helps me with medication….my niece collects my medication because she studies nearby". [Participant 364, Nepalese, male]*

> *P: “My mother is very important because she’s always making sure wherever I travel I take my medicines with me and she rings up and asks ‘have you taken your medicine’…. my sisters are also very helpful…they also make sure that I do take them regularly….especially when I am travelling. So there is a need for them because they are supporting…every day they ask me in the morning and in the evening…my sister makes sure that she puts all the medicines in my bag”. [Participant 255, Pakistani, male]*

This participant strongly believed that other people in the family should take responsibility for ensuring people with diabetes in the household take their medication and eat the right foods.

> *P: “There has to be someone who has to be on your head in order to make sure that you take the right medication, plus someone in the house should be with the right diet, you know, like they should cook professionally for you so they do that”. [Participant 255, Pakistani, male]*

Only married, retired women with diabetes and other conditions, which affected their mobility, described receiving help from their husband for work related to their diabetes and domestic work in the house.

> *P: “Helps around the house, I go shopping or we go together”*
> *Husband: “Every 3 months we go to the GP for a check-up and he advises whether she needs to change her medication”. [Participant 95, Indian, Female]*

In addition to the husband, some women also described the practical support and work carried out by their children for their diet for diabetes.

> *P: “My husband helps me…we support each other as a family...my children they do all the cooking and shopping at the weekend for the whole week. They prepare all the meals for the week ahead”. [Participant 256, Indian, Female]*

9.12 Information and diabetes – ‘a family affair’

As mentioned earlier, there was a tension between participants suggesting that the GP was the best person to seek information for diabetes, but knowing that he/she was pressured for time.

Some women commented on how their children helped to provide information and practical support for work related to diet. For instance, the children would either look up information on the Internet or read aloud and interpret the written information on diabetes. This was also because the children of these participants were born in the UK and were more literate with the English language and knew how to use the Internet.

> *I: "Where or who do you find out about more about diabetes?"*
> *Daughter: "It would be me or my brother or my father".*
> *I: "Do you read any literature on diabetes?"*
> *Daughter: "We translate it for her, so we read it to her…my mum doesn't know much but my brother he likes to read…he has a laptop so he sits with my mum on the Internet and they look up things together". [Participant 304, Pakistani, female]*

In contrast to men, women with diabetes described the everyday *practical* 'work' and responsibilities they had in the house in addition to managing their own diabetes.

> *P: "We women have a lot to do - washing, cooking, and cleaning apart from when you're pregnant that's like the rest period from all the work in our culture". [Community participant 26, Indian, female]*
>
> *P: "Women especially they do have a lot of stress. We are running…we have two sides of the family and are pulled in all ways. You've got husband who wants this, his mother there and all parents. I think we have a lot of roles…you don't have time….until you become a certain age, when the children are older and your left on your own. I think also we don't look after our diet a lot….I find a lot of people don't worry about diet so it's what other people want to eat - it's not their own choice". [Community participants 21, Pakistani, female]*

For these women managing their diabetes, particularly their diet seemed to be secondary to the everyday work they had to do for their immediate and extended families.

9.13 Diabetes and emotion – a family affair

A minority of female participants described providing both emotional and practical support to their husbands for both their diabetes and mental health condition too.

As a result, they often sacrificed the tasks related to looking after their own diabetes and health.

> *P: "My husband used to support me, we were partners but from the last 5 years has been suffering from depression since he retired…. I have to care for him a lot… my day starts with my husband - putting him in the shower, getting his clothes out… his dependant on me 24 7….my husband makes life difficult for me. He was diabetic but his cured because he doesn't eat". [Community participant, 35, Pakistani, female]*

> *P: "My husband has been ill since 1991. He had a mental breakdown. He was diagnosed with schizophrenia, and all three children were small at the time… he's got diabetes since four or five years and his is fine. But it's only me and mine…I think because I've led such a stressful life, being the mum, wife, everything and it's all on me". [Participant 333, Indian, female]*

Moreover some women also described the emotional effect their own health was having on their children and this was because the women were aware of their concerns for them.

> *P: "My second twin whose studying medicine is giving me a hard time because I am not looking after myself and she cried one day. She said she sees people's heart, people with diabetes and blocked arteries and once she cried and said this is my mum in 5 years". (Participant starts to cry) [Community participant, 35, Pakistani, female]*

> *P: "My children, they are very concerned about me and my health. They always tell me to look after myself, especially my eldest daughter she is very concerned". [Community participant 42, Pakistani, female]*

An emerging finding was that some women were aware of the effect their health and diabetes was having on family members, especially their children. The women described their children(s) concern about their diabetes, which seemed to encourage some women to better manage their diabetes and health.

Emotions in relation to religion and diabetes management will be discussed in the next chapter 10.

9.14 Giving and receiving information

In addition to the immediate family; networking and engaging in conversation with the extended family and friends in the community with diabetes was also common. There was no evidence of stigma or shame of disclosing diabetes to the community as previously found in the literature (Goenka et al, 2004). Rather participants described how much they liked to talk about diabetes and receive new information on foods and medication to help improve diabetes control (this is discussed further in Chapter 10).

> *P: "I also like talking with other people who have diabetes and getting information and advice from them too" [Participant 313, Pakistani, male]*

A minority of participants who were fluent with English language described the use of email to exchange information on diabetes.

> *P: "We have conversations about it and my friend K actually sent me an email the other day about a diet regime he has tried…..and yeah if somebody said that cut out the chapattis and eat more rice or vice versa then I'm quite happy to listen to that". [Community participant 34, Indian, male]*

Most of the networking took place in informal settings such as the place of worship, each other's houses or the community centres. Some participants also described helping and giving advice to other people with diabetes.

> *P: "If somebody asks me…I give them advice on taking medication regularly and go on a diet and eat in moderation and take some exercise". [Participant 96, Indian, male].*

Some participants also liked the idea of giving information on changing lifestyle to improve diabetes control using examples from their own experience. This was so that others could learn how to maintain good control and reduce the risk of future complications. Again, this presents the tensions between fatalistic beliefs regarding diabetes control and future health, but at the same time trying to improve self-care and helping others to improve personal control.

> *P: "I tell them because I want other people to realise that with diabetes you don't have to suffer, you can control it and live a good healthy lifestyle and I like them to understand that if you eat healthy and look after yourself then*

> *you won't suffer. So people get so many problems which slowly, slowly creep up". [Participant 79, Indian, female]*

However, one participant described receiving too much information from her family for her diabetes, especially her husband.

> *P: "He always, always, always, always, always gives me a lecture don't eat this, don't do that, go for exercise….check your diabetes everyday but I can't check every day because it's painful, I have to inject needles twice a day and I said 'no' don't push me please [laugh] ….all his friends are doctors, wives are GPs, so I always get advice and new advice. If I have any problems I just discuss with my husband and he would discuss with the diabetes specialist…but he supports me a lot, he brings new things….literature with new, new up to date information".*
>
> *I: "Do you like to read it?"*
>
> *P: "Sometimes but not all the time [laugh] because you get fed up". [Community participant 42, Pakistani, female]*

This was a deviant case and is likely to be due to the participant's husband being a healthcare professional (a consultant) working in secondary care with access to unlimited information on diabetes from colleagues, and the Internet. This participant was recruited through snowball sampling strategy and her demographic status was only disclosed at point of the interview.

Some of the participants were also trusted sources of information for their families 'back home' in the East (this will be discussed in further detail in the next qualitative results Chapter 11), therefore, talking about diabetes and sharing information over the telephone or Skype was described as a regular activity.

> *P: "I do tell my mum (in Pakistan) because she's diabetic, so I tell her don't eat this and don't eat that…they think what I do is right that's what they think". [Participant 267 Pakistani, female]*

9.15 Chapter Summary

The qualitative data presented in this chapter covered three main themes: Fatalism, normalising diabetes and social networks. The fatalism theme showed that fatalistic beliefs were prominent for the *cause* of diabetes and/or the *control* of diabetes.

However, there were also tensions between believing and relating the cause of diabetes to fate and being aware of and having knowledge about the scientific facts about the cause of diabetes. Similar tensions were also evident for beliefs related to control of diabetes, with British born South Asians less likely to attribute diabetes control to fatalism. The belief that God had control of their diabetes seemed to be a common way of coping with the condition, especially in the older British migrant South Asians.

Normalising the diagnosis of diabetes as part of life for South Asians was common in this study. This was either due to the knowledge of diabetes being hereditary, with friends and family already living with the condition, pre-existing knowledge of the association between South Asians diet as one of the factors in the high prevalence of diabetes. Normalising diabetes seemed to reduce the emotional distress of the diagnosis, but it also reinforced the expectation and/or anticipation amongst participants of the diagnosis of diabetes; refraining them from engaging in preventative behaviours to reduce their risk of diagnosis.

In addition to the findings of the quantitative study in relation to social networks; the accounts on social networks provided a richer, more comprehensive understanding into which network members carry out specific diabetes-related ‘work’. This data also highlighted the significance of family, specifically women, children and friends in providing emotional and practical support for diabetes. However, the significance of the family in providing practical support for diabetes also differed between the types of relationship participants had with family members. Men seemed more reliant on their wives for work related to diet and medication, whilst women were more dependent on their children for information and support for diabetes because their children were more fluent in English. The children translated information on diabetes from English to the relevant South Asian language. Some children also searched for information on diabetes using the Internet for their mother. In addition to managing their own diabetes, some women also had the responsibility of being a housewife and in a minority of cases had the responsibility of providing full-time support to their husbands suffering with mental health problems. Finally, networking and sharing information with friends and family in informal settings on diet and medication was a regular activity which participants described as helpful. The interpretation of these findings is discussed in Chapter 11.

The next chapter provides further results of the qualitative study and focuses on the influence of culture and religion on diabetes management.

Chapter 10

Results of Qualitative Study 2: Social, ccultural and religious influences on diabetes management

10.1 Introduction

This chapter will present further qualitative themes (Figure 9.1 – thematic map) and describe how specific cultural and religious beliefs can influence diabetes management. The focus of this chapter is on three key themes that emerged from the PhD qualitative interviews: alternative therapies, travelling ‘back home’ to the East (India, Pakistan or Bangladesh), as well as the changes people make to their medication and dietary regimes when fasting during religious occasions. It is important to note that the South Asians in this study were predominantly migrants (n=33) from the Indian subcontinent. Therefore, the first two themes presented in this chapter relate mainly to the migrant South Asians with T2DM, using oral medication to control their diabetes.

10.2 Using alternative therapies

Some South Asian people in the UK have been known to use alternative therapies (e.g. food therapies, herbal medicine, Ayurvedic medicine) for their diabetes. This is often due to cultural differences (East vs. West) in conceptualisation and treatment of diabetes and a lack of understanding and communication between patients and healthcare providers (Qureshi, 1990). Alternative therapies pose a challenge for the allopathic medicine for diabetes in that some people may choose not to adhere to their GP prescribed medication, which may have serious implications for diabetes.

10.3 Beliefs about food therapies – South Asians migrants with T2DM, using oral medication

The findings of this qualitative study found that alternative therapies were believed to improve diabetes control in conjunction with the GP prescribed allopathic medication. This was particularly evident for migrant participants with T2DM taking oral medication to control their diabetes.

Karella (also known as 'Momordica charanita', or 'bitter melon') was the most common food used. Participants believed that the bitterness from the vegetable Karella, would improve diabetes control by regulating sugar levels.

> *P: "I have Karella and Karella bhaji they are very good. It brings the sugar level down yeah Karella bhaji and green chilli [laugh]. I have the aloe vera juice. My Pakistani friend says that Aloe Vera very small aloe vera…it makes the glucose levels go down because it is so bitter". [Participant 5, Bangladeshi, male]*
> *Daughter: "Very, very good actually the Karella and the juice".*
> *I: "How did your mum find about Karella?"*
> *Daughter: "All the Asian families, they all know, everybody knows.*
> *It gives you more energy for diabetes people, gets you more stronger, it gets your kidneys even more stronger all around the system, so it keep that stronger and it keeps the diabetes in level as well. In small towns in Pakistan, people who have diabetes they will check it out and doctors will say do this and that but to keep them in control they will have Karella not take tablets or anything else, so will just eat Karella". [Community participant, pilot study 6 Pakistani, female]*

In the actual interview participants were asked if they were using any alternative medicines. The findings of this study showed that participants were in fact using food therapies. Therefore for clarity the term 'food therapies' will be used hereafter.

In addition to Karella, some participants described taking a mix of herbs that were also thought to reduce blood sugar levels and improve diabetes control.

> *P: "I've got my own remedy as well as the medical…so I use that….it's a mix of herbs, which my wife usually does for me. It just reduces the blood sugar…it's a mix of ginger, rosemary and wheat. In fact they said if you take it for 30 continuous…three months…continuous, all the time, it will get rid of your diabetes altogether. It's a good remedy, it helps. …Honey and cinnamon*

> *as well, I've found it good for diabetes". [Participant 134, Pakistani, male]*

Although participants described taking the allopathic medication for their diabetes prescribed by their GP, there was a stronger preference for food therapies made from so called natural ingredients. These were believed to be less harmful to the body, with fewer side effects than the chemicals used to make allopathic medicines for diabetes.

> *P: "Karella is a vegetable so if you eat there is no side effect it's very good. I used to eat it a lot before and it worked". [Participant 326, Pakistani, female]*
>
> *P: "The thing with herbal medicine is that you don't get any side effects". [Participant 256, Indian, female]*
>
> *P: "I like to know a lot about herbal medicine…even before the diabetes I was always interested in that, because I think it's a better alternative than the medicine we get from the doctor". [Participant 134, Pakistani, male]*

There was a strong belief amongst some participants that frequent use of food therapies would help to one-day cure their diabetes, after believing the stories they heard about food therapies curing diabetes from other people in their community.

> *P:"I think err…..jamboora powder controls my diabetes better than the English medication. Using these medicines some people have permanently free of diabetes. [Participant 296, Pakistani, male]*

In addition to foods mentioned above, Box 10.1 lists all the other herbs and foods which participants reported that they had either tried or were currently using.

Box 10.1 List of foods believed to lower blood glucose levels and improve diabetes control

Green tea	Spiced tea
Black pepper	Dates
Lemon	Goats milk
Green chilli	Ginger
Cardamom	Rosemary
Cinnamon	Honey
Chick pea flour	Fenugreek
Chick peas	Okra

Participants enthusiastically described the procedure of preparing the Alternative therapies. One participant during the interview took a bag of chopped okra from the fridge and explained how he soaked them in some water overnight and then in the morning drank the water, which he believed reduced his blood sugar levels.

> *P: "Yes it's good to drink Karella water because it's good for diabetes. Also okra chop them into small pieces in the evening and put them in a glass with water and soak overnight. Then in the morning after praying on an empty stomach I drink the water". [Patient gets up from his chair and goes to the fridge and shows the chopped okra and demonstrates what he does] [Participant 373, Bangladeshi, male]*

For some participants the ritual for preparing and seeking food therapies involved family members both in the West and 'back home' in the East.

> *Daughter: "She has this herbal tea which somebody from back home used to have it. It keeps her body system clean inside, her kidneys function better and you put a couple of things in it".*
> *I: "How often does she have that?"*
> *Daughter: "She has that all day long…She has it in a bottle so she will just drink it….she feels a lot better with that, it keeps her blood sugars down, keeps her blood pressure in control and helps with weight loss because it doesn't keep much fat in the system, it keeps it clean and the ginger in it is good for the joints, seen it on TV as well". [Participant 6 & Daughter, Pakistani, female]*

As mentioned earlier, one of the major factors reinforcing participants to use food therapies were the information they received from people in their social networks (e.g. in the community), especially family and friends in the East and the West.

> *P: "Because lots of people in the family have it (in Lahore, Pakistan) so they used to tell me try this and that to reduce my sugar levels like Karella juice". [Participant 393, Pakistani]*
>
> *P: "Last time he (nephew) went to India, he told me about Jambu seeds, they are bitter and he brought me back the powder and I tried it. So if he finds out anything new he will tell me about it". [Participant 401, Indian, male]*
>
> *I: "I've spoken to a few people who have tried lots of different alternatives…"*
> *P: "Yeah like basin roti [chick pea flour bread] I know because my friend who has gone to Pakistan, her mother does these things… I eat this basin roti" [Community participant 42, Pakistani, female]*

Participants described receiving and exchanging recipes about the latest food therapies through networking with friends and family. However, these foods were not seen as alternatives but complementary to the allopathic prescribed medicines.

> *P: "Karella tablets, herbal tablets and somebody has now told me about Bhinda [okra] [voice heightened with excitement]….Mr Ali he also gives me advice on 'desi' [back home] medicines but also tells me to take the English medicines. [Participant 296, Pakistani, male]*

In addition to these networks, the satellite Asian television channel was also stated as another source of information from where some participants learned about new recipes for food therapies. For instance, participants described how a health programme on one of the Asian satellite channel's from Dubai gave information on supplementing the diet to include foods to improve blood sugar levels for South Asians with diabetes.

> *P: "Again, another thing which I do which helps me, is I take three or four dates in the morning, with a bit of water…with a glass or two glasses of water, and that helps to control the diabetes".*
> *I: "And how did you find out about the dates?"*
> *P: "From an herbal doctor on TV….on the Arabic channel…from Dubai. He's an herbal medicine person…and I think what it does is it kick starts the insulin in the body, so the body starts producing insulin quickly, and it helps to reduce the sugar". [Participant 134, Pakistani, male]*

A minority of participants described the uncertainties of the potential side effects of the food therapies.

> *P: "There are a lot of other medicines, I know someone in Preston who had something".*
> *Wife: "It (diabetes) goes away completely, some sort of powder you take".*
> *P: "He kept telling me to, you know get this powder ordered from India. I said it's alright because the thing is it might be good but I am always wary about trying new stuff because of the side effects or anything like that so you've got to be careful". [Participant 7, Indian, male]*

Despite recommendations from social networks on the benefits of taking the food therapies, some participants hesitated to try them. As mentioned earlier, the preference for food therapies was stronger for participants on oral medication than those on insulin injections.

> *P: "I think that for people on insulin it probably doesn't have much of an effect… whereas if its diet control you might be able to change it [Community Participant 38, Pakistani, Female]*

10.4 Beliefs about food therapies – UK born and migrant South Asians with T1DM

UK born and migrant South Asians with T1DM and/or taking insulin to control their diabetes reported hesitating from trying food therapies for different reasons. Few migrant participants on insulin injections reported that they believed and felt it was too late to try food therapies, and some suggested that they regretted not using them earlier.

> P: *"I have tried it but it doesn't work. I've tried this thing from Pakistan [kala jauw] but they are very bitter…it doesn't make a difference. I feel that had I done all this before the insulin it may have helped but now I am on insulin and this is now a must for me. There is another friend I know who is much younger and has diabetes and is on tablets. I passed those black seeds to her to try because she is still not on insulin. The doctor has told her to start insulin but I have told her to try this alternative first". [Participant 393, Pakistani, female]*

A small minority of migrant participants, when probed, described discussing food therapies with the GP. One participant reported that his GP had advised him that it was the 'best thing for diabetes'.

> *I: "Have you ever spoken to your GP about the herbal medicines you've tried?"*
> *P: "I did once with the Asian doctor who advised me about the Jamboora powder and told me it's the best thing for diabetes". [Participant 296, Pakistani, male]*

However, the UK born participants with T1DM reported to have knowledge about food therapies (and other alternative medicines) and believed it was a waste of time talking about it with their GP.

> *P: "I've heard of it but I don't feel like trying it. People say it all the time that it will reduce the sugar levels but if you're educated enough then you will know what's in it and what's not".*
> *I: "Have you ever discussed this with your GP?"*

> *P: "No it's just a waste of time" [laugh] [Participant 313, Pakistani, male]*

These participants seemed to relate using food therapies to people who were not adequately educated or did not have the correct information about diabetes, and the ingredients used to make the food therapies.

10.5 Travel back to the East

As mentioned in the preceding section, the majority of South Asian participants with T2DM in this study were migrants from the Indian subcontinent. Thus, the data in this section relates mainly to this group, along with reference to UK born South Asians where appropriate.

Compared to the UK born South Asians, it was more common, especially amongst the migrant participants to travel 'back home' (India, Pakistan, Nepal or Bangladesh) for a prolonged period of time (six weeks to two months or more). However, going 'back home' had an influence on diabetes management, mainly attributed to the hot weather conditions in the East.

10.6 Sweating out the 'sugar' in the heat

A majority of migrant participants preferred the hot weather in the East because they were able to spend more time outdoors and sweat in the heat. Sweating was believed to help eliminate excess sugar and impurities from the blood to improve diabetes control:

> *P: "The heat and sweat…when you sweat the sugar levels stays in control". (Participant 296, Pakistani, male)*
>
> *P: "When I go there and sweat it out all my impurities you're just sweating it out" (Community participant 26, Indian, female)*

The meaning of a holiday for some participants in this sample was also to have a break from their medication for diabetes. For instance, some participants described stopping their diabetes medication for diabetes or altering their medication regime whilst on holiday ‘back home’.

> *I: “Did you take all your medication with you?”*
> *P: “I think I didn’t need it”*
> *I: “So you stopped taking it?”*
> *P: “Yeah because I didn’t need to take it because my sugar levels were in very good control”. (Participant 296, Pakistani, male)*
>
> *P: “Every time I’ve been it’s in July when it’s hot and I like hot weather. Everybody keeps saying how I can cope with the heat but I like it…I never take any medicine when I am there… for 6 or 7 weeks that I am there, I never take”. (Community participant 27, Pakistani, female)*

A minority of participants also described how their GP had advised them to go ‘back home’ when the weather is warm there because it was good for their health and diabetes.

> *P: “The heat is there and I sweat it out…my GP has also advised me to go away back home for 3 months when the weather is warm”. (Participant 329, Bangladeshi, male).*

Some participants believed that they had better control of their diabetes in the East, even without medication.

> *P: “When I go there my diabetes is gone….I feel good but when I come back it’s gone higher". (Community participant 42, Pakistani, female)*

Compared to when they are in the UK (West), some participants believed that their diabetes was cured or had disappeared whilst ‘back home’ in the East.

10.7 Diet and exercise in the East

Most of the migrant South Asian participants with T2DM on oral medication believed that their diet was much healthier ‘back home’ due to the availability and consumption of more fruits and vegetables daily.

> *P: “You get fresh fruit and vegetables every day, they come to the house with a cart every day or there are markets nearby too but it’s fresh every day”. (Participant 401, Indian, male)*

The foods in the East were also believed to be fresher and easier to access compared to the West, where participants often described using frozen foods instead of going to the supermarket every day to buy fresh foods.

> *Daughter: "Here you cannot get fresh vegetables; there* [*Pakistan*] *you can so she has fresh stuff all the time. Here whatever is in the freezer she will take it out and cook it? She gets a lot of fresh fruit and vegetables from there. So there is a big difference with how she deals with things here and how she does it there. There she is healthier so she is active down there, fresh fruit is always better, so she takes care of herself down there. She can't take care of herself much down here* [UK] *because my brother is always at work, I am at my place, my sisters are always at college or busy so she is always on her own but Pakistan she has her dad, brothers and sisters and their kids". [Community participant, pilot study participant 6, Pakistani, female]*

In addition to availability, the family members in the East also seemed to have an important role in facilitating diet (e.g. in Pakistani and India).

> *P: "There the family makes it and here* [UK] *I have to do it myself or go out to eat…it depends on the weather. I have frozen items like fish… it's in a tub and I put it in the oven and its ready in 15 minutes and I have that with some vegetables" [Participants 313, Pakistani, male]*

In addition to eating a healthier diet in the East, participants described how the hot weather provided more opportunities to exercise outdoors and gave them further opportunities sweat in the heat. As mentioned earlier, sweating in the heat was associated with better health and diabetes control.

> P:*"Here most of the time its damp and raining we stay indoors and don't move much but in Pakistan you go out more and walk more, the sun is out and you sweat and you have less health problems". [Participant 398, Pakistani, female]*

Participants described walking more with family members, and making attempts to model their family's perceived healthy lifestyle, whilst on holiday 'back home' in the East, compared to when they are in the UK.

> *P: "When I came from Pakistan I was healthier than I was here and I felt much better because my sister-in law everyday she goes to the park and still I think she goes to the park and walks for 2 hours and comes home. When*

> *she comes home she will eat. I copied her and I felt much better". [Participant 326, Pakistani, female]*

> *P: "You can't get out and enjoy and you don't have the freedom to go out and do things like go for walks for a start but err everybody gets a bit low in the winter times…I would like to live in India for 6 months and here for 6 months". [Community participant, pilot study 7, Indian male]*

Holidaying 'back home' seemed to give a sense of freedom and motivation to engage in healthy behaviours and live a healthy lifestyle, despite non-adherence to diabetes medication.

> *P: "Whenever I go India….you feel like going out and you're not restricted to do anything, whereas, as soon as you come here, you're in front of the box (TV) twenty four seven and that's your life now". [Participant 332, Indian, male]*

On return to the UK (West), participants described being less active (in the West) due to poor weather conditions, especially in the winter. However, for some participants the lack of exercise in the West was also related to poor mobility.

> *P: "I used to go walking but I've got knee problem and sometimes foot problem. I think these days because of the weather I feel worse…the doctor told me I need vitamin D and has given me tablets to take". [Participant 326, Pakistani, female]*

> *P: " I don't do enough exercise here (West) because the climate is different from Bangladesh errm… the glucose stays in the blood and the cholesterol is higher which it normally wouldn't be in Bangladesh… because I don't do any form of exercise (in the West) I don't sweat it off that's what I think". [Community participant, pilot study 5, Bangladeshi, male]*

There were tensions between participants having knowledge about the importance of exercise for diabetes, and being self-aware of the little time they actually spent exercising and the potential effect this maybe having on their diabetes.

Some participants also related other health problems in addition to diabetes to not being able to sweat or eat a healthy diet. Thus the lack of opportunity to sweat and the availability of fresh food in the UK were generally associated with poor health and poor diet.

10.8 ‘Not all good’ – UK born South Asians with T1DM

A small number of UK born participants described the difficulties of managing their diabetes when holidaying in the East. One of the main difficulties was travelling with insulin and not being able to store it at the correct temperatures. Even when fridges were available, participants reported that there was no guarantee that electricity would be available for the whole day in certain parts of Pakistan.

> *P: "These days in Pakistan it’s terrible conditions, no electricity for about 8 hours….so in the summer it’s very difficult and because I take insulin I have nowhere to store it when the electricity goes. It’s supposed to be stored between 2-8c and sometimes it can take up to 16 hours for the electricity to come back….the problem is the fridge won’t work which means the efficacy of my insulin will reduce…and I get sick there”. [Participant 313, Pakistani, male]*

For the UK born South Asians, adapting to the diet in the East was a strong concern and one participant in particular described being reluctant to try any of the food or drink tap water whilst on holiday in Pakistan due to the fears of becoming ill.

> *P: “As far as the diet goes, it’s nil and void, basically….when we got there, I bought a fridge and, basically, I just bought, because the water’s not very good there, so I bought bottled water, I bought sprite, I bought coke, several things, I filled the fridge with these thing…. if you eat from there (Pakistan), your stomach is going to go so, basically, I just instructed my wife to get…we went shopping and just get, like, you know, beans and get loads of potatoes and stuff like that and just chips and beans for a fortnight when we were there, you know….that’s all we ate and, obviously, we drank stuff from the bottles, I didn’t want to have any water from there….. I’ll eat probably a thousand calories a meal and then have my medication so, obviously, that’s in my system, I take it with me all the time but it’s…diet wise it’s not very good”. [Participant 398, Pakistani, male]*

This participant was a deviant case in the sample data set. His diet was quite the opposite in comparison to the migrant group, and he did not prefer or trust the fruit and vegetables in Pakistan. Instead he believed it was better to restrict his diet and preferred to eat Western/English foods whilst in the East. The interpretations of these findings are discussed in Chapter 11.

10.9 Diabetes and Fasting

The previous two sections of this chapter focussed on some social and cultural factors that influence diabetes management. The next section of this chapter moves beyond these factors to explore the role of religion on diabetes management, by specifically focusing on how South Asians report altering their diet and medication regimes during auspicious and religious occasions.

Some of the respondents reported participating in fasting at some point during the year, to either mark a religious ritual or other auspicious occasion such as Ramadan. However the meaning of fasting differed according to the sub-ethnic group (Indian, Pakistani, Bangladeshi and Nepalese) and identified religion (Islam and Hindu). It was evident from the findings that fasting was practised in participants with T2DM therefore most of the findings described in this section of the chapter relate to participants with T2DM.

10.10 The importance of fasting

Of the participants from the four sub-ethnic South Asian groups interviewed, the Bangladeshi and Pakistani (n=21) participants followed the Islam religion and the Nepalese (n=1) and Indian (n= 22) participants followed the Hindu religion.

Some of the Pakistani and Bangladeshi Muslim participants described fasting during the holy month of Ramadan. The Muslim participants believed that fasting during Ramadan was as a religious duty that should be fulfilled in spite of living with diabetes.

> *P: "For Muslim people it is vital to fast. Yes I am ill but my faith keeps me strong and if I am going to get worse health wise I am going to get worse no matter what". [Participant 373, Bangladeshi, male]*

However, some of the Indian participants described fasting more frequently throughout the year, for instance during Ekadashi (*spiritually beneficial day 11th day of every month*). For these participants, fasting not only marked an auspicious day in the Hindu calendar, but also a day to do God's work, gain will power by abstaining from everyday foods and a good way of detoxifying and cleansing the body.

> *P: "Why we do Ekadashi is because our Hindu culture says whatever time you spend every day eating and cooking, you should spare that day and do gods work… its controlling of the mind and errr give your tummy a bit of a rest because we put everything in our stomach so one day you should give a bit of a break" [Participant 96, Indian, male].*

This participant was a deviant case in the sample data set. The participant explained how one GP told him that fasting once a week was a good way to clean the system, and another GP advised him to stop taking his medication during the fast, to prevent low blood sugar levels.

> *P: "My doctor told me not to take medicine when I fast…he told me not to take diabetes medication because the blood sugar will go low, so I am not taking it. Another doctor said it's good, it's alright….Once a week you fast it cleans your system. When we break the fast we take the medicine but on Thursday's I fast and I don't take medicine" [Participant 401, Indian, Male]*

In addition to the religious significance of fasting, some participants described some of the social activities that were a significant part of the fasting ritual. For instance, exchanging foods, eating as a family, going to the mosque, and praying with the family.

> *P: "We meet each other, we support each other, and you find plates of food are being exchanged in the streets [laugh] from Muslim to non-Muslim…we all eat at the same time not come back from school and have dinner or come back from work and have dinner without waiting for others. Everybody eats at the same time. We all walk to the mosque and open fast there, my husband he likes that. We have lots of visitors I love Ramadan!" [Community participant 19, Pakistani, female]*
>
> *I: "Do you have a lot of social gatherings during Ramadan?"*
> *P: "Yes we do…parties, when we open fast…I invite my brother, my daughter, son…we go there" [Community participant, 27, Pakistani, female]*
>
> *P: "I like the family thing because the kids fast as well and the eleven year old fasts and the younger one will sometimes, she's only five now but she gets up in the morning she says. "I want to fast as well' so it's good, its family time, isn't it?" [Participant 398, Pakistani, male]*

10.11 The joys of fasting

Across both the religious groups there seemed to be mixed feelings and emotions about fasting. Some of the participants described feeling happier, more energetic and revitalised during fasting.

> *P: "At the beginning I feel weak but then I am okay. It makes me feel mentally and physically strong, very, very strong more lighter". [Community participant pilot study 5, Bangladeshi, male]*

Some of these participants also described having better control of their diabetes during fasting.

> *P: "I have better control during Ramadan. I eat once in the morning and then I don't eat anything throughout the day and when it's time to eat my sugar level is usually between 3.6-4.2mmol". [Participant 313, Pakistani, male]*

These beliefs were further exacerbated by deeply held beliefs that 'Allah' was helping and giving them the strength to fast which further reinforced fasting behaviours.

> *P: "Allah made it or us and he helps us, Allah helps us loads, it doesn't make any difference. You feel very fresh, very happy and very calm". [Community participant 27, Pakistani, female]*

> *P: "I feel much better and active during Ramadan"*
> *I: "Why is that?"*
> *P: "I don't know…it's just because its nature and god helping me and because I feel good during fasting". [Participant 303, Pakistani, male]*

The positive emotions of fasting were also heightened by the spiritual feelings experienced during fasting.

> *P: "It's something emotional, gives you a feeling that you have a guest in the house which you love err…you feel you have somebody with you in the house". [Community participant 19, Pakistani, female]*

10.12 To disclose or not to disclose?

Similar to the issue of not disclosing using food therapies for diabetes, most participants described how they were not willing to disclose fasting to their GP, due to the fears of being told not to fast.

> *P: "I don't bother to tell my GP. It doesn't matter whether the doctor says yes or no I will still fast…my doctor never advises anything for Ramadan even though he is a Muslim doctor himself. I am really surprised about this. I am not very happy about my GP". [Community participant, pilot study 5, Bangladeshi, male]*

Some participants believed that their GP or practice nurse (PN), who was often the primary care professional they saw most often about their diabetes, did not understand the significance of fasting and would therefore not be able to support them.

> *P: "I suppose if they are not from that cultural background they won't understand it anyhow. To them it's what you've got to do for your health". [Community participant 38, Pakistani, female]*

The reluctance to disclose fasting did not seem to be influenced by the ethnicity of the GP. Regardless of whether the GP was reported to be Pakistani Muslim or White British, participants still perceived their GP to have a lack of expertise to support them effectively during fasting.

> *P: "I've not openly told her I fast but she knows I am Muslim she should tell me…she knows but she doesn't say anything. It would help to know what to eat when I open my fast because I jump on to the dates and sweets. [Community participant 19, Pakistani, female]*

There was also a tension between assuming that the GP did not have knowledge about fasting but believing that GPs practicing in an area where there was a predominately large population of South Asians should have knowledge about Ramadan and be able to support patients wishing to fast.

> *I: "Have you spoke or told your GP about fasting?"*
> *Daughter In-law: "They tell us make an appointment".*
> *P: "They know because so many Asians living there… they never give any advice and they ask me when I feel dizzy do I not want to drink water and I*

> *just say no. You not even drinking water? I say no I am not drinking anything and she asks how I can survive. I just say that I can survive it [laugh]". [Community participants 27, Pakistani, female]*

10.13 Changing medication regime

It was common for participants to make changes to their medication regime during fasting without further consulting their GP or PN. Participants seemed to be aware of the potential risks of fasting to their diabetes control and described frequently monitoring their blood sugar levels to prevent the onset of a hypoglycaemic episode.

> *P: "I manage very well - I lower my dose of insulin and bring my sugars high and drink orange juice. You've got to have it high to last the whole day, and if I started with low sugars I would not survive the day. I would have a hypo. I am very, very careful and I do monitor my sugar very carefully". [Community participant, 21, Pakistani, female]*

Only a small number or participants reported informing their GP about fasting, and whether or not to fast.

> *P: "I took advice from my medical nurse, so if they say 'you can fast' then I'm going to fast because I can and I've been told I can". [Participant 398, Pakistani, male]*

A minority of participants with T2DM believed that fasting was detrimental to their diabetes and some were told by their GP not too fast.

> *P: "I used to. But since I became diabetic, the nurses told me, they said I can't do the fasting anymore. So I've stopped fasting…..but I used to do a lot of fasting". [Participant 333, Indian, Female]*

However, people still continued to fast, despite reporting that their GP had advised them not to.

> *P: "They mainly advise not to fast but I never really took that advice. I follow my own pattern….I have a lot of control over my diabetes and I've never made it an issue that I have diabetes and I can't do this and that". [Community participant 21, Pakistani, female]*

> P: *"They think that because I am diabetic I shouldn't fast but I don't follow that rule because you know I am not at a high stage. To be honest with you there is one verse in the Quran and it says that 'the person is a doctor to himself' if you find out you are ill and it's going to affect you, you have to break it. Luckily I have not reached that stage and I fast" [Community participant 19, Pakistani, female]*

The majority of participants described diabetes-related consultations with their GP and PN as unsatisfactory, with no help being offered.

> P**: "***I've discussed it with my nurse and she said, 'the choice is yours, but you've got your medication.' She pointed out that I will have long gaps. I never really know how it's going to affect me…even though I've asked them they say it's my choice". [Participant 244, Pakistani, female]*

There was also a tension between not disclosing fasting but wanting support and advice from the GP on fasting. This was particularly the case for Muslims during Ramadan. Some Muslim participants described how they refrained from accessing health services or going to see their GP during Ramadan.

> *P: "In that month I never go to the doctor – that one month I feel fine [laugh]. If I am not well, I still don't go because they will tell me not to fast". [Community participant 27, Pakistani, female]*

It seemed that most of the participants would welcome support from their GP providing he/she was trained, empathetic and understood the significance of fasting for people with diabetes.

> *P: "Maybe if she said eat this and don't eat this I would find it helpful but I haven't asked and maybe if they had training about Ramadan or if it was a Muslim doctor I would ask". [Community participant 19, Pakistani, female]*

10.14 Guilt of not fasting

Some participants described their attempts to fast after being diagnosed with diabetes, especially those who had been fasting since childhood. These participants described the difficulty and guilt they experienced breaking the tradition.

> *P: "I do feel bad because I'd done it for all these years….I used to fast every Monday since I was 8 or 9 years old but the doctor said not to fast because of my medication - you get that drummed into you. At first I did feel bad but*

> *then accepted it. I've fasted all my life, but for my health's sake, to get my diabetes in control I stopped". [Community participant 26, Indian, female]*
>
> *P: "It's because of my diabetes. I can cope without food for four hours and more or less after that I like my head is going round and round. I can't concentrate on jobs and then I don't like to drive things like that…. I wish I could you know. [Community participant, pilot study 4, Pakistani, male]*

Some of the participants also described feeling guilty and ashamed for not fasting and not doing right by their religion and beliefs.

> P: "*I feel guilty. It's still the inner feeling, like I feel like I'm not doing the right thing by my religion and my beliefs. In our religion it says that if somebody is on medication, and you're ill, you're not compelled to do it. And my husband convinced me of that and said, 'you're not to blame. And you do need your medication and you do need to eat small amounts. So that's why I don't fast anymore". [Participant 244, Pakistani, female]*

In addition, some were also told by their family members not to fast because of fears of poor diabetes control or the consequences fasting would have for their diabetes.

> *P: "My husband he won't let me fast. If he finds out he'll kill me....I still miss out on my fasting….every Thursday come I thought 'oh I should be fasting' but I can't do fast anymore… I feel like fasting because I'm Indian you do so many fasting. I used to fast every Thursday and so many like in the years a time you get so many fast ...I used to do everything but after I'm diabetic I can't fast. My husband said no you're not fasting anymore. He won't let me do it". [Participant 267, Indian, female]*

However participants reflected back and described how they used to fast before they got diabetes and how they wanted to fast for religious reasons, but felt restricted not to fast because of their diabetes and the pressure from the family not too fast.

10.15 Chapter Summary

The use of food therapies in conjunction with the GP prescribed medication for diabetes was more evident for British migrant South Asians. There were tensions between the perceived benefits of GP prescribed medication for the treatment of diabetes and the concerns about the side effects of the ingredients used to make them. The main reason for taking food therapies was to improve diabetes control in the hope that one day their diabetes would be cured. Networking with friends and family both in the West and in the East for the latest recipes on food therapies for diabetes was common. Travelling back home to the East to visit friends and family was an important tradition for South Asian migrants living in the UK. There was a strong preference for being in a warmer climate, than the wet and damp conditions in the UK. Migrant South Asians with T2DM believed that being back in a hot climate improved their diabetes control as a result of sweating in the heat and having more freedom to go outdoors and walk more. Most of these participants also believed they had a healthier diet in the East due to daily access to fresher foods. Consequently, some of the migrant South Asian participants with T2DM believed their diabetes disappeared in the East, and as a result stopped taking their oral medication until they returned to the UK. Fasting during religious and auspicious occasions was an important part of both the Islam and Hindu religions. Fasting also had a social significance. Nonetheless participants were reluctant to disclose fasting to their GP and/or PN due to the fears of being told not to fast. Some also believed that the HCPs would not understand the importance of fasting, even for people with diabetes. Those who did seek advice on fasting described consultations with their GP and PN as unsatisfactory with no help being offered. Some participants also admitted to fast even when their GP or PN advised not to. They also believed that they had better control during fasting despite abstaining from their diabetes medication and in some cases, abstaining from food and drink for up to 12 hours. Participants suggested that HCPS should be able to support patients with diabetes who choose to fast.

Chapter 11

Discussion

11.1 Introduction

This chapter will begin by summarising the main findings of the quantitative and qualitative studies. The following section will compare and contrast the findings of this mixed methods study with previous research, and the implications for the findings in relation to previous research and the CS-SRM. A critique of both the quantitative and qualitative study and the wider implications for research, education, policy and practice will be considered towards the latter part of the chapter.

11.2 Summary of the main findings from the quantitative and qualitative studies

The overall aim of this study was to explore the role of illness beliefs and social networks in diabetes for South Asian people, using a mixed-methods approach**.** Examined individually, the analyses of the quantitative study in Chapter 8 showed that certain social network characteristics: *size of the support network, number of supportive females, practical and emotional work* was related to diabetes-related beliefs, as measured by the BIPQ. However, after multivariate analysis only one of these characteristics, *emotional work*, remained a significant predictor of concern and emotional distress related to diabetes. Fatalism was associated with two demographic variables (rent and accommodation) (Table 11.1). These findings are discussed in further detail later in this chapter.

The aim of the qualitative study was to explore in-depth, beliefs about diabetes management in relation to the social, cultural and religious context in which South Asian people live and manage their condition. This study complemented, elaborated and extended some of the findings in the quantitative study, particularly the data on social networks and fatalism beliefs (Table 11.1). In addition, this study informs on *how* and *why* individual beliefs about diabetes are influenced by factors such as culture and religion.

11.3 A framework for mixed methods integration

There is a debate in the literature on the 'best' method for integrating the findings from mixed methods studies. Bryman (2007) argues that a common barrier and difficulty in conducting mixed methods research is that of merging analysis of quantitative and qualitative studies to provide integrated analysis. Using the aims of the study aims as a platform for integrating the data from the quantitative and qualitative studies has been suggested to overcome the issue of integration (Byrman, 2007). Thus, to elaborate on the findings of both studies, the next section will be structured using the research aims, as well as the sub-research questions presented in Chapter 4. The main reason for structuring the discussion in this way is to:

- Present the findings from the two studies (Table 11.1);
- Show where the findings from both studies complement and contrast each other;
- Show where and how the qualitative study informs and extends the findings of the quantitative study, as intended when using a 'sequential embedded mixed methods design'.

Table 11.1: Main findings of the quantitative and qualitative studies

Aims	**1.Quantitative Study** **To explore the role of diabetes-related beliefs (including fatalistic beliefs) and social networks in the management of diabetes in people of South Asian origin.**	**2.Qualitative Study** **To explore the personal, social, cultural and religious context in which people of South Asian origin live and manage their condition**
Sub-questions	**Findings**	**Themes**
1. What demographic and social network factors are associated with illness and fatalism beliefs?	• *Fatalism* was associated with *deprivation, accommodation status* and *mix of agents*. • *Consequences* of diabetes were significantly associated with *total number of conditions.* • *Emotional work* was a significant predictor of *concern* and *emotional representation.*	**Fatalism** • The *cause* and *control* of diabetes was attributed to fatalism, especially in the migrant South Asian group. **Normalisation** • Diagnosis of diabetes was normalised and accepted as part of life.
2. How do illness and fatalistic beliefs differ between sub-ethnic South Asian groups?	• *Identity* of symptoms and *fatalism beliefs* were greater in the Pakistani group than the Indian group.	**Social Networks** • Family members were important in doing diabetes-related *practical work (e.g.* diet, cooking and medication).
3. How do illness and fatalistic beliefs relate to other health outcomes?	• *Fatalism* had no significant association *with health outcomes.* • *Consequences, control, identity, treatment control, concern and emotional response* were positively associated with at least one health outcome.	**Alternative Food Therapies** • Migrant South Asians with T2DM commonly used food and alternative therapies, made from 'natural ingredients' in conjunction with their GP prescribed oral medication for diabetes.
4. What social, cultural and religious beliefs influence the experience and practices of diabetes management in the South Asian population?		**Travel to the East** • During the summer season in the East to visit friends and family. • Important tradition, especially amongst the older British South Asian migrant population, but had implications for their diabetes management. **Religion and diabetes** • Fasting during religious and auspicious occasions (part of both the Islam and Hindu religions).

Key 🟪 Qualitative study findings compliment, contrast and/or extend the findings of the quantitative study.
🟩 Qualitative study findings unique to the findings of the quantitative study.

This next section begins by interpreting the findings of the quantitative study outlined in Table 11.1, as well as using the findings of the qualitative study to elaborate on the quantitative results.

11.4 Demographic, social network illness and fatalism beliefs (sub question 1)

In the quantitative study, deprivation (as measured by the Index of Multiple Deprivation) and accommodation status was significantly associated with fatalism beliefs (item 2 –*'there is little I can personally do to improve my health')*. After the removal of an outlier, one social network (mix of agents) became significant with fatalistic beliefs. None of the other social network factors were associated with fatalistic beliefs. This suggests that South Asians living in renting accommodation and in deprived areas of Greater Manchester, with a mix of different relationships held more fatalistic beliefs about their diabetes and were more likely to attribute control to external sources. This lends support to previous evidence on the relationship between demographic variables such as age, social class and sex and health beliefs (Bhopal et al, 2002). The way in which people cope with an illness has also been related to social class membership and the types of resources people have to cope with the demands of an illness (Radley, 1994). Furthermore, Cockerham (2007) suggests that people, especially those from lower social class backgrounds with a lack of personal resources to cope with their illness are more likely to feel powerlessness with respect to their health and have fatalistic attitudes. As mentioned in Chapter 2, Pakistani and Bangladeshi groups have been reported to have lower levels of material and social deprivation Indians (Nazroo, 2009).

Further analysis between the two sub-ethnic groups: Indian and Pakistani showed that, compared to the Indian group, *identity of symptoms* and *fatalistic* beliefs were stronger in the Pakistani group **(sub question 2)**. This suggests that fatalism in relation to diabetes differs between the sub-ethnic South Asian groups. This also lends support to the debates in the literature on the importance of considering the heterogeneity between the sub-ethnic South Asian groups (Bhopal, 1999), especially due to the differences in socio-economic status (Health Survey England, 2004).

The relationship between beliefs in fatalism and diabetes management was further explored in the qualitative study. This method proved to be more acceptable in understanding this relationship, lending support to previous qualitative studies in this field. It also enabled finding out which participants from the sample were more likely to attribute diabetes control to external forces such as God and to believe that deities were more powerful in controlling their diabetes. The quantitative study did not control for migration, therefore it is not possible to make these types of distinctions between participants for this study. The importance of this relates back to the earlier point on accounting for the heterogeneity amongst South Asians, as not all South Asians in the qualitative sample held fatalistic beliefs about diabetes. In comparison to the findings of the quantitative study which suggest that fatalism may be related to South Asians living in disadvantage areas of Greater Manchester, the findings of the qualitative study suggest that these beliefs were more common in the migrant South Asians, than the British born South Asians. As mentioned in Chapter 2, some South Asians, especially those who have migrated to the UK and have difficulty understanding English, tend to prefer a more paternalistic style of care due to the belief that somebody or something else (e.g. the GP or God) has to take control of their diabetes rather than recognising it as their own responsibility (Kannayiram et al, 2006). The findings of this study provide further evidence for this and suggest that participants (migrants) who believe their diabetes is controlled by external forces may be less likely to take action or responsibility to influence self-management behaviours.

The fatalism items which measured whether participants believed their diabetes was dependant on chance or fate *('my illness is largely dependent on chance or fate')* was not associated with any of the social network variables or other health outcome measures. Despite both the fatalism items being validated in previous studies (Lange & Pettie, 2006); it raises questions as to whether this item is actually measuring fatalism or locus of control. This item resonates with one of the sub-sections of the Health Locus of Control measure (Wallston et al, 1978), which assesses whether one believes health is personally controlled; controlled by powerful others or by external factors such as fate or chance. Thus, it can be argued that the findings of the quantitative study also resonate with Rotter's (1966) theory of Locus of Control (LoC) due to the distinction this theory makes between those who attribute responsibility for events to themselves (i.e. internal LoC) or to external factors (i.e. external LoC) (Morrison & Bennett, 2009 p.126). This fatalism item is also quite ambiguous in combining together two opposing explanatory mechanisms (chance and fate). Thus, it is quite possible that respondents may have had difficulty understanding or deciding how to respond to the question and requires further validation. Yet the qualitative study has shown that some South Asians did believe their diabetes was part of their fate and the next section discusses this in relation to the causal BIPQ item.

11.5 Causal beliefs, BIPQ and Fatalism

The open-ended causal dimension of the BIPQ has shown that South Asian participants ranked the cause of diabetes in order of: *genetics, diet, stress, lifestyle, weight and consumption of too many sugary foods*. This suggests that participants had some knowledge of the medical and scientific factors related to the cause of diabetes in addition to their own personal beliefs about cause. Although participants ranked *genetics, diet, and stress,* as the three main causes of the onset of diabetes; some participants also attributed the *cause* of diabetes to fatalism, as shown by the findings of the qualitative study. The belief that diabetes was part of their 'fate' was further supported by the knowledge of diabetes being hereditary and living with family members already the condition. This also suggests that people who believe diabetes to be part of their 'fate' do so in the sense of it being genetic, rather than ordained by God alone. Previous studies in the literature have also found that South Asian people, like many other people from other ethnic minority groups, commonly attribute the cause of illness to heredity factors, the actions of others, the environment, fate or chance (Fleming & Gillibrand 2009; Landrine & Klonoff, 1994).

As mentioned in Chapter 3, beliefs in fatalism are often due to cultural, as well as religious differences in the meaning and understanding of illness (Sanborn & Katz, 1977). Compared to the quantitative study, the findings of the qualitative study have provided more explicit evidence for fatalism beliefs about diabetes. In addition, the findings of the qualitative study have shown that some participants also normalised the diagnosis of diabetes and accepted it as part of life and the next section discusses this in further detail.

11.6 Normalising diabetes

Normalising an illness and regimen means '*making them routine and treating whatever changes and improvisations required as ordinary and adapting to the situation at hand'* (Charmaz 2005, p. 283). There is a literature on normalisation of chronic conditions which focuses on individuals with a physical disability, for example parents of children with a chronic illness adapting and coping with their child's illness (Robinson, 1993). Yet the accounts of the qualitative study in Chapter 9 have shown that participants often anticipated or expected the diagnosis of diabetes as a 'normal' part of life, due to the knowledge and beliefs of diabetes being a hereditary condition in the family and common within the South Asian community. This finding is different to the evidence in the literature which suggest that the diagnosis of a chronic illness such as diabetes disrupts a person's life, particularly when it occurs during young or middle adulthood (Bury, 1982). Although the un-expectedness of the diagnosis of a chronic illness is thought to cause a disparity between diagnosis and the self (Charmaz 2005); this was not evident from the accounts of the qualitative study. Rather the impact of diabetes on daily life was appeared to be quickly normalised. To proceed with normal activities 'as if normal' and minimizing the impact of an illness and regimen on daily life (Drummons & Mason, 1990) have also been suggested to be a part of the normalisation process (Blaxter, 2010).

Furthermore, ‘Explanatory Models’ may also guide coping behaviours and the social meaning given to an illness (Kleinman, 1980) such as diabetes. One’s schemata *i.e. representations* may be activated under a variety of conditions in the social environment, for example, through conversation, discussions and media (Markus & Zajonc, 1985). The relevance of schemata in this study is that there was no evidence of stigma arising from diabetes in this study; rather participants enjoyed sharing their experiences and talking about diabetes. However, schemata may have been responsible for the normalising of diabetes and conceptualisation of diabetes in this target population.

In the qualitative study, there were also tensions between lay representations of diabetes and the medical conceptualisation of diabetes. This was due to the exposure to and observation of other people’s behaviour and experiences known as social norms (Turner, 1991). Normative influences and expectations have been stated to influence health behaviours and health care decisions (Fishbein & Ajzen, 1974). This concept stems from the social psychology literature and suggests that social judgements of what is appropriate and inappropriate are derived from contact with individuals in the surrounding context. The importance of social context and networks will be discussed further in section 11.9.

11.7 Consequences and the total number of conditions

As shown in Table 11.1, consequences of diabetes was significantly associated with total number of conditions (p=.005). This suggests that diabetes had more *consequences* for South Asian participants with increasing numbers of conditions. Most of the participants had some form of heart disease, as well as diabetes, as shown by Table 8.5 in Chapter 8. Thus, there is a possibility that the findings of this study were influenced by some of the participants living with co-morbidities. Previous studies report that people with vascular conditions in addition to diabetes (e.g. heart disease) are more likely to need additional support with managing their diabetes often due to diabetes being placed as a lower priority, resulting in poor health outcomes (Kerr et al, 2007). More recently, multimorbidity (the presence of more than one long-term health condition in a patient) in the general population has been reported to have implications for patient illness beliefs, particularly in relation to prioritising conditions and the burden of medication management (Bower et al, 2012). However, the analysis of the quantitative study was restricted to the sub-research questions, in which a count of the total number of conditions was explored. Therefore, it was not possible to know which conditions, in addition to diabetes had more consequences for participants, and is a limitation of this study, and an area of future research. The influence of co-morbidity or multimorbidity was not explored in any detail in the qualitative study either. This was because exploring the relationship between co-morbidities and diabetes was not a specific aim of this study.

11.8 Emotional work, concern and emotional representations related to diabetes

In the quantitative study *emotional work* was a significant predictor of *concern* and *emotional representations* of diabetes. This suggests that the more emotional support received within the network, the less concerned and less emotional South Asians were about their diabetes. It is also relevant to mention here that *concern* beliefs *and emotional representations* were also negatively associated with health status (SF-12), suggesting that participants who had lower *emotional representations* and lower *concern* about diabetes, also reported having better health status.

These findings lend some support to the previous literature on the availability of supportive ties in reducing emotional arousal in patients (Berkman & Glass, 2000) and guide health behaviour (Quah, 2005). Furthermore, the findings suggest that South Asians in this study may be been dependent on their social networks, especially their family, for emotional support for their diabetes. The family and people emotionally close to the patient have been known to play an important role in determining how the affected person reacts, defines and manages their illness (Cockerham, 2007). As mentioned in Chapter 2 and 3, current evidence identifies the importance of managing emotions related to diabetes in order to reduce the risk of emotional distress and complications associated with poorly controlled emotions in the general population (Anderson et al, 2001; Roy et al, 2012). However, a focus on only the individual managing emotions neglects the role that others (e.g. social networks) may have in providing emotional support and mediating beliefs related to diabetes.

In comparison to *practical work, emotional work* related to diabetes was not explored in any specific depth in the qualitative study, as this topic was not a specific aim of this study. However, through conversation with South Asian women on *practical work* (e.g. the responsibility of being a housewife), it became evident that the emotional representations item on the BIPQ may not be sufficient in capturing the cognitive representation of the actual emotions experienced by participants. This is because in a minority of cases women, who were full time carers to their husband suffering with mental health problems, had difficulty managing their own diabetes and emotions. These women were concerned about the impact their health was having on their children, which furthered their heightened emotions. The women in the qualitative study were more likely to describe receiving practical support from their children for their diabetes than emotional support.

The difference in *practical* and *emotional work* between genders in relation to diabetes was not explored in detail. Again, this was because exploring differences in gender for diabetes management was not a specific aim of this study. However, on speculation and from the pattern emerging from the qualitative data it seemed that *emotional work* (support) for women was sought from external factors such as religion and God. The role of religion will be discussed in detail in the latter section of this chapter. However, the findings of this study suggest that diabetes-related issues in this culture are often seen as a family concern, rather than an individual's concern, with family members providing emotional, as well as and practical support ('work') for diabetes. This lends support to the two qualitative studies with that have provided some information on the psychological impact of receiving a diagnosis of T2DM and living with the condition in South Asians. In one interview study with Indians, the most commonly cited cause of diabetes-related anxiety was the perceived difficulty of coping with changes to diet (Stone et al, 2005). The impact of dietary modification on anxiety levels was also highlighted in another qualitative study involving people of both Pakistani and Indian origin (Lawton et al, 2008). Both these studies suggested that cultural perceptions about the importance of family and social patterns of eating often contribute to anxiety and may hinder lifestyle modification for optimum diabetes control. The next section discusses the qualitative theme on the 'social networks' in particular practical work in further detail.

11.9 Social networks - practical work related to diabetes management

The social network theme in the qualitative study has shown the importance of specific family members in doing diabetes-related *practical work* such as providing information, managing all things related to diet, cooking and medication. South Asians have been known to have closer ties with family members (Chandarana & Pellizzari, 2001). As mentioned in Chapter 3, previous research into the social networks of the South Asian population has reported on the significant role family and friends have in providing and exchanging information related to diabetes (Stone et al, 2005; Greenhalgh et al 1998; Hawthorne et al, 2009; Alam et al, 2008). Although this study has shown that family members do more than just provide information; certain members were accountable for specific 'work' related to diabetes management. In particular, men with diabetes were more likely to be dependent on their wife for *practical work* related to diet and medication, whilst South Asian women with diabetes were more dependent on their children for information and support for diabetes. This suggests that depending on family members for certain 'work' related to diabetes is linked to the types of relationship, (e.g. spouse) and the gender of person with diabetes. For example, male respondents tended to depend on women in relation to controlling their diet and doing the cooking. It can be argued that the duty of the wife to cook for her husband and family is not specific to this culture only. Across many western and non-western cultures, housewives have traditionally been responsible for cooking. However, within the South Asian culture, family members and close friends are expected to participate and help with providing care and attention to the individual who is unwell. It is perceived as a valuable opportunity and a social obligation to provide support to the individual and the family. Chandarana & Pellizzari (2001) state that this *'sacrifice is offered with pride and is strongly encouraged by the community'* (p.433). Furthermore, the 'self' as an autonomous individual is not significant. Rather what matters and what is expected, is the maintenance of inter-dependence and connectedness within the family in times of need (Markus & Kitayama, 1991). In addition to family, sharing and talking about information on diabetes with friends in informal settings and on a regular basis was also commonly reported in the qualitative study. This refutes previous research reports on the stigma (Goenka et al, 2004; Hill, 2006) of being labelled with an illness such as diabetes (as mentioned in Chapter 2) in this target population. In contrast, the qualitative study found that most participants appreciated, enjoyed and welcomed discussing diabetes with friends nearby, as well as receiving information on diabetes from their support network in the UK and 'back home' in the East. For some, it seemed to be a comfort and a relief to know other people in the family and the wider community with diabetes, whom they could talk to, share and exchange information with about diabetes treatment, control and diet. This type of environment and context seemed to eliminate any language barriers and formal authoritarian roles. Thus stigma was not seen to be a problem and people seemed more likely to act on information provided by their social networks, especially information on alternative food therapies to improve diabetes control, as mentioned earlier. Therefore, the findings of both the quantitative and qualitative studies demonstrate the importance of social networks, especially the family for beliefs related to diabetes management as well as providing emotional and practical support for diabetes.

11.10 Fatalism beliefs and health outcomes (sub question 2 & 3)

With the exception of understanding and timeline beliefs, consequences, identity, treatment and personal control were associated with at least one health outcome. The association between concern beliefs and emotional representation were discussed in the previous section. Fatalism was not associated with any of the health outcome variables. Each of the remaining associations will be discussed in the next section, along with findings from the qualitative study, where appropriate.

11.11 Personal control, health status, and normalisation

Health status (SF-12) *(p=.003)* and the items on the COPE (normalisation) *(p=.013)* measure were negatively associated with personal control which indicates that participants who believed they had personal control were more able to cope with their diabetes and had better health status. These findings contradict the findings of the qualitative study which show that compared to the British born South Asians, the migrant South Asians commonly attributed control to fatalism and God or made lifestyle changes with the help of their family members. Furthermore, it has been argued that some South Asians do not believe the concept of control to be possible or desirable, as it is in Western societies (Chandarana & Pellizzari, 2001). Rather it is more common for health to be conceived as a balance between people and the supernatural world (Landrine & Klonoff, 1992). However, it is not clear whether these findings refer to the migrant or British born South Asian groups, as this distinction was not made in the analysis of the quantitative study.

11.12 Treatment control, self-care and health status

Treatment control beliefs were negatively associated with self-care behaviours *(p=.028)* (SDSCA) and health status (SF-12) *(p=.002).* This suggests that those participants who believed that their treatment controlled their diabetes were more likely to have better health status and engage in self-care behaviours for diabetes. However, it is important to note that the question about treatment control on the BIPQ measure does not explicitly state which type of 'treatment' for diabetes the question is referring to, and is one of the limitations of using closed-questions in quantitative research in that exploring the exact meaning of the question is not always possible (the limitation of methods will be discussed later in this chapter). The significance of this distinction and the meaning of 'treatment control' is that the findings of the qualitative study show that it was common for South Asians, especially the migrant group with T2DM to use alternative food therapies in conjunction with their GP prescribed oral medication for diabetes. The next section discusses the use alternative food therapies for diabetes management in further detail.

11.13 Alternative food therapies

The findings of the qualitative study showed that there was a belief amongst some participants that the alternative food therapies, made from 'natural ingredients' were more effective in controlling their diabetes, improving diabetes control and/ or providing a cure for diabetes. For example, the vegetable Karella was most common food discussed as used in conjunction with GP prescribed medication. Evidence that Karella helps to lower blood sugar levels dates back a number of decades (Bailey et al, 1986). Studies on rats have suggested that Karella may have a glucose lowering effect and improve glucose tolerance in diabetes (Leatherdale et al, 1981). However, there is insufficient evidence on the efficacy of herbs for diabetes control and they are not part of the UK clinical guidelines for diabetes. A recent review into the clinical evidence supporting the use of alternative medicine reported little evidence on food therapies for improving glycaemic control in T2DM, and recommends further research into Karella and diabetes (Nahas & Moher, 2009; Nivitabishekam et al, 2009).

Descriptions of the fears of side effects from the GP prescribed medication, and the harm it may cause to other parts of the body was evident in the findings of the qualitative study. These findings resonate with the literature presented on beliefs about diabetes in Chapter 3 of this thesis. In their qualitative study, Lawton et al (2006a) explored beliefs about oral medication for diabetes and found that South Asian participants strongly believed that Western medication may have detrimental consequences to health if taken for a long period of time. Similarly, compared to participants with T1DM, participants with T2DM on oral medication in this qualitative study had a stronger preference for traditional homemade medicines. This suggests that treatment beliefs and the type of diabetes (T1DM or T2DM) determine the use of food therapies in South Asians. However, beliefs about the effectiveness of alternative treatments are not exclusive to the South Asian culture as other non-western cultures e.g. African, Americans, Asian Americans, Chinese and western cultures also use alternative treatments alongside allopathic medicines (Helman, 1978). For this reason Greenhalgh (2005b) has argued that, aside from culture, concordance between the patient and practitioner is a prominent factor in explaining beliefs about diabetes. Thus, differences in illness beliefs are not always subject to one's culture, but may also be due to the '*differences in the lay and medical concepts of illness which are embodied in the western approach to medicine'* (Qureshi, 1990, p. 94). Despite free prescriptions for people with diabetes in the UK, the preference for alternative therapies has also been suggested to be influenced by the quality of medical encounters, language and communication difficulties (Ahmed & Lemkau, 2000).

Participants in this study reported that they were not likely to discuss the use of food therapies with their GP or PN, but seek advice and information on these treatments and food therapies through their personal social networks both in the UK and 'back home' in the East. These findings lend support to previous work in the literature. As mentioned earlier, Kleinman (1980) suggests that it is common for people to develop Explanatory Models (*i.e. interpretations of illness and treatment*) from different sources and different levels including personal experience, family knowledge and cultural beliefs within the community. Explanatory Models offer explanations for sickness and treatment through the social meaning of the experience. The findings of this qualitative study also lend support to the literature on Personal Models (*i.e. patient's beliefs about treatment effectiveness),* which has previously been associated with diabetes self-care behaviours in the general population (Lawson et al, 2007). In particular, some qualitative studies have also drawn on the CS-SRM (Leventhal et al, 1984) to explore whether Personal Models predict how one reacts and copes with a health threat. Personal Models have been useful in identifying behaviours which are unhelpful in maintaining control of diabetes (Harvey & Lawson, 2008).

11.14 Identity, consequences, self-efficacy, health status and self-care

Identity was negatively associated with self-efficacy (HEiQ) and health status (SF-12). This suggests that South Asians with higher levels of self-efficacy (*p*=.004) and better health status (*p*=.000) reported fewer symptoms related to diabetes.

Consequences were negatively associated with self-efficacy (HEiQ), health status (SF-12) and self-care (SDSCA). This suggests that South Asians with higher levels of self-efficacy (*p*=.014), with a better health status (*p*=.000), engaged in more self-care behaviours (*p*=.012) and reported fewer *consequences* related to diabetes. These findings also lend some support to the Bean et al (2007) study, which found that South Asians with higher levels of self-efficacy reported fewer consequences related to diabetes.

Although it can be argued that these findings on self-efficacy contradict the literature on South Asians being a part of a 'collectivist culture' with a stronger preference for inter-dependant behaviours (Chandarana & Pellizzari, 2001), the findings of the qualitative study have shown that self-care of diabetes was a 'family affair'. Specific family members took responsibility for tasks related to diet, medication and providing information on diabetes, as mentioned earlier in section 11.8. Therefore the relationship between the variables in the quantitative study and self-management behaviours has to be treated with caution, as the scores provided for self-care behaviours (e.g. on the SCSCA) may not be a true representation of the actual self-care behaviours due to the amount of support provided by social networks.

Identity of symptoms was not explored in any specific detail in the qualitative study, as this topic was not part of the overall aim of this study or research question. Furthermore, the paucity of studies using the BIPQ in the South Asian population with diabetes has continued up to the writing of this thesis. Therefore it was it was difficult to compare the results with previous studies.

11.15 Qualitative study: social, cultural and religious beliefs (sub question 4)

The following two themes: *Travelling back to home* and *religious beliefs* is related specifically to the qualitative study, extend beyond the quantitative study and provide insight into the wider social and cultural factors related diabetes management in South Asians.

11.16 Travelling back home

In comparison to the quantitative study, the findings of the qualitative study suggest that South Asians had a poor understanding of diabetes. This was particularly evident in the theme *travelling back home* whereby participants travelled back to their native country during the summer season in the East to visit friends and family. This was an important tradition, especially amongst the older British South Asian migrant population. Some participants abstained from taking their medication until they returned to the UK, due to beliefs that exposure to a hot climate in the East either cured diabetes or improved their diabetes control temporarily. This suggests that participants did not identify themselves as having diabetes or experience any symptoms related to diabetes whilst on holiday in the East, with a poor understanding of the potential consequences of stopping their medication for diabetes for a long period of time. This implies that the *social context* in relation to the location in which the participants manage their diabetes (i.e. in the company of family members with diabetes in the East) has an impact on beliefs about diabetes and management practices. Furthermore, being back in a hot climate was believed to improve diabetes control, with explanations given such as going outdoors for a walk (often with family members), sweating in the heat and eating a healthier and fresher diet. This suggests that participants seemed to carefully observe and draw on the knowledge and practices of others to make sense of their own diabetes in this social context. When and how the social context shapes one's health and well being has recently been studied using *social identity theory* (Jetten, 2012). It is important to note that the concept and theory of social identity also has roots in the Medical Sociology discipline and literature. The work on identity in sociology has focused on social systems, as a basis of identity rather than the cognitive processes involved in identity per se (Kelly & Millward, 2004). However, this study has a specific focus on subjective beliefs (e.g. individual cognitions) about diabetes and the influence of social networks in shaping these beliefs; thus social psychology will be drawn on, as this approach is more relevant for the findings of this thesis.

The social identity theory in the context of social psychology stipulates that '*in many social contexts people use their sense of self in terms of group membership (i.e. in terms of social identity*)*'* (Haslam et al, 2009) (p.5). This theory helps to explain some of the findings of the qualitative study in that some of the social relationships participants had in the East not only seemed to be a part of their social identity of when they used to live there before they were diagnosed with diabetes, but this identity and context also provided an important lens through which they chose to manage their diabetes whilst on holiday there. These findings relate to some of the studies, which have drawn on the social identity theory to investigate the determinant of symptom appraisals (*identity*). For example, Adams et al (1997) found that asthma sufferers were much more likely to take their medication if they categorised themselves as members of a group that suffered from asthma. Similarly, Oyserman et al (2007) found that African Americans and American Indians who did not identify themselves with health-related messages about dieting were less likely to adopt a healthy lifestyle and were more fatalistic about their health. They suggested that people engage in health behaviours that are congruent with the norms of their social identity. In addition, Turner (1994) states that '*a shared sense of social identity of group members makes it possible for* *them to produce socially validated knowledge, and shared beliefs*' about ways of perceiving, thinking and doing (p.460), also known as 'self-categorisation'. The self-categorisation theory postulates that one's social context provides individuals with motive, and opportunities to compare their behaviour with others, also known as *social comparison* (Turner et al, 1994; Bauman, 2003). The self-categorisation theory resonates with the present findings of the qualitative study, which has shown that participants whilst living with family in the East made lifestyle changes such as, walking and eating healthier foods with the family, compared to lifestyle behaviours in the UK. Turner (1994) argues that '*self-categories are social definitions of the individual. They represent the perceiver in social terms, in terms of social relationships of similarities and differences to others in relation to a social context'. (p.458).* In this study, participants described engaging in self-care behaviours collectively with family members whilst in the East, but struggled to engage in self-care behaviours independently when they returned back to the UK, with the climate and mobility being stated as barriers. Thus, the way in which participants perceived themselves in the East and the West seemed to have implications for how South Asian participants choose to manage their diabetes. The next theme discusses the importance of religious beliefs for diabetes management.

11.17 Religious beliefs and diabetes

Religious beliefs are not accounted for in the BIPQ, nor are they part of the CS-SRM and were therefore not assessed in the quantitative study. However, the qualitative study explored the influence of religious beliefs for diabetes management and identified participants who fasted, despite living with diabetes. One of the key findings emerging from this theme was that fasting during religious and auspicious occasions (part of both the Islam and Hindu religions) was important to participants. The relationship between a person's belief system arising from a religious background and from an ethnic and cultural tradition is complex. In previous research, religion has been stated to strongly affect how people from the South Asian population interpret and respond to an illness and treatment (Spector,

2004) (e.g. how they alter their diabetes regime during fasting: Aslam & Healy, 1986; Barber et al, 1979), and limit their access to primary care due to the fears of being told not to fast. This study found evidence for this too as participants described abstaining from food, medication and drink for up to 12 hours during fasting. In comparison to previous research in this field, which has reported mainly on the clinical implications of fasting for people with diabetes, (for example, ketoacidosis and dehydration: Piner et al, 2002; Salti et al, 2009, mortality, morbidity and poor quality of life: Ameil et al, 2008); this study found that participants believed themselves to have better control of their diabetes, have more energy, be happier and better able to enjoy the social aspect of fasting with family and friends. Being part of a religious group with the support of others has been suggested to provide a sense of achievement with increased self-efficacy and perceived control (Hye-Cheon Kim & Koeing, 2007, p.185). This may provide a further explanation for participant's motivation to adjust their medication and dietary regimen without the consent of their GP or PN. Although small in number, previous studies, which have explored the relationship between religious beliefs and diabetes, have found that dietary restrictions of Islam were more important than the treatment or dietary advice prescribed by the doctor (Kelleher & Islam, 1996). Sissons-Joshi (1991) found that Indians regarded cultural rules and obligations to be important, even when this was clearly acknowledged to be detrimental to health.

The findings of these studies resonates with findings of this qualitative study in that participants were reluctant to disclose fasting to their GP and/or PN due to fears of being told not to fast, believing that the healthcare professionals would not understand the significance of fasting, even for people with diabetes. Those that did seek advice on fasting described consultations with their GP and PN as unsatisfactory with no help being offered. Some participants also admitted to fasting even when their GP or PN advised them not to, indicating that participating in religious traditions such as fasting was more important than the advice given by the GP or PN for fasting.

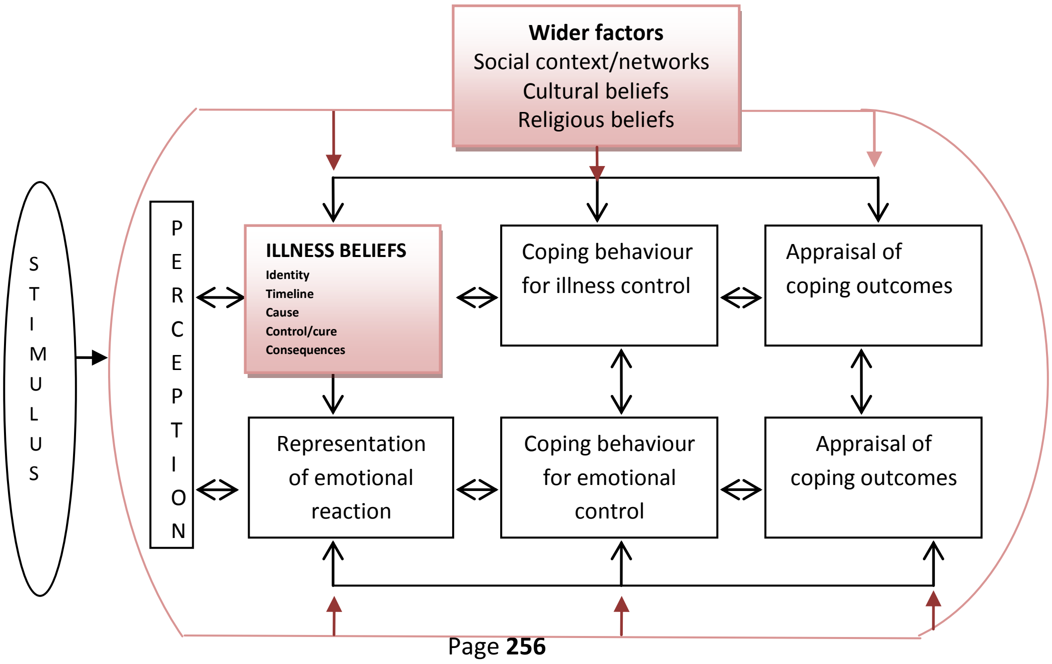
Research into the relationship between religion and health is not new (Hye-cheon & Koeing, 2007). Empirical studies, particularly in psychology, that have studied relationships between religion, spirituality and health have found positive associations between these factors and longevity (McCullough, et al, 2000), physical (Powell et al, 2003) and mental health (Koenig et al, 2012). As mentioned in Chapter 3, more recently studies in the wider literature on religion and illness have begun to examine the beneficial and harmful effects of religious/spiritual coping resources on adjustment to breast cancer diagnosis after surgery (Thuné-Boyle et al, 2012). In their cross-sectional, longitudinal study, Thuné-Boyle et al (2012) found that 'feeling punished and abandoned by God' significantly explained 5% of the variance in increased levels of anxiety but was partially mediated by denial coping. Feeling punished and abandoned by God was also a significant independent predictor of depressed mood. Such resources are thought to play an important role in the adjustment to an illness (Paragament et al, 1997). Although participants in this study did not mention feeling punished or abandoned by God for not fasting, the majority described feeling guilty for not fasting and as a result believed that they were not doing right by their religion. Despite being aware of the Holy Scriptures in their religion (e.g. Quran in Islam) which exempt those who are sick and on medication from fasting (Johnson, 2004), most participants still continued to fast. It is therefore evident from this study, that religious belief for some South Asians are powerful influences over behaviours related to diabetes management.

Recent recommendations have been made to address religious beliefs, in order to identify the potential barriers to adjustment to an illness, (Thuné-Boyle et al, 2012). Although religious beliefs may conflict with the biomedical model of diabetes, the knowledge of how people from the South Asian population conceptualise disease and cope with an illness is essential for reducing health inequalities, increasing understanding and supporting health behaviour of diverse populations and other ethnic minority groups.

11.18 Implications for the CS-SRM

As outlined in Chapter 3, The CS-SRM claims that illness beliefs are thought to develop from exposure to a variety of social sources of information which guide coping behaviours and outcomes (Leventhal et al, 1984). Beliefs regarding one's risk of an illness commonly develop through matching beliefs, family history and beliefs about cause of the illness are also known as social comparison (Kaptein & Weinman, 2004). Social comparison is '*the process by which a person compares themselves (their behaviour or characteristic) with others*' (Morrison & Bennett, 2009, p.455). Therefore, comparing their diagnosis to their family and friends, individuals may perceive diabetes not only as part of their genetic 'make-up' but also as part of their social identity. Although the CS-SRM and BIPQ measures do not explicitly assess the social context, the qualitative study in this thesis has shown the powerful influence that the social context can have in reinforcing the interpretation and meanings assigned to diabetes management. Figure 11.1 provides a revised diagram of the CS-SRM framework presented in earlier in Chapter 3 but as a result of the findings of this study, it also includes the wider factors associated with illness beliefs in South Asians with diabetes. The relevance and association of these factors to the other dimensions of the CS-SRM in Figure 11.1 requires further research.

Figure 11.1: The wider factors associated with illness beliefs



11.19 Critique of quantitative study

This section provides a critique of the design, recruitment, sample and survey measures used in this study.

11.20 Cross-sectional design

A cross-sectional design was used to collect data for the postal health survey and social networks survey interview. This was an efficient and cost-effective method of collecting data in the time available. Moreover, this design enabled the exploration of illness beliefs of South Asian people with diabetes using the BIPQ as recommended by the narrative systematic review in this thesis (Chapter 5). However, the overall aim of this study was to explore and describe the associations between the variables, not to imply causality. Thus, all the significant results in this study have to be treated with caution or as exploratory results, requiring validation in further confirmatory studies. From a methodological perspective it would have been preferable to use a longitudinal, prospective design to determine the direction of causality or assess change over time. Although the wider CLAHRC LTC study used a prospective design to assess change at 12 months, it was not possible to this design due to the time constraints of recruiting further participants and conducting and transcribing the qualitative interviews.

11.21 Recruitment

The author was involved in the project and developed a close working relationship with the wider team and ensured that there was on-going and regular communication, especially with regards to recruitment. Full team meetings took place weekly at the start of recruitment and then a minimum of bi-weekly and monthly meetings throughout the project. Using methods of recruitment such as postal letters have proven difficult and less successful in recruiting participants from the South Asian population (Rooney et al, 2011). However, in this study using a combination of non-verbal (e.g. postal letters) and verbal recruitment strategies proved to be successful in reaching the required sample size of n=64 for this study, and in fact the sample size exceeded this figure by n=3.

11.22 Representativeness of the sample

As mentioned in Chapter 7, a total of n=30 South Asian participants were recruited using random sampling. However, early observations indicated that this sample was mainly dominated by older Indian and Pakistani groups with a lack of sufficient representation of younger people from other sub-ethnic South Asian groups (e.g. Bangladeshi, younger Pakistani females). Being aware of the difficulties of recruiting people from the South Asian community into research, especially using impersonal techniques such as random sampling, as reported by other studies, alternative arrangements were made to recruit participants by going out into the community.

Despite using a purposive and snowballing sampling strategy to recruit participants from a range of local community and religious groups, recruiting Bangladeshi participants into this study was difficult. There was a poor attendance of people from this group at the community groups, compared to the number of people from the Indian and Pakistani groups. The Bangladeshi community in the UK are a marginalised ethnic group. They have poor access to care and services and report the highest levels of chronic disease of any ethnic group in the UK (Philipson et al, 2003). The difficulties of recruiting Bangladeshis into research have been noted in other diabetes studies (Alam et al, 2012; Khunti et al, 2008). Since the target sample size of n=67 participants was reached, no further attempts were made to recruit Bangladeshi people.

As mentioned in Chapter 1, Greater Manchester has a large Bangladeshi population. Therefore, it could be argued that the quantitative study reported here lacks representation within each South Asian group (especially from Bangladeshi participants) in order to generalise findings specifically to each group. However, the primary aim of this research was to explore the factors impacting on beliefs about diabetes in South Asians generally, and not within each distinct South Asian sub-group. Therefore, it can be argued that the lack of adequate representation of participants from the Bangladeshi population may not have adversely affected the findings of this study.

Compared to other cross-sectional studies in this field, this study had a smaller sample size due to the mixed methods design, time and resource constraints. Thus, the sample size of both the postal health survey and social networks survey interview affected the type of analysis that could be carried out. The descriptive analysis demonstrated that the data were not normally distributed and therefore did not meet the assumptions of parametric test that resulted in using non-parametric tests for most of the analysis. It is not recommended to use multiple regressions on skewed data but for exploratory purposes this test was used.

11.23 Survey measures

Quantitative methods of data collection have been rarely used in research with this population, due to the language difficulties and the potential difficulties of comprehending written questions on a survey. To increase acceptability, studies have often made efforts to translate existing measures from English into the appropriate South Asian languages (Lloyd et al, 2006). Recommendations for translating measures have been reported by other researchers (Lloyd et al, 2012).

Due to this study being embedded within a wider project, it was not possible to translate the postal health survey questionnaire due to time and resource constraints, despite some of the measures such as the BIPQ already being available in several of the South Asian languages (http://www.uib.no/ipq/index.html). Furthermore, as mentioned earlier in Chapter 6, the design and content of both the postal health survey began prior to the planning of the research for this study. Therefore, it was not possible to establish utility of the measures with the sample of South Asians in this study. Consequently, the scales with ceiling and floor effects (identified in Chapter 8) may have reduced the chances of finding significant relationships to other variables in the study. Although there is no single method for handing missing data (McKnight et al, 2007), it is difficult to determine the impact of data that might have been present if the BIPQ had been imputed for missing data. Some studies on this topic suggest that results would have been the same whatever imputing method is used due to the small number of missing data (Kromrey & Hines, 1994). Furthermore, checking for outliers at the start of the data cleaning process rather than screening for them during the analysis (to assess whether the significant relationships were due to outliers) may have also had an impact on the data. Therefore, it is possible that some of the findings in this study may reflect a bias, posing a threat to the validity, reliability and generalisability, as well as the conclusions about the relationships between variables. To reduce bias, conducting a small-scale pilot study with a sample of South Asians, prior to the main study to assess the appropriateness of the BIPQ (and the other measures) may have avoided floor and ceiling effects and reduced the chances of missing data and outliers on the BIPQ. This would have also been a useful way of establishing utility of questionnaires, and demonstrate reliability and construct and face validity of the BIPQ (other measures) in South Asians (Lloyd et al, 2012). This is because some of the participants may not have fully understood the meaning of the terms ‘concern’ and ‘timeline’ even in if the translated format of this measure was used in this study. Thus the significant associations in this study have to be treated with caution.

11.24 Methods used to map social networks

Most of the research into social networks and health has been conducted using questionnaires, as mentioned in Chapters 2 and 3. The method used to quantitatively map social networks and the impact of networks on illness beliefs in the UK South Asian population has not been undertaken before. Previous studies assessing the social networks of patients adjusting to an illness have used similar mapping techniques and the results have been interpreted by using visual techniques such as visualising the network details provided by patients on the map (Price, 2011). This technique may not have improved the findings of the present study, but may be an effective method for illustrating network details or assessing the social networks involved in diabetes management in clinical practice.

Notwithstanding the limitations of the quantitative study, the findings from this study has progressed the use of this design and method, forming a basis for further research and design of interventions.

11.25 Critique of the qualitative study - design

The design of the qualitative study and the topic guide was informed by the gaps identified in the literature. The pilot study provided an opportunity to administer the topic guide, gain experience of recruiting from the local South Asian community and conduct semi-structured interviews. Despite the time involved in adopting the iterative approach to data collection and analysis, this approach enabled the qualitative study to evolve and gain a deeper understanding into the beliefs about diabetes.

11.26 Recruitment

The sample for this study was drawn from the quantitative study as mentioned in Chapters 6 and 7. However a follow up focus group with participants would have been ideal to explore specific issues further through a group perspective. This is because participants would have been able to engage in a discussion and challenge one another's statements to generate rich data (Willig, 2008). The interactive nature and the data generated using this method have been suggested to have higher ecological validity (Willig, 2008). A follow up focus group may have provided an opportunity to recruit people from the Bangladeshi community. However, due to time and resource constraints, this was not possible.

Interviews with healthcare professionals to explore their views on providing diabetes care to South Asians and their understanding of the social, cultural and religious beliefs impacting diabetes management, would have further strengthened this study. This would have enabled exploring some of the issues discussed (e.g. treatment beliefs) and those described in Chapter 3 such as doctor-patient communication and the difficulties of promoting working partnership in consultation with South Asian patients from a healthcare professionals perspective.

Most of the data was collected from only a single interview with each participant, apart from those which required language support from the interpreter as discussed in Chapter 7.

Other interpretative approaches such as grounded theory and ethnography could have been applicable to the research question of this thesis, as mentioned in Chapter 7. On reflection grounded theory, for example, could have enabled using theoretical sampling whereby the sample of South Asians would have been recruited for theory construction rather than representativeness. The theory emerged from the data would have been used to explain behaviour and processes, related to diabetes management (Charmaz, 2003). Although the findings of the qualitative study cannot be generalised to all South Asian people with diabetes, the findings further existing knowledge and understanding on illness beliefs particularly the role of social networks, culture and religion for diabetes management.

11.27 Interviews in multiple languages

The bilingual skills of the author enabled several interviews to be conducted in Gujarati and Hindi as requested by participants. The audio recordings were also transcribed and interpreted by the author. However, it was not possible to check the validity of the audio recordings or transcripts with another expert who spoke these languages due to the time and financial constraints of this study.

11.28 Issues related to using an interpreter

A female, Pakistani professional interpreter was recruited to assist with language support for Urdu speaking participants who were not able to speak English and issues related to validity were addressed to the best possible extent as discussed in Chapter 7. However, after a few interviews it was soon realised that there was colloquial overlap between the Urdu and Hindi languages. Being able to understand most of the conversation between the interpreter and the participant ended up being a validation process in itself. This was due to being able to identify when the interpreter missed out questions; answered the questions on behalf of the participant; changed the meaning of the question(s); assisted the participant to come up with answers to the questions, particularly the social network questions that the interpreter seemed to find difficult to translate. On some occasions the interpreter also asked participants questions that were not part of the interview guide for her own interests and gave them advice on managing diabetes. Similar issues were also evident when using the Link Workers in the pilot phase of this thesis. Therefore, in these circumstances the author had to politely and assertively instruct the interpreter to either repeat the question(s) or let the participant answer the question(s) before moving on to maintain trust. Despite assisting to overcome language barriers, the issues and debates of using interpreters have been reported by other researchers (Zeh et al, 2012). Nonetheless, having the interpreter present in the interview facilitated a good rapport and relaxed atmosphere for some of the interviews, and participants seemed to appreciate the language support and seemed more comfortable talking about sensitive issues. This was important since some of the participants needed reassurance that the information they provided during the interview would not be reported back to their GP practice.

11.29 Strengths of using a mixed methods approach

Overall the mixed methods approach was useful in answering the different research questions in this thesis, as well as addressing the limitations of both methods to strengthen this study and provide a more holistic insight in the management of diabetes in the South Asian population. Both methods of data collection have their own limitations as discussed in Chapter 4. However, the quantitative study enabled the examination of the number and impact of social network on beliefs about diabetes using survey measures. The qualitative study extended beyond the quantitative study and explored *how* and *why* social networks are involved in the management of diabetes; it was also a better method for exploring fatalism and has shown the specific role of the networks and gender roles. Moreover, the qualitative arm of this thesis also explored the influence of social and cultural factors on beliefs about diabetes management using open-ended questions. Religious beliefs also emerged to influence diabetes management too, providing further strength to the research. Two distinct methods of data collection resulted in two separate analyses of data sets which ended in a discussion that integrated the findings of both the studies together along with a comparison of the findings; also known as 'concurrent triangulation' (Creswell et al, 2008). Being able to identify the characteristics of the study in this way has been suggested to convey the rigour of the study. Mixing methods is often thought to elucidate complementary aspects of the same phenomena; and it is the norm to expect conflicts (e.g. measuring different things) in findings from both methods, and such conflicts has been suggested to be accepted with credibility (Teddlie & Tashakkori, 2003).

11.30 Weaknesses of the using a mixed methods approach

Both methods required equal amounts of time and attention. Therefore this limited the number of participants recruited to each arm of the study. For example, it was not possible to recruit more Bangladeshi people and it did not allow any time to interview healthcare professionals. Furthermore, additional data that were collected in the social networks survey interview (e.g. the amount of negative work carried out in the network) could not be explored due to time constraints. Time also had to be allocated for the author to have training in qualitative methods and analysis of statistical data using SPSS.

11.31 Implications

This section describes the implications of this study that are relevant to clinical practice, education and training, policy and future research.

11.32 Clinical Practice

The findings of this thesis have shown that individual beliefs about diabetes in South Asian people are influenced by a number of factors. In order to address these beliefs, they first need to become known and accounted for by the healthcare professionals responsible for providing diabetes care, for example GPs, PNs, and/or health trainers. The Health Trainer Service was outlined in the 2004 as a result of recommendations from the UK Government White paper 'Choosing Health' to reduce health inequalities (Health Trainers England, 2012). The aim of this service is to give practical advice and support to people in their local communities who want to lead a healthier lifestyle, especially 'hard to reach'; and disadvantaged groups. In some parts of the UK the service is offered in many languages including Turkish, Urdu, Punjabi, Somali, Hindi, Gujarati and English. However, recent reports suggests that there is a lack of awareness amongst the general population of Health Trainers and the support they are able to offer in some parts of the UK (CLAHRC North West London, 2012).

11.33 Education and training

Developing policies for education guidelines for practitioners involved in providing diabetes care on how to account for beliefs about diabetes using measures such as the BIPQ in routine care (Petrie & Weinman, 2006) could be another step closer to providing culturally-sensitive care to South Asian patients, providing the existing measure(s) is modified to account for social, cultural and religious beliefs. Recent research has reported preliminary feasibility/effectiveness for a CS-SRM based intervention in primary care to improve patient adherence for chronic illness (Phillips et al, 2011). Addressing beliefs in primary care may also facilitate in identifying barriers to effective self-management and behaviour change for South Asian people. The UK guidelines on behaviour change are in the process of being updated, however the current guidelines (NICE, 2007) recommend that research studies on behaviour change consider the needs of minority ethnic and religious groups in order to ensure cultural acceptability of the intervention. Although these guidelines provide some preliminary information for healthcare professionals, more detailed guidelines are required to ensure professionals have the relevant education and skills to sensitively modify beliefs that are deeply rooted in people's culture and religion. Despite recommendations for undergraduate medical curricula to include training and education on the wider issues (e.g. religion, spirituality, culture) related to managing chronic conditions and health (Koenig, 2004; Kazarian & Evans, 2001), a few higher education providers have responded to this gap (Von Fragstein et al 2008; Cooper et al, 2012) and it is not clear whether this has been embedded in to the UK medical training curriculum. The inclusion of this training into routine education for future healthcare professionals working in primary care (GPs, PNs) may be a significant breakthrough in equipping practitioners to provide culturally sensitive care. Health psychologists have a role in training healthcare professionals in the skills needed to elicit and work with patient's illness models (Theunissen et al, 2003; de Ridder et al, 2007). Education initiatives could be delivered online using the Internet, workshops funded by the NHS and/or accredited by professional bodies such as the Royal College of General Practitioners (RCGP, 2012) and Royal College of Nursing (RCN, 2012). For example, an important aspect for healthcare professionals working in primary care is the need to raise awareness of the changes some South Asian people make to their diabetes regime when travelling 'back home' to the East and the implications this may have for their diabetes whilst on holiday and on their return back to the UK. This study has clearly demonstrated that beliefs about diabetes varied depending on participant's social and cultural context (i.e. East vs. West), which influenced adherence to medication for diabetes and other lifestyle behaviours. Similar education initiatives may also need to be developed for South Asians patients. Networking and developing working relationships between Primary Care healthcare professionals and religious leaders and/or informal community groups may provide further opportunity for healthcare professionals to learn about the influence of cultural and religious beliefs and practices for diabetes management (Grace et al, 2008). It could also lead to the potential to develop community-based interventions involving both South Asian people with diabetes and their family and friends to help facilitate behaviour change.

11.34 Policy

Current UK policy for diabetes does not specifically account for the needs of the South Asian population, other than the differences in the incidence of diabetes in comparison to different ethnic groups. Moreover, there are no specific guidelines on how to account for the social, psychological, cultural and religious factors surrounding the daily management of the condition. Therefore, in view of the findings reported in this thesis and the estimated prevalence and rise in diabetes, it may be worthwhile and cost effective for policy makers to consider planning strategies which include support and information for social networks (i.e. family members or friends) involved in helping patients manage their condition to reduce the burden on the NHS (Smith & Christakis, 2008). This is because the findings of this thesis have shown the importance of family and friends in providing support related to diet, cooking, medication (*practical work*) and reducing concern and emotions related to diabetes (*emotional work*). Yet the findings suggest that the networks involved do not receive information or support for diabetes 'work' from any formal routes. Rather information is sought from informal routes such as friends from the community and family with diabetes both in the UK (West) and in the East. This suggests that social networks also need some level of support and education involved in providing support for diabetes. Ideally, this would open up possibilities for both the person living with diabetes and for people in their social networks to have a common understanding of the tasks involved for effective diabetes control.

11.35 Research

In the first instance, the work of this thesis has contributed to the wider CLAHRC LTC study by exploring specifically the networks and support needs of South Asian people with diabetes. It has also shown how certain social network factors, for example, the *emotional work* and *practical work* undertaken within the network to support the individual with diabetes. Some of these findings were complemented with findings of the qualitative study which has demonstrated the importance of social networks for diabetes management, as well as the relationship between social networks, cultural and religious beliefs for diabetes management.

11.36 Recommendations for future work

This thesis has shown that social networks also impact on individual beliefs about diabetes, as measured by the BIPQ and fatalism questionnaires. It has also drawn on the literature in cultural health psychology and a number of other disciplines to explain the possible reasons why diabetes management is a ‘family affair’ and why certain cultural and religious beliefs have a powerful impact on management behaviours. However, the finding of this thesis challenges the applicability of health behaviour models such as the CS-SRM (Leventhal et al, 1984) and the BIPQ for assessing beliefs of minority ethnic groups such as South Asian people. This work has suggested several possibilities for future research to:

- Modify the psychological model on illness beliefs to ensure the model and IPQs are sensitive in accounting for the social, cultural and religious related to beliefs about diabetes for South Asians;
- Develop a more comprehensive fatalism measure and assess the validity and utility of the all measures used in research with the UK South Asian population.
- Develop a large scale prospective study to examine the predictive ability of illness beliefs for self-care behaviours of diabetes including clinical measures of diabetes;
- Develop a large scale prospective study to compare illness and fatalistic beliefs and the impact of social networks to facilitate further understanding into the specific differences across different ethnic groups as well as examine change overtime;
- Develop a gender based study to explore gender specific issues among South Asian families in relation to diabetes management in the UK to enhance our understanding about the specific diabetes ‘work’ done by family members.

- In CLAHRC 2, it may be worthwhile to conduct a similar study with younger South Asians (British born) to explore the types of networks, support needs and beliefs about diabetes of this population.
- To conduct a large scale, comparative study on the role of social networks and illness beliefs (across different age groups) between South Asians with diabetes in the UK and South Asians with diabetes in South Asia (India, Pakistani or Bangladesh) in order to understand the impact of westernisation or living in a western context for diabetes management. This may help to address the differences in cultural and religious beliefs for diabetes management between first and second generation South Asians in order to tailor health promotion activities and diabetes care.

11.37 Funding awarded to the author for future work

Research Capability Funding (RCF) has been awarded to the author to build on the findings of this thesis for a period of 8 months. The aim of the bid is to conduct secondary analysis of the existing data from this thesis, particularly the influence of religious beliefs for diabetes management, engagement with key stakeholders and to prepare an application to the NIHR Research for Patient Benefit (RFPB, 2012) in 2013 which aims to:

- Develop and evaluate improved ways for the NHS to support people of the Muslim faith to manage their condition well whilst practicing requirements of fasting for religious purposes;
- Develop a project to implement culturally sensitive interventions to support Muslim people with diabetes in NHS trusts across Greater Manchester.

11.38 Conclusion

Using a mixed methods approach, this study has informed on the importance of social networks and health outcomes on beliefs about diabetes in South Asian people. The sample of South Asians was drawn from across four sub-ethnic groups (Indian, Pakistani, Bangladeshi and Nepalese) with a variety of cultural, religious and linguistic backgrounds. The sample also varied in terms of disease type, (T1DM, T2DM) time since diagnosis, patterns of socio-economic status and migration into the UK. Most were Indian or Pakistani migrants from the Indian subcontinent with T2DM. However, this study has addressed the gap in knowledge with regards to the role of social context and illness beliefs about diabetes, as measured by five dimensions of the CS-SRM developed by Leventhal et al (1980). The findings have described the importance of the social context particularly the family members in being at the forefront and undertaking practical and emotional 'work' related to diabetes. This suggests that the management of diabetes involves more than just the 'self' living with the condition. In addition, the findings of the qualitative study have demonstrated the importance of cultural and religious beliefs for diabetes management; especially in the migrant South Asian group with T2DM compared to the British born South Asians with T2DM and T1DM. Although the CS-SRM is an influential psychological theory concerning beliefs about health and illness, the five dimensions of the theory, lack key elements to allow full understanding of the illness beliefs in South Asians. However, it is important to note that the current results of the quantitative study are limited to the describing associations only. Furthermore, it may be worthwhile for future studies to validate the appropriateness of the BIPQ in the UK South Asians to ensure it is sensitive enough to account for the wider contextual factors relevant to the experience of diabetes, especially in the migrant South Asian group who often experience difficulties with English. Thus, both the CS-SRM and the BIPQ need greater emphasis on these aspects of health behaviour. Not least because until broader beliefs about diabetes are dealt with, it may be difficult to use such health behaviour models to inform development of interventions to improve support for South Asian people with diabetes. There is also a pressing need for policy guidelines on diabetes to move beyond the notion of ‘self’ to include support and education for the social networks, with a recognition of the impact of cultural and religious beliefs on diabetes management. Efforts need to be made to modify the present approach to diabetes care, as it does not provide healthcare professionals working in primary care with the skills or knowledge of how to offer culturally sensitive advice to patients from South Asian groups.

11.39 Contribution to knowledge

The work presented in this thesis provides a unique contribution to the research and literature on the management of diabetes in British South Asians through the perspective of the CS-SRM developed by Leventhal et al (1980). The study addresses the illness beliefs dimension of the CS-SRM and extends the knowledge base using a mixed methods approach. Whilst the BIPQ has been useful in describing patterns of beliefs for patients who live with diabetes, it can tell us little about wider determinants of behaviour underlying them and the differences between the different South Asian groups and requires further development. The qualitative study showed that most of the participants in this study were first and second-generation migrant South Asians with T2DM. Whilst it is likely that some sort of social and cultural factors described above will attenuate over time, especially amongst the British born South Asians; at present the findings underline the importance of educating the social networks of South Asian people, especially the immediate family about the importance of diabetes management. Understanding the wider determinants of self-management practices, especially the cultural and religious beliefs and the association between these factors are equally important in improving support for diabetes care. These need to be accounted for in future studies using the CS-SRM and subsequent BIPQ measure. The combined impact of the work has also been to inform clinical practice, policy and health care practice.

Chapter 12

Reflections

This final chapter reflects on the journey of this research, commencing with working in the wider CLAHRC LTC team, using a mixed methods design, recruitment, supervision and lastly, a reflection on the impact the research has had on my personal experience of diabetes, as outlined in Chapter 1 – 'The author'.

12.1 Working within the wider CLAHRC LTC team

There have been other challenging occasions during the past three years in terms of balancing my work with the wider CLAHRC LTC recruitment objectives and research activities, planning my Stage II Health Psychology training (British Psychological Society) and prioritising time to write papers and attend conferences and training courses. These tasks and responsibilities have enhanced my time management, communication, team working and project planning skills.

More challenging has been to read literature outside of health psychology for example, medical sociology and anthropology and to enter and understand concepts from other disciplines which I have not worked in before. Exploring literature from multiple disciplines has been the key to the development of the main research question, sub-questions, methodology and conceptual development to ensure this thesis provides a holistic representation of beliefs about diabetes in South Asian people.

As mentioned from the outset of this thesis, this PhD research was embedded within the CLAHRC LTC programme and benefited from a number of available resources, particularly with regards to the surveys for data collection and support from the wider research team on analysis of the survey data. However, on reflection if the quantitative study was to be re-administered again to South Asian people, efforts would be made to ensure that only the questions relevant to the research questions were included into the survey to avoid burdening both the participants and the researcher responsible for analysis with questions irrelevant to the research question. The questionnaires would preferably be translated into the appropriate South Asian languages to further ensure acceptability of this method of data collection.

12.2 Using a mixed methods approach

Designing and conducting a mixed method thesis has been a useful learning experience and one that has given me the opportunity to develop skills and appreciate the complexity of using both quantitative and qualitative methods in research. Field work, particularly interviewing participants in their homes was an enjoyable experience because I was able to develop rapport with participant(s), and appreciate that beliefs were not important for managing their diabetes, but were also a lens through which people lived their lives to. Apart from the time and resources required for the methods; prioritising analysis and continuously exploring where the findings complement and contrast one another during the data analysis stage has further been a challenging experience.

12.3 Recruitment and working with bilingual interpreters

On reflection, recruiting for this study was at times a challenging experience. For example, attending a mosque for the first time in my life to try and recruit participants was a strange experience, but one which gave me insight into the different faiths and cultures living with diabetes other than my own (Indian). Collecting data in multiple languages has given me an insight into the flexibility required in research and the importance of tailoring research methods to suit the needs of the participant for successful recruitment. I have also had the opportunity to conduct this research working with Urdu speaking interpreters. However from the outset I was not aware of the overlap between the Urdu and Hindi languages. As mentioned in Chapter 7, I am a fluent speaker of Hindi, and was able to understand some of the conversations between the participant and interpreter during the interviews. At times, I had extreme concerns and was surprised with how the interpreters (hired professional and Diabetes Asian Link workers) were conducting the interviews. On several occasions I became really frustrated with the interpreter for answering the questions on behalf of the participants, giving them ideas about how to answer the question, making assumptions about what they thought the participants answer would be and by passing some of the difficult questions. It was here that I developed my assertive skills, because in these instances I politely instructed the interpreter(s) to either ask the question again and to let the participant give their answer.

12.4 Supervision

Support from a multidisciplinary supervisory team has been a crucial part of this PhD, particularly due to the mixed methods research design. Regular meetings and discussions with supervisors were important in progressing with the study. In addition, the support and encouragement my supervisors have given to disseminate my work has resulted in three conference presentations and two peer-review publications, which otherwise would not have been possible. All work and progress related to my Stage II Health Psychology training was regularly discussed in supervision too.

12.5 The author

As mentioned in Chapter 1, prior to commencing this PhD I worked for Diabetes UK. During my time at this organisation, I met a lot of people from the community with diabetes but rarely had the opportunity to talk to people for more than five minutes about their diabetes. Unfortunately, I also never had the opportunity to understand my father's experience about living with diabetes or his beliefs about managing the condition. However, embarking on this research has given first hand insight into the complexity surrounding beliefs related to diabetes, and the role of the social, cultural and religious context has upon shaping beliefs and the management of diabetes for South Asian people. Moreover, this research has shed light on my longstanding curiosity as to *'why my mother managed my father's diet?'* Learning about the importance participants in this research placed upon the support given by their social networks, particularly their family for *practical* and *emotional* 'work' related to diabetes, has vividly informed me that caring for family member(s) with a long term condition in South Asian people is a 'family affair', undertaken with respect and hesitation.

Through regular updates on the literature and attending annual conferences (e.g. South Asian Health Foundation), I have been impressed with the amount of research undertaken in the UK to better understand and improve diabetes care for South Asian people. Nonetheless the lack of policies and guidelines, tailored to the needs of South Asian people remain sparse. Thus, it is hoped that in the near future the recommendations made to policy makers for improving diabetes management are translated into practice.

12.6 Future work

The next stage of my career begins by commencing work on the findings of this thesis, particularly the influence of religious beliefs for diabetes management, paper (as mentioned in Chapter 11). I will prepare an application to the NIHR Research for Patient Benefit (RfPB), alongside the publication of my fasting and diabetes findings. I also plan to fulfil the remaining competency (Behaviour Change) for my Stage II Health Psychology Training, as well as write and submit my training portfolio to the British Psychological Society for examination.

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Appendix 1: Wider peer-review publication entitled 'Targeting Black Ethnic Minority (BME) Groups in to future health psychology research'.

Conference Reviews

Targeting Black and Ethnic Minority (BME) groups into future health psychology research

Neesha Patel

I WAS DELIGHTED to have received a student bursary to attend the Silver Jubilee Division of Health Psychology (DHP) Annual Conference. Not only was it my first visit to Southampton, but the first time I was attending and presenting at the DHP conference. I particularly enjoyed the talks on chronic illness management, behaviour change interventions and the illness perceptions symposium chaired by Professor John Weinman. However, what was evident from the talks I attended was the lack of research and data presented on Black and Minority Ethnic (BME) groups at the conference.

Recruiting BME groups into research: Where are we now?

It is known that targeting certain ethnic minority groups into research can be extremely challenging (Rooney et al., 2011). Some of the common challenges include:

- Recruitment
- Language and communication especially if the person's first language is not English
- Establishing rapport
- Gaining trust from participants.

In some ethnic groups there are the additional challenges of knowing whether people actually understand and accept the diagnosis of an acute/chronic condition. For some people there is the issue of consenting to participate in research or having to seek approval from the family or spouse to participate in research (Lloyd, Johnson & Mughal, 2008). Various methods have been proposed to overcome these barriers such as using interpreters (BPS, 2008), translating written information into appropriate languages to increase accessibility, using community-based recruitment strategies or accessing certain populations through community and religious leaders (Sheikh et al., 2009). The latter recruitment methods have frequently been used in research with the South Asian population with diabetes (Samsudeen, Douglas & Bhopal, 2011). People from the South Asian population in the UK have a higher prevalence of diabetes than the general UK population (Diabetes UK, 2011). Yet there are very few studies in health psychology which have used psychological theory such as the Self-Regulatory Theory (Levethal, Nerenz & Steele, 1984) to explore the relationship between psychological variables such as illness beliefs and diabetes management within the BME groups (Patel, Kennedy, Chew-Graham et al., 2012; Kart et al., 2007). To date most of the research with BME groups has been a-theoretical with the absence of health psychological theory and mainly using qualitative methods (Fleming & Gillibrand, 2009; Lawton, Ahmed, Peel et al., 2005; Samsudeen, Douglas & Bhopal, 2011).

My current PhD work, is embedded within the Greater Manchester, Collaboration for Leadership in Applied Health Research (CLAHRC) Long-Term Conditions pro-gramme and explores some of the above issues. In particular, I am examining the role of illness beliefs and social networks in the South Asian population with diabetes, using a mixed-methods approach. One of the core aims of this research is to use the data from this work to inform the wider CLAHRC project on improving self-management support for South Asians living with diabetes in Greater Manchester. My personal experience of recruiting South Asian people into my PhD research studies has been to use a combination of random (e.g. GP practice lists), and opportunistic sampling, (e.g. face-to-face approaches) via the community route. In circumstances where participants have difficulty understanding, reading or speaking the English language; interpreters have been used.

Future health psychology research

Health psychology has the advantage of using some robust theories in order to target and understand specific health behaviours of the BME population. As psychologists, we have the opportunity and skills to design and conduct high quality research through to grant writing, delivering complex interventions and informing UK health policy. Engaging and conducting more research with BME groups will not only enhance the generalisability of research findings but also allow the opportunity for development of interventions in a population with significant scope to benefit from such interventions. Most of all, we can be sure that we will be making a positive difference to the health and well-being of the cosmopolitan society we all live in today.

It is suggested that the DHP can help to address this important topic by:

1. Continuing to promote the role of health psychologists in the UK but target, also, network and collaborate with health organisations who work with BME groups.
2. Ensuring health psychologists in the UK have access to the appropriate support, advice and resources necessary to work with BME groups, as quite often it might be the case of *wanting too* but not knowing *how too.*

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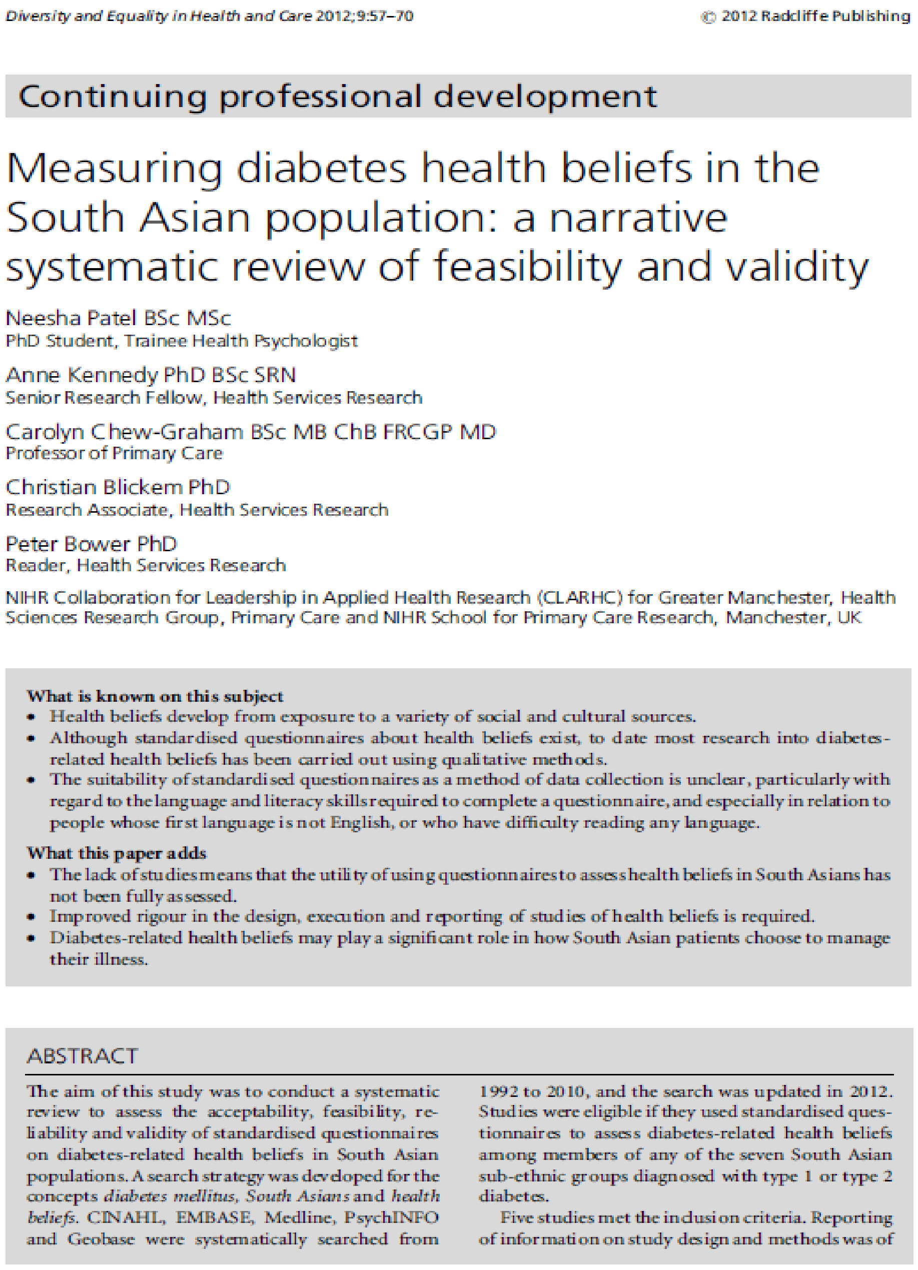
Appendix 2: Journal paper entitled ‘Measuring diabetes health beliefs in the South Asian population: a narrative systematic review of feasibility and validity’.



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Continuing professional development

Measuring diabetes health beliefs in the South Asian population: a narrative systematic review of feasibility and validity

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What is known on this subject

- Health beliefs develop from exposure to a variety of social and cultural sources.
- Although standardised questionnaires about health beliefs exist, to date most research into diabetes-related health beliefs has been carried out using qualitative methods.
- The suitability of standardised questionnaires as a method of data collection is unclear, particularly with regard to the language and literacy skills required to complete a questionnaire, and especially in relation to people whose first language is not English, or who have difficulty reading any language.

What this paper adds

- The lack of studies means that the utility of using questionnaires to assess health beliefs in South Asians has not been fully assessed.
- Improved rigour in the design, execution and reporting of studies of health beliefs is required.
- Diabetes-related health beliefs may play a significant role in how South Asian patients choose to manage their illness.

ABSTRACT

The aim of this study was to conduct a systematic review to assess the acceptability, feasibility, reliability and validity of standardised questionnaires on diabetes-related health beliefs in South Asian populations. A search strategy was developed for the concepts *diabetes mellitus, South Asians* and *health beliefs*. CINAHL, EMBASE, Medline, PsychINFO and Geobase were systematically searched from 1992 to 2010, and the search was updated in 2012. Studies were eligible if they used standardised questionnaires to assess diabetes-related health beliefs among members of any of the seven South Asian sub-ethnic groups diagnosed with type 1 or type 2 diabetes.

Five studies met the inclusion criteria. Reporting of information on study design and methods was of

variable quality across the five studies, making it difficult to assess acceptability and feasibility. Most studies required researchers to provide face-to-face support to respondents to aid feasibility. Only two studies used questionnaires about diabetes-related health beliefs as predictors of self-management behaviour.

Despite the high prevalence of diabetes in South Asians, to date there has been little research on the acceptability, feasibility, reliability and validity of questionnaires about health beliefs. This must be addressed if this population is to benefit from future research on health beliefs and related interventions.

Keywords: diabetes, health beliefs, questionnaires, self-management, South Asians

Introduction

The South Asian culture is diverse, encompassing seven ethnic sub-groups (Indian, Pakistani, Bangladeshi, Sri Lankan, Bhutanese, Nepalese and Mauritian), together with a number of different languages and religions (Johnson *et al*, 1999). The prevalence of diabetes is six times higher in people of South Asian descent (Diabetes UK, 2011). The serious complications and comorbidities associated with diabetes (e.g. heart disease, stroke, kidney disease) are more likely to affect South Asians because of poor glycaemic control and insufficient lifestyle changes, especially with regard to diet and increasing physical activity (Bellary *et al*, 2008; Khunti *et al*, 2009). Empowering patients to reduce the burden of the disease by effectively managing their diabetes has been an important goal for healthcare systems worldwide (Wanless, 2004). However, in the UK, education programmes and resources developed to support self-management have had limited success in the South Asian population (Hawthorne *et al*, 2010; Khunti *et al*, 2009). A number of barriers have been proposed, including poor access to health services, structural and material deprivation, experiences of migration, and language and communication difficulties (Greenhalgh *et al*, 1998; Choudhury *et al*, 2009; Hill, 2006).

Diabetes-related health beliefs may play a significant role in how South Asian patients choose to manage their illness (see Box 1). There is no one universal definition of health beliefs, but for the purposes of this review the following definition has been chosen. Health beliefs have been defined as:

> socially acquired and shared expectancies that reflect, among others, thoughts about the attributes of some situation or condition, as well as consideration of outcomes of specific courses of action.
>
> (de Wit and Stroebe, 2004, p. 54)

Health beliefs develop from exposure to a variety of social and cultural sources (Ogden, 2007). In the psychology literature there are various health belief theories which aim to explain how beliefs develop, and how they relate to the management of disorders and self-care behaviours (Harvey and Lawson, 2009).

In the health psychology literature, the Illness Perception Questionnaires (IPQ) (Weinman *et al*, 1996; Moss-Morris *et al*, 2002; Broadbent *et al*, 2006) have been used to measure beliefs about a number of chronic conditions, such as diabetes, using five key components of the self-regulatory theory, namely *identity*, *cause*, *timeline*, *consequences* and *control/cure* (Leventhal *et al*, 1998). Previous findings from these questionnaires demonstrate a positive relationship between illness perceptions and diabetes management in

Box 1 Diabetes and health beliefs in the South Asian population

Diabetes
A lifelong, chronic and progressive condition that occurs either when the pancreas does not produce enough insulin, or when the body cannot effectively use the insulin that it produces. Diabetes is more common in people of South Asian origin.

South Asians
The term 'South Asian' encompasses seven ethnic sub-groups (Indian, Pakistani, Bangladeshi, Sri Lankan, Bhutanese, Nepalese and Mauritian), together with a number of different languages and religions (Johnson *et al*, 1999).

Diabetes-related health beliefs
A person's thoughts and opinions about diabetes influence self-management of this condition.

the UK white and European populations. For instance, patients who believe that their diabetes is controllable manage their diet, exercise and glucose testing well (Glasgow *et al*, 1997; Hampson *et al*, 1990). Interventions designed to alter illness perceptions report long-term improvements in management (Cox and Gonder-Frederick, 1992; Griva *et al*, 2000). However, the extent to which health beliefs predict diabetes management in South Asian populations has yet to be confirmed.

To date most research into diabetes-related health beliefs in the South Asian population in the UK has been carried out using qualitative methods, such as focus groups, interviews (Lawton *et al*, 2007) and storytelling narratives (Greenhalgh *et al*, 1998, 2005). There is evidence from these studies to suggest that the health beliefs and practices of this population are heterogeneous and often related to the religion of the individual (Fleming and Gillibrand, 2009; Bhopal *et al*, 1999). A meta-synthesis of qualitative studies exploring culture, diabetes and nursing in the South Asian community (Fleming and Gillibrand, 2009) found that beliefs about the cause of diabetes are related to dietary behaviours, stress, and heredity and life experiences, such as migration to the UK (Lawton *et al*, 2006). Another casual factor is fatalism, especially in the Muslim population (Stone *et al*, 2005; Naeem, 2003; Lawton *et al*, 2006). Fatalistic beliefs have been suggested to lead to poor diabetes control (Lange and Piette, 2006; Egede and Bonadonna, 2003) and poor quality of life.

Some of this research has informed various interventions and structured education programmes for South Asians in the UK (Greenhalgh *et al*, 2005; Khunti *et al*, 2008). For example, Greenhalgh *et al* (2005) developed a storytelling intervention which aimed to provide an alternative way of delivering diabetes education to people who do not speak English. This study found that storytelling methods encouraged an empathetic response from participants, and so were an effective way of meeting the personal education needs of South Asians with diabetes.

Although qualitative methods have many advantages (de Leewu, 2008), standardised self-report questionnaires such as the IPQ have utility in that they enable a large population to be sampled efficiently, provide comparable data across population groups, and allow quantification of the relationships between health beliefs, self-management behaviours and outcomes. Attempts have been made to establish face validity through the use of focus groups to ensure that standardised questionnaires are culturally appropriate for South Asian populations (Lloyd *et al*, 2008, 2012). However, the suitability of standardised questionnaires as a method of data collection for measuring health beliefs is unclear. This is due to the language and literacy skills required to complete a questionnaire, especially for people whose first language is not English or who have difficulty reading any language (Lloyd *et al*, 2006). There are also doubts about the applicability of some health psychology concepts in minority populations. For instance, the IPQ measures beliefs about illness control, but it does not specifically account for external control factors such as fatalism. The study reported here aimed to examine in more depth the use of questionnaires with South Asians diagnosed with diabetes.

Aims

The study aimed to:

- identify studies using standardised questionnaires to assess diabetes-related health beliefs in the South Asian population
- assess the acceptability and feasibility of using standardised questionnaires in a South Asian population
- assess the reliability and validity of standardised questionnaires in capturing diabetes-related beliefs.

Methods

Inclusion criteria

Studies were eligible for inclusion in the study if they had used standardised questionnaires to assess South Asian adult patients' health beliefs about their diabetes. Type 1 and type 2 diabetes were included, and patients could belong to any of the seven South Asian ethnic groups listed above.

Search strategy

A search strategy was developed using a combination of text terms and subject headings for *diabetes, South Asians* and *illness beliefs* (see Table 1). We searched the following databases from 1992 to 2010: CINAHL, EMBASE, Medline, PsychINFO and Geobase. Searches were conducted from February to March 2010, and updated in January 2012. In addition, the NHS Specialist Library for Ethnicity and Health (NHS Evidence, 2011) was searched. To supplement the database search, the journals *Ethnicity and Health, Diabetes Care* and *Diabetic Medicine* were hand-searched from 1992 to 2010. Reference lists of key articles and other reviews were scanned for potentially relevant articles, as was the 'grey literature' using Google Scholar. Four authors of the papers included in the review were contacted to help to identify further relevant published and unpublished papers. The search results were imported

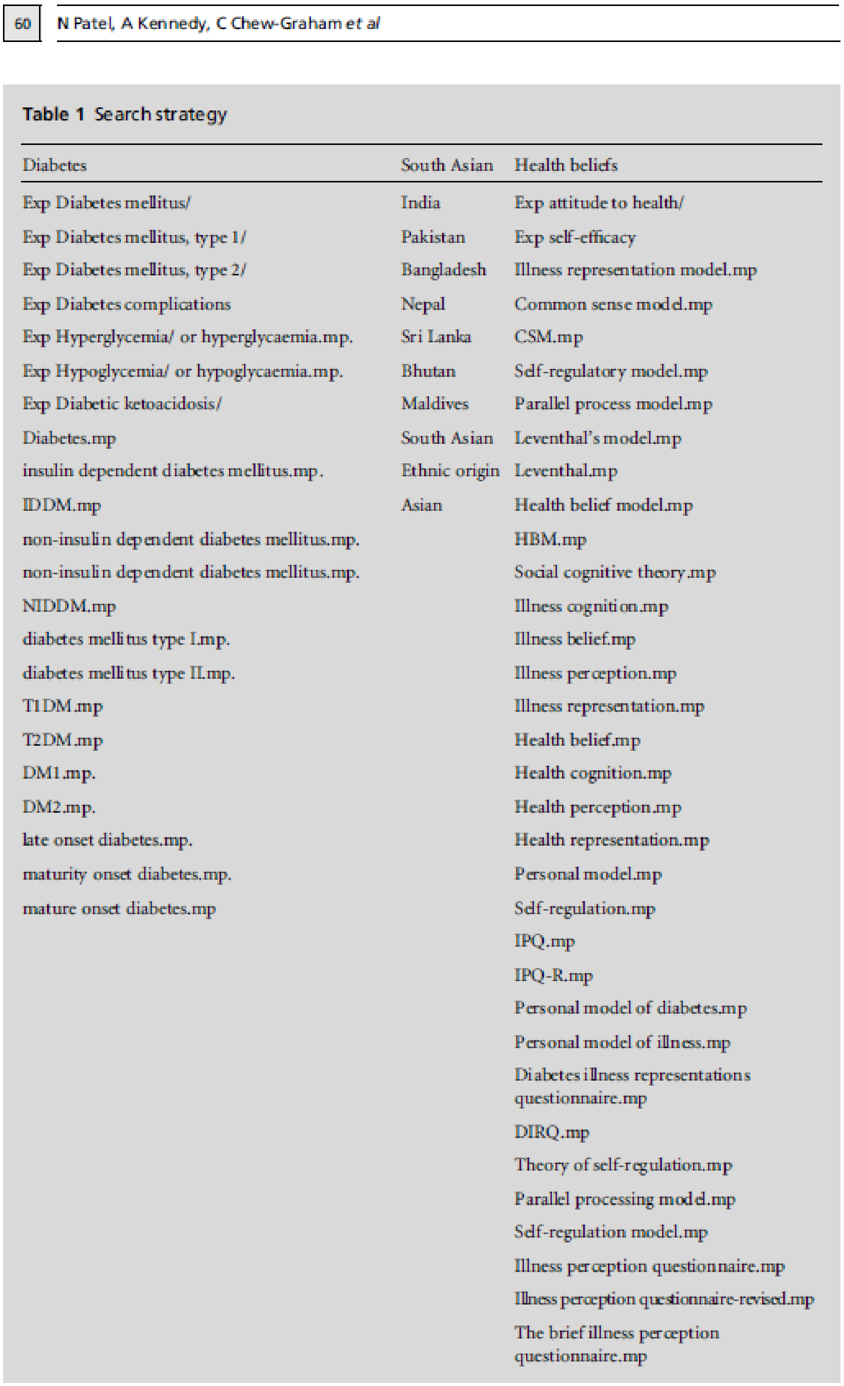

Table 1 Search strategy

Diabetes	South Asian	Health beliefs
Exp Diabetes mellitus/	India	Exp attitude to health/
Exp Diabetes mellitus, type 1/	Pakistan	Exp self-efficacy
Exp Diabetes mellitus, type 2/	Bangladesh	Illness representation model.mp
Exp Diabetes complications	Nepal	Common sense model.mp
Exp Hyperglycemia/ or hyperglycaemia.mp.	Sri Lanka	CSM.mp
Exp Hypoglycemia/ or hypoglycaemia.mp.	Bhutan	Self-regulatory model.mp
Exp Diabetic ketoacidosis/	Maldives	Parallel process model.mp
Diabetes.mp	South Asian	Leventhal's model.mp
insulin dependent diabetes mellitus.mp.	Ethnic origin	Leventhal.mp
IDDM.mp	Asian	Health belief model.mp
non-insulin dependent diabetes mellitus.mp.		HBM.mp
non-insulin dependent diabetes mellitus.mp.		Social cognitive theory.mp
NIDDM.mp		Illness cognition.mp
diabetes mellitus type I.mp.		Illness belief.mp
diabetes mellitus type II.mp.		Illness perception.mp
T1DM.mp		Illness representation.mp
T2DM.mp		Health belief.mp
DM1.mp.		Health cognition.mp
DM2.mp.		Health perception.mp
late onset diabetes.mp.		Health representation.mp
maturity onset diabetes.mp.		Personal model.mp
mature onset diabetes.mp		Self-regulation.mp
		IPQ.mp
		IPQ-R.mp
		Personal model of diabetes.mp
		Personal model of illness.mp
		Diabetes illness representations questionnaire.mp
		DIRQ.mp
		Theory of self-regulation.mp
		Parallel processing model.mp
		Self-regulation model.mp
		Illness perception questionnaire.mp
		Illness perception questionnaire-revised.mp
		The brief illness perception questionnaire.mp

into Reference Manager 11 in order to manage the review process.

Data extraction

All titles and abstracts identified were assessed for eligibility by the first author (NP), and data were extracted. All data extraction was independently checked by another researcher, and any discrepancies were resolved through discussion and/or contact with the study authors.

Measure appraisal criteria

Questionnaires in each study were appraised using formal criteria designed to assess patient-reported outcomes in clinical trials (Fitzpatrick *et al*, 1998). These criteria consist of eight dimensions, but for the purpose of this review only four criteria (see below) were selected. These criteria were most relevant for assessing the overall utility of health belief questionnaires.

Acceptability

To assess the acceptability of the questions, we extracted data on the time taken to complete the scales, the length in terms of the number of items, the response rate and the rates of missing data.

Feasibility

To assess feasibility we extracted data about the resources required to administer the questionnaire. We assessed the ease of administering and processing information from the questionnaire, such as the need for face-to-face support for participants, the coding schemes required to produce questionnaire scores, and the training required for staff to use and interpret the scale.

Reliability

To assess the internal reliability of the questionnaire used, we extracted the estimates of Cronbach's alpha. We judged the internal reliability to be acceptable if the estimate was 0.70 or higher. To assess the test–retest reliability of the questionnaire, we extracted data from the questionnaire about the correlation of scores or other measures of agreement, in repeated administrations over time.

Validity

To determine validity, we first assessed whether the studies followed and/or adhered to specific translation guidelines, such as back translation (International Test Commission, 2010). Back translation involves translating the revised questionnaire back into the original language, by a third translator who has command of both languages (Rahman *et al*, 2003). However, Rahman *et al* (2003) also state that such simple methods of translation are insufficient, and they recommend testing translation using a focus group to ensure validity and reliability.

We also assessed construct validity by exploring whether the questionnaires predicted diabetes-related variables. This involves cross-sectional or longitudinal assessments of the relationships between scores on the questionnaires and self- or observer-report measures of relevant behaviours, such as adherence to medication, exercise, diet, and other self-care behaviours or health outcomes (e.g. HbA1c, quality of life).

Data analysis

Given the heterogeneity of the studies with regard to questionnaires used, research settings and ethnic groups, a narrative synthesis was deemed most appropriate. A narrative synthesis is an approach used to summarise the findings of multiple studies, mainly using text and words (Pope *et al*, 2007). Thus this process of synthesis is descriptive, rather than statistical.

Results

Search strategy

The search strategy identified 312 abstracts, of which 186 full text papers were checked for eligibility. Five studies were eligible for inclusion. Each of the five studies was systematically assessed against the four appraisal criteria, and the next section provides further details of that assessment.

What standardised questionnaires have been used to assess diabetes-related health beliefs?

The health belief questionnaires varied between studies. Two studies used different versions of the standardised IPQ (Bean *et al*, 2007; Kart *et al*, 2007). One study (Bean *et al*, 2007) also included questionnaires about self-efficacy, metabolic rate and retinopathy, in order to further assess the relationship between beliefs and health outcomes.

Two studies (Rafique *et al*, 2006; Rankin and Bhopal, 2001) adapted existing health questionnaires by adding their own questions to specifically assess diabetes-related beliefs. Rankin and Bhopal (2001) developed a questionnaire based on the Newcastle Health and Lifestyle Survey (White *et al*, 1993), the Rose Angina

Questionnaire (Rose *et al*, 1982) and the West of Scotland Twenty-07 Study (Macintyre *et al*, 1989). Participants were given a definition of diabetes and asked what they understood by the term. Rafique *et al* (2006) developed a questionnaire using the reliability and validity of a brief diabetes knowledge test (Fitzgerald *et al*, 1998) and diabetes knowledge and sources of information among African American and white older women (Schoenberg *et al*, 1998). They also included questions on local myths about diabetes and beliefs about medication, diet, exercise and nutrition.

The remaining study designed and pre-tested a new health belief questionnaire with no specific justification. Therefore it was difficult to assess this measure in any detail using our selected appraisal criteria (Sivagnanam *et al*, 2002) (see Table 2).

Are the questionnaires acceptable?

Data about measures of acceptability were relatively limited. Only one study (Bean *et al*, 2007) stated the response rate with regard to the number of completed questionnaires. The remaining studies only reported the achieved sample size, with no specific information on response rates or rates of missing data. The length of the questionnaires ranged from 7 to 39 questions across the five studies, and none of the studies provided specific information on the time taken to complete the questionnaires. All five studies included additional questions on self-management, with the longest questionnaire containing 53 items.

Are the questionnaires feasible?

Measures of feasibility were very limited. Three studies (Rankin and Bhopal, 2001; Rafique *et al*, 2006; Kart *et al*, 2007) employed a member of the research team to either distribute questionnaires or help respondents to complete it during an interview.

Are the questionnaires reliable?

Two studies (Bean *et al*, 2007; Kart *et al*, 2007) stated that the questionnaires had internal consistency, but none of them reported on test–retest reliability (see Table 2). Three studies (Bean *et al*, 2007; Kart *et al*, 2007; Rafique *et al*, 2006) translated the questionnaires, but only two of these (Kart *et al*, 2007; Rafique *et al*, 2006) met international standards for translation by adopting the method of back translation. Although back translation is reported to be one of the most common methods of translation in survey research (Brislin, 1970), none of the studies referred to translation guidelines.

Are the questionnaires valid?

The studies differed in terms of how they assessed the relationship between beliefs and diabetes management. Bean *et al* (2007), using the IPQ, found these health beliefs to be predictive of self-care and metabolic rate. For example, *personal control* beliefs were positively associated with dietary self-care and exercise, *identity* beliefs were associated with medication taking, and beliefs about *treatment control* predicted better glucose testing, whereas *emotional representation* predicted HbA1c outcomes (see Table 2). Kart *et al* (2007) also found that *treatment control* was significantly correlated with exercise, complementary alternative medicine, stress and lower use of medication. Beliefs about the *chronic* and *cyclicality* elements of diabetes predicted healthy eating and adherence to medication, whereas *emotional representation* was predictive of foot care (see Table 2).

The remaining three studies were more descriptive and did not provide any additional information about the relationship between beliefs and other health outcomes associated with diabetes. These studies only stated the findings from the belief questions. For example, 85% of the respondents in the study by Sivagnanam *et al* (2002) believed that wheat played a crucial part in the diet for people with diabetes, and over 50% believed that diabetes only affected adults. Rankin and Bhopal (2001) reported that controlling and reducing sugar intake and eating a healthy diet were factors believed to prevent diabetes. Similarly, Rafique *et al* (2006) found that people with diabetes significantly held diet-related beliefs about managing their diabetes.

Discussion

Summary of main findings

The aim of this review was to identify studies in which standardised questionnaires were used to assess health beliefs in South Asians with diabetes. Each questionnaire was assessed for feasibility, acceptability, reliability and validity using established appraisal criteria. Five studies were identified, of which four used pre-existing questionnaires from the literature, and one study designed a new questionnaire. Two studies showed that diabetes-related health beliefs may predict relevant health outcomes in the South Asian population. However, the studies conducted to date have been of varying quality, and there are only limited data on acceptability, feasibility, reliability and validity.

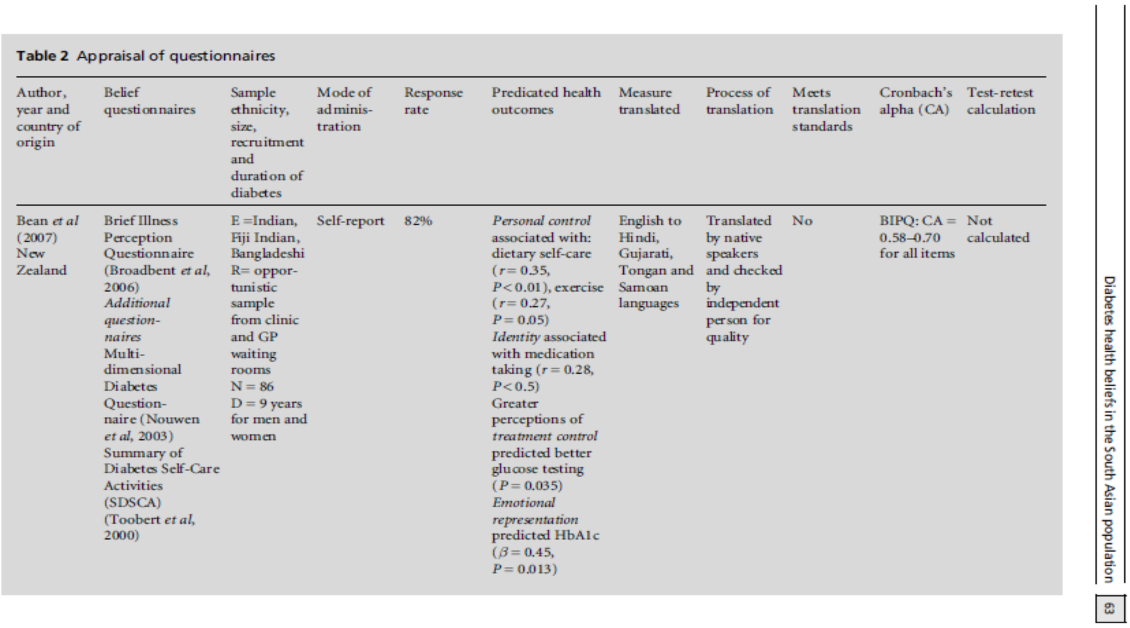

Table 2 Appraisal of questionnaires

Author, year and country of origin	Belief questionnaires	Sample ethnicity, size, recruitment and duration of diabetes	Mode of adminis-tration	Response rate	Predicated health outcomes	Measure translated	Process of translation	Meets translation standards	Cronbach's alpha (CA)	Test-retest calculation
Bean *et al* (2007) New Zealand	Brief Illness Perception Questionnaire (Broadbent *et al*, 2006) *Additional questionnaires* Multi-dimensional Diabetes Questionnaire (Nouwen *et al*, 2003) Summary of Diabetes Self-Care Activities (SDSCA) (Toobert *et al*, 2000)	E =Indian, Fiji Indian, Bangladeshi R= opportunistic sample from clinic and GP waiting rooms N = 86 D = 9 years for men and women	Self-report	82%	*Personal control* associated with: dietary self-care ($r = 0.35$, $P < 0.01$), exercise ($r = 0.27$, $P = 0.05$) *Identity* associated with medication taking ($r = 0.28$, $P < 0.5$) Greater perceptions of *treatment control* predicted better glucose testing ($P = 0.035$) *Emotional representation* predicted HbA1c ($\beta = 0.45$, $P = 0.013$)	English to Hindi, Gujarati, Tongan and Samoan languages	Translated by native speakers and checked by independent person for quality	No	BIPQ: CA = 0.58–0.70 for all items	Not calculated

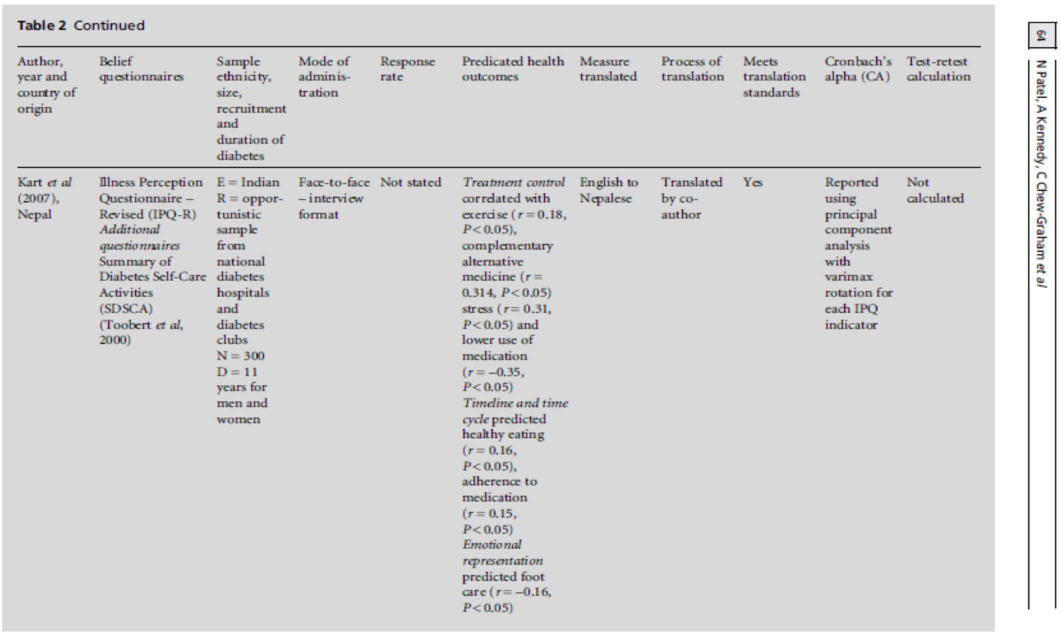

Table 2 Continued

Author, year and country of origin	Belief questionnaires	Sample ethnicity, size, recruitment and duration of diabetes	Mode of adminis-tration	Response rate	Predicated health outcomes	Measure translated	Process of translation	Meets translation standards	Cronbach's alpha (CA)	Test-retest calculation
Kart *et al* (2007), Nepal	Illness Perception Questionnaire – Revised (IPQ-R) *Additional questionnaires* Summary of Diabetes Self-Care Activities (SDSCA) (Toobert *et al*, 2000)	E = Indian R = opportunistic sample from national diabetes hospitals and diabetes clubs N = 300 D = 11 years for men and women	Face-to-face – interview format	Not stated	*Treatment control* correlated with exercise ($r = 0.18$, $P < 0.05$), complementary alternative medicine ($r = 0.314$, $P < 0.05$) stress ($r = 0.31$, $P < 0.05$) and lower use of medication ($r = -0.35$, $P < 0.05$) *Timeline and time cycle* predicted healthy eating ($r = 0.16$, $P < 0.05$), adherence to medication ($r = 0.15$, $P < 0.05$) *Emotional representation* predicted foot care ($r = -0.16$, $P < 0.05$)	English to Nepalese	Translated by co-author	Yes	Reported using principal component analysis with varimax rotation for each IPQ indicator	Not calculated

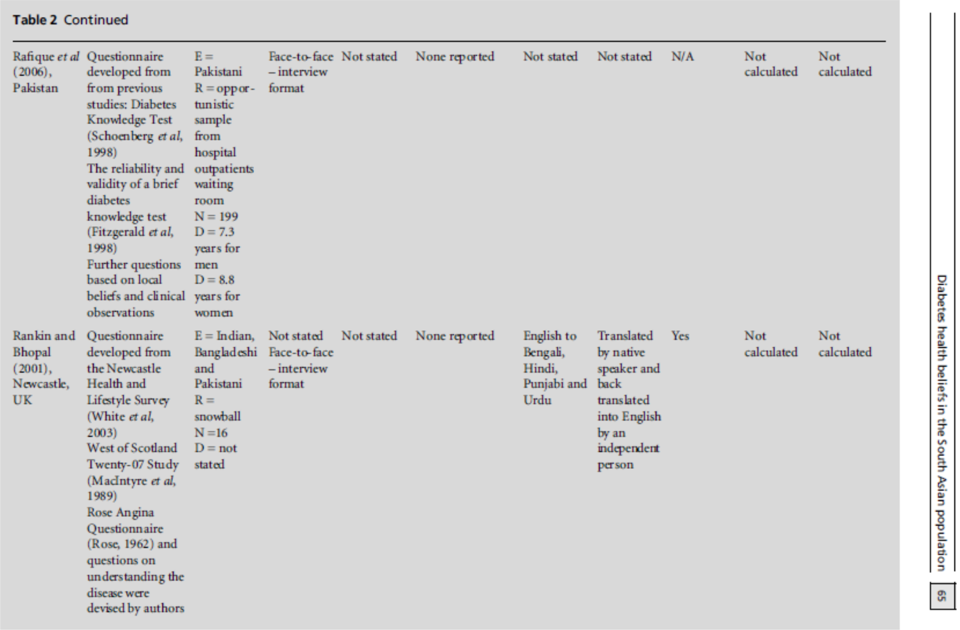

Table 2 Continued

Rafique *et al* (2006), Pakistan	Questionnaire developed from from previous studies: Diabetes Knowledge Test (Schoenberg *et al*, 1998) The reliability and validity of a brief diabetes knowledge test (Fitzgerald *et al*, 1998) Further questions based on local beliefs and clinical observations	E = Pakistani R = opportunistic sample from hospital outpatients waiting room N = 199 D = 7.3 years for men D = 8.8 years for women	Face-to-face – interview format	Not stated	None reported	Not stated	Not stated	N/A	Not calculated	Not calculated
Rankin and Bhopal (2001), Newcastle, UK	Questionnaire developed from the Newcastle Health and Lifestyle Survey (White *et al*, 2003) West of Scotland Twenty-07 Study (MacIntyre *et al*, 1989) Rose Angina Questionnaire (Rose, 1962) and questions on understanding the disease were devised by authors	E = Indian, Bangladeshi and Pakistani R = snowball N =16 D = not stated	Not stated Face-to-face – interview format	Not stated	None reported	English to Bengali, Hindi, Punjabi and Urdu	Translated by native speaker and back translated into English by an independent person	Yes	Not calculated	Not calculated

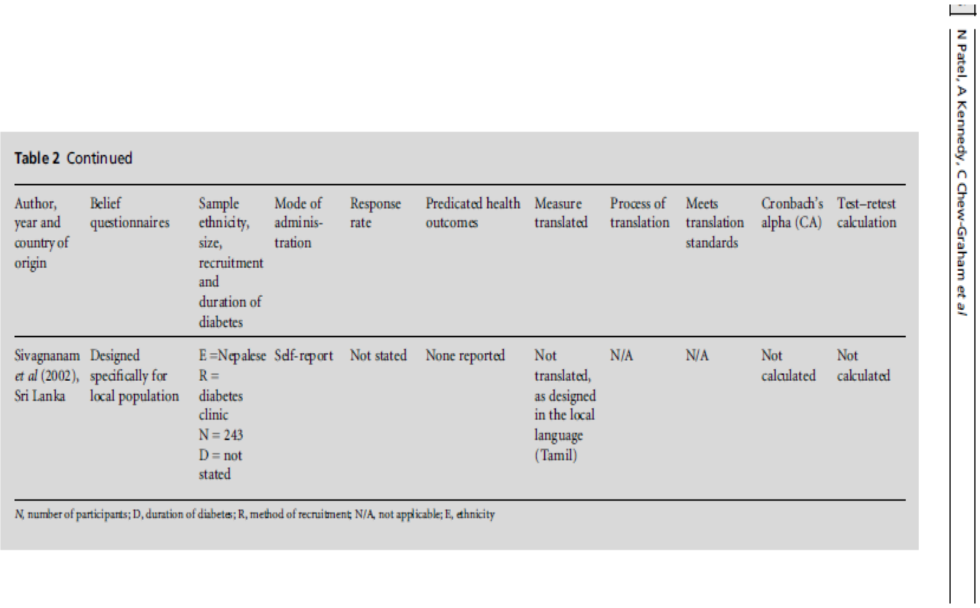

Table 2 Continued

Author, year and country of origin	Belief questionnaires	Sample ethnicity, size, recruitment and duration of diabetes	Mode of adminis-tration	Response rate	Predicated health outcomes	Measure translated	Process of translation	Meets translation standards	Cronbach's alpha (CA)	Test–retest calculation
Sivagnanam *et al* (2002), Sri Lanka	Designed specifically for local population	E =Nepalese R = diabetes clinic N = 243 D = not stated	Self-report	Not stated	None reported	Not translated, as designed in the local language (Tamil)	N/A	N/A	Not calculated	Not calculated

N, number of participants; D, duration of diabetes; R, method of recruitment; N/A, not applicable; E, ethnicity

The utility of using questionnaires to assess diabetes-related health beliefs

The studies in this review show that using questionnaires to assess beliefs in the South Asian population with diabetes has some utility. The studies varied with regard to the types of questionnaires used, and provided very limited information about acceptability and feasibility, making it difficult to assess them against these two criteria. Most studies required a high level of resources because researchers provided face-to-face support for either recruitment or assisting participants to complete the questionnaire. This is consistent with previous research in the literature which has reported barriers to the use of questionnaires with the South Asian population (Lloyd *et al*, 2006, 2008). The main problem with some of the studies in this review was the lack of information about and justification of the choice of questionnaire. For instance, in the study by Sivagnanam *et al* (2002) it is unclear why the authors of that study decided to develop a new measure when other researchers had used modified or existing questionnaires.

Comparison with the literature

The South Asian diet has commonly been used to explain the high prevalence of diabetes in this population (Misra *et al*, 2009). The findings from three studies in this review (Rankin and Bhopal, 2001, Sivagnanam *et al*, 2002; Rafique *et al*, 2006) also found beliefs about the cause of diabetes to be commonly associated with diet. These findings reflect those of the qualitative studies discussed earlier (Fleming and Gillibrand, 2009; Stone *et al*, 2005). We also speculated that fatalism was one of the beliefs related to the management of diabetes, yet the studies in this review did not include specific questions to measure fatalistic beliefs. The relationship between fatalistic beliefs and diabetes management requires further study. This could potentially be assessed by extending the causal or controllability dimensions of the IPQ questionnaires in future studies.

Earlier we identified the importance of language and literacy and good-quality translation. Although some of the studies in this review attempted to overcome language barriers, current evidence in this field suggests that South Asians are often illiterate in both English and their native language. For example, a randomised controlled trial investigating an education package to improve understanding of diabetes care among South Asians in the UK found that only 30% of the sample were fluent in English, and 21% were unable to read their own languages (Vyas *et al*, 2004). This reflects the situation of countries such as India which have high rates of illiteracy (Bansal, 1999). Moreover, it is thought that first-generation immigrants who are illiterate and over the age of 40 years are unlikely to become literate (Hawthorne, 2001). The utility of questionnaires must therefore be questioned, but there may be other ways of collecting data using modern technology to overcome these issues (e.g. computer-assisted administration based on the use of voice rather than the written word).

Finally, the aim of this review was to assess the acceptability, feasibility, reliability and validity of using questionnaires to measure health beliefs in the South Asian population with diabetes. It was not our primary aim to explore illness perceptions in relation to self-management. However, the evidence from the two studies that used illness perception questionnaires and additional health outcome questionnaires (Bean *et al*, 2007; Kart *et al*, 2007) helps us to better understand the link between beliefs and diabetes management. For example, both studies found that beliefs about treatment, identity, emotions and personal control influenced specific self-management behaviours, but more research is needed for a rigorous assessment of the utility of these questionnaires, and to ascertain whether there is comparable utility in other populations.

Limitations

This review focused only on diabetes-related beliefs. The extent to which beliefs predict self-management behaviours in other long-term conditions in South Asians has yet to be confirmed. The search strategy was comprehensive and used a combination of approaches to identify studies, but the search terms were specifically tailored to seven South Asian sub-ethnic groups. The review included data from a range of healthcare systems and research settings. The data retrieved by this review were limited. The lack of studies means that the utility of using questionnaires to assess health beliefs in South Asians cannot be fully assessed.

Implications for future research

The lack of evidence about the use of questionnaires to determine health beliefs among South Asian people with diabetes is a cause for concern because it may hinder the development of disease management strategies for this population. Prospective longitudinal studies with larger patient samples are required to further assess the ability of health beliefs to predict diabetes management and other relevant outcomes over time. However, future studies should take account of the need for improved rigour in the design, execution and reporting of research (see Box 2),

Box 2 Self-test questions for future research

What health belief measures are currently available?

How useful are they?

What are their limitations?

Do I need to design a new questionnaire?

What process do I need to follow to ensure my questionnaire will be acceptable, valid and reliable?

Does the questionnaire need to be translated?

What translation guidelines do I need to follow?

Box 3 Useful resources

International Test Commission (2010). (www.intestcom.org/upload/sitefiles/40.pdf)

Translated copies of the illness perception questionnaires (www.uib.no/ipq)

Diabetes UK (www.diabetes.org.uk): a leading non-government organisation that provides support, information and advice for people with diabetes.

especially with regard to translation (see Box 3), as inadequate translation has the potential to invalidate questionnaires.

Conclusion

Very few studies have used questionnaires to assess diabetes-related health beliefs in the South Asian population. There are some preliminary data which suggest that it is possible to measure health beliefs using questionnaires in these populations, and there is some evidence that these beliefs may predict self-management in this target population. However, a significant programme of work on the development and validation of measures is required if the potential of health belief interventions is to be realised in this population.

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CONFLICTS OF INTEREST

None.

ADDRESS FOR CORRESPONDENCE

Neesha Patel, Health Sciences Research Group – Primary Care, University of Manchester, 5th Floor Williamson Building, Oxford Road, Manchester M13 9PL, UK. Tel: +44 (0) 161 275 0327; fax: +44 (0) 161 275 7600; email: neesha.patel@postgrad.manchester.ac.uk

Received 17 October 2011
Accepted 2 February 2012

Appendix 3: CLAHRC LTC Aims and Objectives

COLLABORATIONS FOR LEADERSHIP IN APPLIED HEALTH RESEARCH AND CARE: Research Theme 1

Self-care Support for People with Long Term Conditions diabetes, heart and kidney disease

This programme will contribute to the promotion of self-care support through a) research on patient need, access to resources, ways of managing chronic illness and the development and b) implementation of patient and social network-centred self-care support strategies. This proposal is divided into three phases and six studies. This document presents phase 1 in detail and Phases 2 & 3 in outline**.**

Phase 1	
Project 1: (Nov 2008- Nov 2009)	**Evidence Synthesis**
	Social networks, social deprivation and chronic illness
	Information, self-care support, alternative strategies
Project 2: **(Oct 2009–Dec 2010)**	**Survey and Qualitative study of social networks and access to resources**.
May- Feb 20010	*Focus groups and working with patient groups*
Jan- Aug 2010	*Survey and mapping of local health and support resources*
Jan – Dec 2010 (July 2011 writing up/analysis)	*In-depth interviews/Ethnographic field work*

Phase 2	
Project 3: (Nov 2009 – Dec 2010)	**Development of self-management materials and strategies within social networks**
	For CKD - Focus groups with health professionals
	Focus groups with patients for each condition
	Draft of content • *Written for CKD* • *Filming for DVD/online version*
	Working with relationships and social networks – developing an approach
Project 4: (Jan - Sep 2011)	**Studies of acceptability**
	Patient use
	Professional acceptability
Phase 3	
Project 5: (Oct 2011- Oct 2013)	**Evaluation of implementation and effectiveness of the self-care support strategies in health settings**
	Quasi-Experimental Trial *1. Individual* *2. Patient plus professional* *3. Patient plus family* *4. In a group setting*
Project 6: (Oct 2011-Oct 2013)	**Process Evaluation Study**

AIMS AND OBJECTIVES OF PEOPLE WITH LONG TERM CONDITIONS RESEARCH THEME 1

The overall aims of the programme are to understand the context and range of influences impacting on ways of managing the long term conditions for people who are socially disadvantaged in order to focus on engagement development, evaluation and implementation of a self-care support strategy for people with heart disease, diabetes and kidney disease. We will develop research for better understanding networks and resources in peoples' domestic, community and work contexts and link this to adapting and implementing a patient-centred guided self-management approach for people with kidney disease, diabetes (Type 1 & 2) and heart disease. Eliciting the personal/emotional needs, social and health contexts and receptivity of socially disadvantaged people with vascular conditions will feed into the development of strategies which will be implemented integrated and evaluated within an existing evidenced based approach to guided self-management support.

The objectives are to:

- Explore the experience, practices and long term condition management needs of socially and health disadvantaged people living with kidney disease, diabetes and/ or heart disease.
- Assess lay peoples' systems of support and access to material, social and personal resources which influence engagement with services, information and coping strategies.
- Modify existing guided self-management support material through the engagement of patients in the development and use of training materials and assessing the ways it can be used in collaboration with professionals and the optimum mode of delivery.
- Develop new strategies of engagement and support for self-care which are sensitive to the differing contexts of patients and ways in which they live with long term conditions (e.g. drawing on and adapting strategies of mindfulness, motivational interviewing access to advice about social and welfare benefits etc.)
- Evaluate the use of informational and other self-care support strategies and its effectiveness in 'real life' primary and secondary care and its relevance and integration into the domestic and community settings of people living with these conditions.
- Evaluate the cost-effectiveness of this for the service and for individuals.

Programme of research

The research programme will consist of 3 phases and 6 projects enabling the building of dedicated and evidence based self-management information and testing its acceptability for use in routine NHS practice.

Phase 1:

Project 1: Evidence Synthesis: (November 2008- November 2009)

The purpose of the evidence synthesis is to inform the development of and implementation of self –care strategies in Phase 2 and Phase 3. It is also linked to identifying gaps requiring follow up via primary qualitative research focussed on identifying the ways in which social networks, capital and resources are used by people with vascular disease living in different social circumstances, and ways in which health information is most appropriately accessed and delivered.

Aims and objectives

We will undertake an evidence synthesis of two areas (one focusing on information and the other on social networks, social capital relevant to self-care support for people in socially deprived situations living with long term conditions generally and kidney disease, diabetes and heart disease. Relevant review topics are likely to include help seeking, utilisation of primary and secondary care, access to financial support, social networks, social capital and adjustments, adaptations, cognitive style and coping strategies adopted by individuals with differing social, demographic and cultural backgrounds and health literacy.

The purpose of the evidence synthesis is to:

- identify gaps requiring follow up via primary research in Phase 1 (project 2 - qualitative study of social networks and access to resources)
- inform the development of information in Phase 2 (project 3 - development of self-management intervention, project 4 - studies of acceptability)
- Inform the implementation in Phase 3 (Evaluation of implementation and effectiveness of the randomised controlled trial, project 6: process evaluation study).
- Better understand the relationship between social networks, information uptake and inequalities.

Appendix 4: Ethical Approval Letter

GM PC ReGrouP
Greater Manchester Primary Care Research Governance Partnership
NHS
NHS SalfoR+D Acute & Primary Care Research

NHS SalfoR+D Director: Professor Bill Ollier
NHS SalfoR+D Associate Director: Dr Lloyd Gregory
ReGrouP Manager: Rachel Georgiou

Enquiries: Email: Salford-Regroup-RD@manchester.ac.uk
Tele: 0161 206 8343
Fax: 0161 206 4205

SalfoR+D web address: http://www.nhssalfordrd.org.uk/
ReGrouP web address: http://www.gmregroup.nhs.uk/index.html

21st June 2010

Mrs Neesha Patel
NPCRDC
5th Floor Williamson Building
University of Manchester
M13 9PL

Dear Neesha,

Study Title: People with Long Term Conditions: Guided information for people with long term conditions implementing self care support in diabetes, heart and kidney disease
REC Reference: 10/H1008/1
R&D Reference: 2010/056

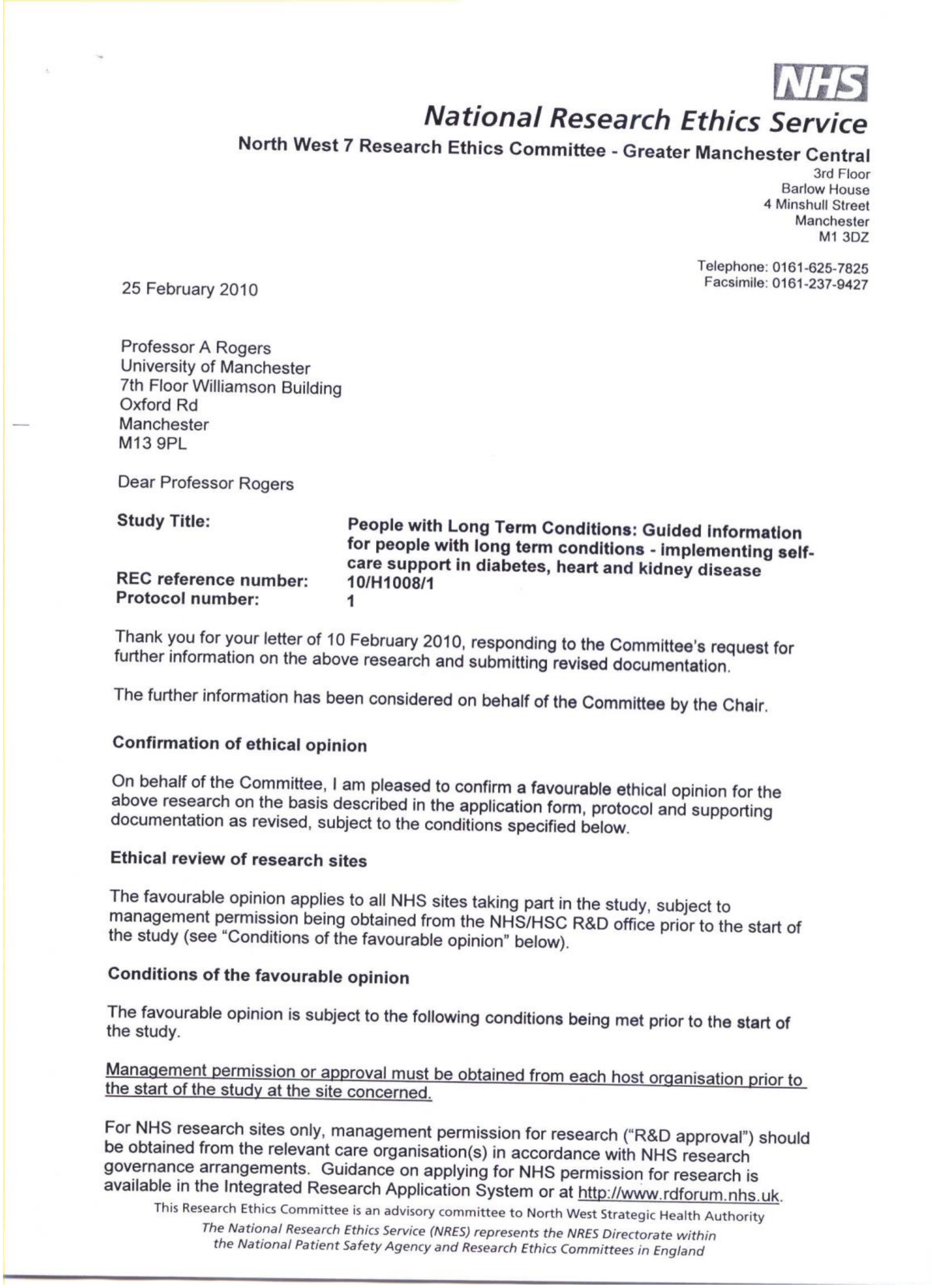
This letter confirms your right of access to conduct research through the following organisation for the purpose and on the terms and conditions set out below:

- Ashton, Leigh & Wigan PCT
- Bolton PCT
- Bury PCT
- Heywood, Middleton & Rochdale PCT
- Manchester PCT
- Oldham PCT
- Tameside & Glossop PCT
- Trafford PCT
- Salford PCT
- Stockport PCT

This right of access commences on 21st June 2010 and ends on 30th September 2013 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at the above mentioned NHS Organisation has been reviewed and you do not require an honorary research contract with these NHS organisations. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.



NHS

National Research Ethics Service

North West 7 Research Ethics Committee - Greater Manchester Central

3rd Floor
Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161-625-7825
Facsimile: 0161-237-9427

25 February 2010

Professor A Rogers
University of Manchester
7th Floor Williamson Building
Oxford Rd
Manchester
M13 9PL

Dear Professor Rogers

Study Title:	**People with Long Term Conditions: Guided information for people with long term conditions - implementing self-care support in diabetes, heart and kidney disease**
REC reference number:	**10/H1008/1**
Protocol number:	**1**

Thank you for your letter of 10 February 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Appendix 5: CLAHRC LTC GP Recruitment Standard Operating Procedure

1. Initial Contact

- Phone/ e-mail PM at surgery to explain study and email/post information sheets
- Arrange to phone back within 10 days.
- Arrange a meeting to discuss the study. At this meeting ascertain the numbers of patients on the diabetes and CHD registers.

2. GP Patient Search

- At the meeting, offer 3 options to PM
    1. PM/ practice admin staff can carry out searches for patients in house
    2. You can do these searches on the system and you will sign the confidentiality/ data protection agreement. N.B. Researchers must take in a copy of their research passport to each practice to show the Practice Manager and also ask to sign the Data Protection/ confidentiality agreement prior to starting the data collection.
    3. PM sends anonymised lists (with patient ID numbers only) to Research Team for randomisation at office.

- When the PM has agreed to one of these options, follow this up with an e-mail confirming what you have agreed.
- If you have not managed to get the patients disease register numbers at the meeting, obtain these via email.
- Email the ethics approval/ R&D approval and Research Passport to the PM if they have asked for it and if you feel it would be necessary.

3. Randomisation

- Contact Cath Fullwood and inform her of the numbers of patients on each register and how many patients you will need to select. Record this on following spreadsheet: GP Surgery Random Numbers Requirements.xls
    1. If there are less than 50-60 patients on each list – you do not need to use random numbers. Mailout to all patients on list
    2. For small practices (60-100 patients per list) select 50 per list
    3. For medium practices (100-200 patients per list) select 60 per list
    4. For large practices (200+ per list) select 75 per list

- Carry out searches

1. If admin staff carry out searches they may give you an electronic copy of ID numbers or paper copy. Take along the random numbers that have been generated by Cath and highlight the numbers of those patients (i.e. if the random number 26 appears, highlight the 26th patient on the list).
2. If you need to do the searches, **discuss further with Christian/ Dharmi.** You will need training on this.
3. If PM sends list to you by e-mail, then use the random numbers to highlight electronically the patients we require and email list back to PM. If possible, do this in a pair to guard against errors.

- List of patients goes to GP to be verified. GP excludes any patients which are not suitable: any patient that they feel does not have the capacity to give informed consent (keep the description vague and it is up to the GP to decide which patients would fall into this category e.g. severe mental health problems, learning difficulties, dementia). **The following must be excluded:**
    - Make sure deceased have been excluded
    - End stage cancer
    - Dementia
- **We are not excluding patients whose first language is not English. Explain to the surgery that we have members of the research team that can speak Guajarati and we have a budget for interpreter costs.**
- If patient has diabetes and CHD, GP is asked to indicate which they feel is the patient's main condition. **If duplicates have not been excluded, check when you do mailout.**

4. Mailout

- Check with the practice whether they are going to
    - print patient labels for you **(this is the preferred option)** or
    - do a mail merge onto the patient invitation letter.
- For labels option, ask the surgery if they can e-mail you the GP Practice headed paper so we can print the invitation letter on to this from our office **(this is the preferred option)**. If they cannot do this, then you will need to e-mail the patient invitation letter to the surgery so they can print copies of this ready for when you visit the practice to do the mail out.
- For mail merge option, the invitation letter will be printed at the surgery but you will need A4 window envelopes for making the packs rather than plain envelopes.
- Offer the practice that we will pay the postage **(this is the preferred option).**
- Buy stamps for the packs using petty cash – check with Kim about this.

- Researcher takes questionnaire pack which includes

    - Invitation letter (if you have already printed it)
    - Patient information sheet
    - Questionnaire

    - Pre-paid envelopes
    - Reply slip
    - Postage if we are paying

- GP Practice codes to be written on and diabetes/ CHD box checked on questionnaire prior to posting out
- Check you have a room to work from at surgery to put labels on/ put invitation letter in.

5. Claiming Support Costs

- **If we pay postage, ask GP surgeries to invoice for £323**
- **If they pay postage, ask GP surgeries to invoice for £413**

Inform surgeries that they invoice for “CLAHRC PATIENT SUPPORT COSTS” (i.e. this is what they are billing for). **They must address their invoice to the below address** but give them one of our freepost envelopes so that the invoice is POSTED to us. Kim will log all invoices and forward them to SRFT for processing.

Salford Royal Foundation Trust
CLAHRC
544 Eccles Old Road
Salford
Manchester
M5 5AP

“CLAHRC PATIENT SUPPORT COSTS”

Total: £323/ £413

Post back in Freepost envelope

Appendix 6: Information sheet GP practice – Invitation letter

Collaboration for Leadership in
Applied Health Research and Care
(CLAHRC) for Greater Manchester

Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease

Information Sheet

The CLAHRC study (Collaboration for Leadership in Applied Health Research and Care) aims to support patient self-management and improve quality of care for people with vascular disease by developing and evaluating patient centred interventions. This study seeks to assess the impact of information, social contacts, and resources on people living with diabetes, chronic heart disease and chronic kidney disease with a focus on socially disadvantaged groups. The CLAHRC study is conducted in partnership with the NHS and will be used to develop interventions specifically designed to meet the self-care support needs of people living with these conditions.

Working with GP practices

We would like to ask participating GP practices to produce a disease register of diabetes and chronic heart disease patients which will then be randomized to produce a shortlist of 40-50 patients per condition. A GP will then be asked to check these lists of patients to assess their suitability to participate in the research. We will then supply information to be sent by the practice to these patients. Participating practices will be provided with service support costs (see document 'Support Costs CLAHRC') and we will provide practices with data on the needs of patients with these conditions which may be of use to practice planning and practice based commissioning.

A different strategy of recruitment will be adopted for CKD patients as some of these patients may not know they have been diagnosed with the condition.

Working with patients

There are 3 stages to this study.

Stage 1: Complete a questionnaire. Participants will meet a member of the research team at a suitable location to complete the questionnaire. These patients will be invited to complete the same questionnaire after 12 months.

Stage 2: Participants will be invited to attend a group meeting, with other people who have or know someone with diabetes, heart disease or kidney disease and/or attend a one hour one-to-one interview with a researcher to talk about:

- What it is like to live with diabetes, heart disease or kidney disease or know someone who does.
- The information needed to help patients manage the condition.
- What patients do at the moment to manage their condition.
- How patients think doctors, nurses, community organisations, family and friends can help and support them.

Participants are not obliged to do both.

Stage 3: After stages 1 and 2 of the study, the research team will use the information to develop self-help resources for people with diabetes, heart disease and kidney disease. All resources produced will be made available to participants first for comments and suggestions.

For further details please visit our website: http://clahrc-gm.nihr.ac.uk and follow the link for 'People with Long Term Conditions'.

If you have any further questions you would like to ask the research team, please contact Dr Christian Blickem on 0161 275 7618 or Dr Ivo Vassilev on 0161 275 7665 who will be happy to phone you back.

CLAHRC Patient Theme
NPCRDC
Williamson Building
University of Manchester
Oxford Road
Manchester M13 9PL

Appendix 7: Participant Invitation Letter sent from GP Practice

PRACTICE HEADED PAPER

Ms PATIENT

ADDRESS

Manchester

M1 POSTCODE

DATE

Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease

Dear Patient,

We are inviting you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve.

Taking part means answering a questionnaire twice over the next year with the help of a researcher who will arrange to meet with you at a time and location convenient for you. All information we collect will be anonymised.

Please take time to read the enclosed information carefully and discuss it with others if you wish. We need your contact details in order to contact you if you decide to take part in the study. If you decide you would like to take part in the study please fill in your contact details on the reply sheet and send to us in the stamped addressed envelope provided. For further details please visit our website: http://clahrc-gm.nihr.ac.uk and follow the link for 'People with Long Term Conditions'. If there is anything that is not clear, or if you would like more information, please feel free to contact us on freephone **0800 0270661**.

Take time to decide whether or not you wish to take part.

Thank you for reading this.

Yours sincerely,

Christian Blickem	Dr
Research Associate	General Practitioner

Ivo Vassilev

Research Associate

Dharmi Kapadia Research Assistant
CLAHRC Patient Theme, 5th Floor, Williamson Building

University of Manchester, Oxford Road, Manchester, M13 9PL

Appendix 8: Participant reply slip

MANCHESTER
1824
The University of Manchester

NHS
National Institute for
Health Research

Collaboration for Leadership in
Applied Health Research and Care
(CLAHRC) for Greater Manchester

Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease

Reply Slip

If you are interested in taking part in the study please fill in the details below and return this slip in the stamped addressed envelope provided.

*Any personal details you provide will be stored securely by the University and **WILL NOT** be passed to any third parties.*

Name:	
Address:	
Contact Number:	
Contact E-mail:	

Appendix 9: Participant Information Sheet

Collaboration for Leadership in
Applied Health Research and Care
(CLAHRC) for Greater Manchester

Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease

Patient Information Sheet

Dear Sir/ Madam,

You are being invited to take part in a research study. Please take time to read the following information to decide whether or not you wish to take part.

What is the aim of the research study?

The study is designed to see how the NHS can help support people with diabetes, heart disease and kidney disease to better manage their health. To do this, we need to ask you how you are managing and about what help you are getting from other people.

What would I be asked to do if I took part?

You will be asked to take part in two interviews; the second interview will be 12 months after the first interview. We will phone you to arrange to visit you at home or meet at a place that you choose, in order to talk about:

- What it is like to live with your condition and how you manage it.
- The information you need to help you manage your condition.
- The support you need to manage your condition, e.g. family, friends and the NHS.

We will record the interviews with a voice recorder. Only members of the research team will have access to this information. When we write about the results of the research, all personal details will be removed so that no-one will know who you are. No real names will be used.

When you contact us we will send you a questionnaire to fill out before the interview. However, if you prefer, a researcher can fill in the questionnaire with you when you meet.

We are also asking for your consent to ask your GP practice to give us information about test results related to your condition. This may include blood glucose levels, cholesterol levels and blood pressure readings. This data will be anonymised and stored securely in a way that cannot be linked to you.

Please note that if you decide to take part, you are free to withdraw at any time/stage without giving a reason. This will not affect the current care you receive.

Will I be paid for participating in the research?

Yes, you will be paid £15 for taking part in the first interview. You will be paid a further £5 for taking part in the second interview.

What do I do now?

If you decide you would like to take part in the study please use the reply slip to send us your contact details in the stamped addressed envelope provided. When you have done this a member of the research team will contact you by telephone.

If you have any further questions you would like to ask the research team, please contact us on freephone **0800 0270661**.

Many thanks for your help

Christian Blickem
Research Associate

Ivo Vassilev
Research Associate

Dharmi Kapadia
Research Assistant

CLAHRC Patient Theme
5th Floor Williamson Building
The University of Manchester
Oxford Road, Manchester, M13 9PL

Appendix 10: Informed consent

MANCHESTER
1824
The University of Manchester

NHS
National Institute for
Health Research

Collaboration for Leadership in
Applied Health Research and Care
(CLAHRC) for Greater Manchester

Consent form: Patient

CLAHRC: Understanding networks of care and information needs of people with Diabetes, Heart Disease and Kidney Disease

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

3. I agree to take part in the above study. ☐

4. I agree that the interview will be voice recorded. ☐

5. I understand that when this research is completed the audio file will be retained and securely archived for a period of 10 years. This archive can only be accessed by request from the research team and all files will be destroyed at the end of that period. ☐

6. I understand that some quotes from interviews may be used in publications but my name and personal details will not be used in these publications and all information will be anonymized. ☐

7. I agree for my GP practice to give the research team information about test results related to my condition. ☐

______________________	________________	____________________
Name of Participant	Signature	Date
_________________________	________________	____________________
Researcher	Signature	Date

1 for participant; 1 for researcher;

Appendix 11: Social networks interview checklist

GP Patient Baseline Checklist

Patient ID					
Interviewer					

	Tick	**Entered on Access DB?**
Phone patient to arrange interview		
Check patient's GP Practice		
Post out questionnaire		
Questionnaire collected		
Interview completed		

Questionnaire Pack (Research Secretary)	**Tick**
Social Networks interview	
Extra ego map	
Spare questionnaire	
Consent Form	
Map of local area (print from Google maps; scale should be 1000ft/ 200m, printed on A3)	
£15 gift vouchers and petty cash receipt	
Baseline Theme Checkboxes	
Voice recorder	
Pack of highlighters	

After Interview	**Person**	**Tick**
Update database (date of survey, date of interview)	GL	
Enter themes from interview on database	GL	
Make note of 12 month follow up interview and add to database	GL	
Upload audio file	Interviewer	
Field notes (type up or dictate)	Interviewer	
Scan map and ego net		
Enter survey data		

Appendix 12: Amendment to the CLAHRC LTC Participant Information sheet

Collaboration for Leadership in
Applied Health Research and Care
(CLAHRC) for Greater Manchester

Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease

Participant Information Sheet

Dear Sir/ Madam,

Please take the time to read the following information to decide whether or not you wish to take part.

What is the aim of the research study?

The study is designed to see how the NHS can help support people with diabetes, heart disease and kidney disease to better manage their health. To do this, we need to ask you how you are managing and about what help you are getting from other people.

What would I be asked to do if I took part?

You will be asked to complete a questionnaire which will take 20 to 30 minutes to complete.

Only members of the research team will have access to this information. When we write about the results of the research, all personal details will be removed so that no-one will know who you are. No real names will be used.

Please note that if you decide to take part, you are free to withdraw at any time/stage without giving a reason. This will not affect the current care you receive.

Will I be paid for participating in the research?

Yes, you will be paid £5 shopping voucher for completing the survey.

What do I do now?

If you decide you would like to take part in the study please complete the questionnaire and send it back in the stamped addressed envelope provided. Once it has been received you will be sent you £5 voucher via post within 5 working days.

If you have any further questions you would like to ask the research team, please contact us on freephone **0800 0270661**.

Many thanks for your time.

Neesha Patel

CLAHRC Patient Theme
5th Floor Williamson Building
The University of Manchester
Oxford Road
Manchester
M13 9PL

Appendix 13: Revised consent form for community participants

MANCHESTER
1824
The University of Manchester

NHS
National Institute for
Health Research

**Collaboration for Leadership in
Applied Health Research and Care
(CLAHRC) for Greater Manchester**

Consent form: Community Participants

CLAHRC: Understanding networks of care and information needs of people with Diabetes

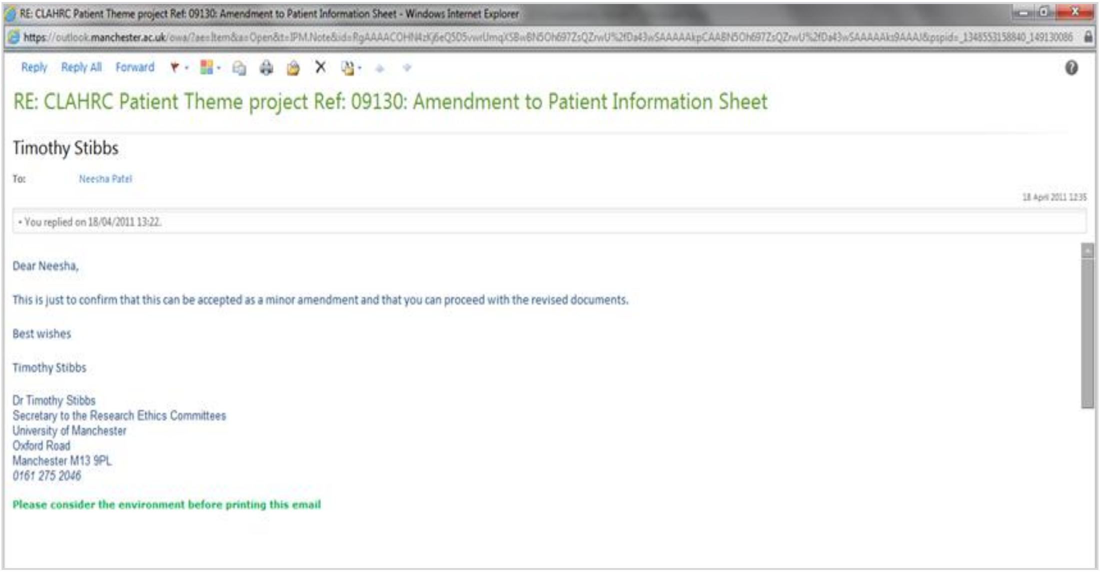
Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in the above study. ☐
4. I understand that my name and personal details will be anonymized. ☐

______________________	________________	____________________
Name of Participant	Date	Signature
______________________	________________	____________________
Researcher	Date	Signature

1 for participant; 1 for researcher

Appendix 14: Ethical Approval for revised consent form and information sheet



RE: CLAHRC Patient Theme project Ref: 09130: Amendment to Patient Information Sheet

Timothy Stibbs

To: Neesha Patel

18 April 2011 12:35

• You replied on 18/04/2011 13:22.

Dear Neesha,

This is just to confirm that this can be accepted as a minor amendment and that you can proceed with the revised documents.

Best wishes

Timothy Stibbs

Dr Timothy Stibbs
Secretary to the Research Ethics Committees
University of Manchester
Oxford Road
Manchester M13 9PL
0161 275 2046

Please consider the environment before printing this email

Appendix 15: CLAHRC LTC Postal Health Survey

FOR OFFICE USE ONLY					
GP Practice ID	▨	▨			
Patient ID					

FOR OFFICE USE ONLY	
CHD	
Diabetes	

Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease

Dear Sir or Madam,

This is a questionnaire to help us to understand the needs of people with diabetes, heart disease and kidney disease.

Please remember to send back the reply slip that came with this questionnaire pack, if you would like to take part in the study.

We would be very grateful if you could complete this questionnaire. If you agree to take part in our research study, the researcher will collect this questionnaire from you when they interview you. The researcher will help you if you have any problems filling in the questionnaire

All the information that you provide will be treated in the strictest confidence.

Many thanks for your help

CLAHRC Patient Theme
5th Floor Williamson Building
The University of Manchester
Oxford Road
Manchester
M13 9PL

A: Long-term health problems

1. Can you tell me for how long have you had Diabetes/Chronic Heart Disease?

Years ☐☐ Months ☐☐

2. What other long-term medical conditions do you have?

Please ***tick*** all boxes that apply. Please also indicate in the last column which you consider to be your main condition.

	Other conditions	**Main condition**
Diabetes Type 1	☐	☐
Diabetes Type 2	☐	☐
Heart problems/ high blood pressure	☐	☐
Kidney problems	☐	☐
Breathing problems / COPD (***Chronic Obstructive Pulmonary Disease)***	☐	☐
IBS (Irritable Bowel Syndrome) or gut problems	☐	☐
Arthritis or painful joints, back trouble, osteoporosis	☐	☐
Chronic fatigue syndrome, ME (Myalgic Encephalopathy) or fibromyalgia	☐	☐
Anxiety, depression or stress	☐	☐
Multiple sclerosis	☐	☐
Other (Please give details) ____ ____ ____________________	☐	☐

B: How you feel about your illness

For the following questions, please ***circle*** the number that best corresponds to your views

1. How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
No affect at all										Severely affects my life

2. How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
A very short time										Forever

3. How much control do you feel you have over your illness?

0	1	2	3	4	5	6	7	8	9	10
Absolutely no control										Extreme amount of control

4. How much do you think your treatment can help your illness?

0	1	2	3	4	5	6	7	8	9	10
Not at all										Extremely helpful

5. How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10
No symptoms at all										Many severe symptoms

6. How concerned are you about your illness?

0	1	2	3	4	5	6	7	8	9	10
Not at all concerned										Extremely concerned

7. How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10
Don't understand at all										Understand very clearly

8. How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

0	1	2	3	4	5	6	7	8	9	10
Not at all affected emotionally										Extremely affected emotionally

9. Please list in rank-order the three most important factors that you believe caused your illness.

The most important causes for me:

1. ___________________________________

2. ___________________________________

3. ___________________________________

Other ___________________________________

For the following questions, please ***circle*** the number that best corresponds to your views

10. My illness is largely dependent on chance or fate

1	2	3	4	5
Strongly disagree				Strongly agree

11. There is very little I can do to personally improve my health status

1	2	3	4	5
Strongly disagree				Strongly agree

C: Your health and day-to-day activities

For each of the following questions, please ***tick*** the best possible answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

2. The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

a) Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf…

Yes, limited a lot	Yes, limited a little	No, not limited at all
☐	☐	☐

b) Climbing several flights of stairs…

Yes, limited a Lot	Yes, limited a little	No, not limited at all
☐	☐	☐

3. During the <u>past 4 weeks</u>, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

a) <u>Accomplished less</u> than you would like…

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

b) Were limited in the <u>kind</u> of work or other activities

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

4. During the <u>past 4 weeks</u>, how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

a) <u>Accomplished less</u> than you would like…

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

b) Were limited in the kind of work or other activities

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks…

a) Have you felt calm and peaceful?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

b) Did you have a lot of energy?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

c) Have you felt downhearted and depressed?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

8. Taking all things together, how happy would you say you are?

Please ***circle*** the number that best corresponds to your views or tick the box for ‘don’t know’.

Extremely unhappy										Extremely happy	(Don’t know)
0	1	2	3	4	5	6	7	8	9	10	☐

D: Coping with your illness

For each of the following questions, please ***tick*** the best possible answer.

		Strongly disagree	Disagree	Agree	Strongly Agree
1.	When I have symptoms, I have the skills that help me cope				
2.	I am very good at using aids and devices to make my life easier				
3.	I have effective skills that help me handle stress				
4.	I have a very good idea of how to manage my health problems				
5.	I have effective ways to prevent my symptoms (e.g. discomfort, pain and stress) from limiting what I can do in my life				
6.	With my health in mind, I have realistic expectations of what I can and cannot do				
7.	As well as seeing my doctor, I regularly monitor changes in my health				
8.	I know what things can trigger my health problems and make them worse				
9.	When I have health problems I have a clear understanding what I need to do to control them				
10.	I have a very good understanding of when and why I am supposed to take my medication				
11.	I carefully watch my health and do what is necessary to keep as healthy as possible				
12.	I know when my lifestyle (e.g., exercise, diet, stress) is creating health problems for me				

13. All things considered, how satisfied are you with your life as a whole nowadays?

Please ***circle*** the number that best corresponds to your views or tick the box for ‘don’t know’.

Extremely dissatisfied										Extremely satisfied	(Don’t know)
0	1	2	3	4	5	6	7	8	9	10	☐

E: Looking after your health

The questions below ask you about your self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.

Please ***circle*** the best possible answer.

1. How many of the last SEVEN DAYS have you followed a healthy eating plan?

0 1 2 3 4 5 6 7

2. On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?

0 1 2 3 4 5 6 7

3. On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?

0 1 2 3 4 5 6 7

4. On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?

0 1 2 3 4 5 6 7

5. On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).

0 1 2 3 4 5 6 7

6. On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, cycling) other than what you do around the house or as part of your work?

0 1 2 3 4 5 6 7

7. Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?

Yes No

☐ ☐

If yes, how many cigarettes did you smoke on an average day?

Please enter here number of cigarettes: ………………………

If you have heart disease please answer the next question:

8. Have you been advised to measure your blood pressure at home?

Yes No

☐ ☐

If yes, what is your average/ usual blood pressure?

Please enter here blood pressure: ………………………

If you have diabetes please answer the following four questions:

Please ***circle*** the best possible answer.

1. On how many of the last SEVEN DAYS did you check your feet?

0 1 2 3 4 5 6 7

2. On how many of the last SEVEN DAYS did you inspect the inside of your shoes?

0 1 2 3 4 5 6 7

3. Do you measure your blood sugar at home?

Yes No

☐ ☐

If yes please answer the following question

Please ***circle*** the best possible answer.

4. On how many of the last SEVEN DAYS did you test your blood sugar?

0	1	2	3	4	5	6	7

F: Using the Internet

1. Do you have access to a computer linked to the Internet?

Please ***tick*** all that apply.

Yes, at home ☐

Yes, elsewhere ☐

No, I don't have access to the Internet ☐

If you have used the Internet at least once for medical information or support please answer the following question:

2. Which of the following have you used the Internet for in the past six months? Please ***tick*** all boxes that apply

a)	To find out about long-term health conditions (things like causes, symptoms and treatments)	☐
b)	To find internet support or self help groups **to read what other people have written**	☐
c)	To find internet support or self help groups **to take part in online discussions**	☐
d)	I use the internet regularly but **not for health related matters**	☐

G: How you use information

What sources of information do you use now and how would you like to get health advice or information in the future?

Please ***tick*** all boxes that apply

	Use now	**Would like in future**
Leaflets from your GP practice, hospital or pharmacy	☐	☐
Health books or magazines	☐	☐
Your family, friends or colleagues	☐	☐
Health professional – GP, nurse, pharmacist, hospital doctor	☐	☐
Health Websites	☐	☐
DVDs	☐	☐
Support groups of people with similar conditions	☐	☐
Internet support groups for people with similar conditions	☐	☐
Other (Please give details) ____ ____ __________________		

H: Your neighbourhood

1. **How long have you lived in your area?**

Years ☐☐ Months ☐☐

2. **Please say how much you agree or disagree with the following statements:**

a) **This area is a place I enjoy living in.** Please tick *one* box

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

b) **This area is a place where neighbours look after each other.** Please tick *one* box.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

c) **This area has good local transport.** Please tick *one* box.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

d) **This area has good leisure things for people like me: for example, leisure centres or community centres, pubs, cafes.** Please tick *one* box.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

e) **This area is well provided with health services.** Please tick *one* box.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

f) **This area is well provided with shops, banks, and postal services.** Please tick *one* box.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

g) **In your local area how much of a problem are teenagers hanging around on the streets?** Please tick *one* box.

Very big problem	Fairly big problem	Not a very big problem	Not a problem at all
☐	☐	☐	☐

h) **In your local area how much of a problem is vandalism, graffiti or deliberate damage to property?** Please tick *one* box.

Very big problem	Fairly big problem	Not a very big problem	Not a problem at all
☐	☐	☐	☐

i) **In your local area how much of a problem is racial or religious harassment (even if itdoesn'taffect you personally)?** Please tick *one* box.

Very big problem	Fairly big problem	Not a very big problem	Not a problem at all	Don't know
☐	☐	☐	☐	☐

j) **In your opinion, most of the people who do not live in this area would tend to think about it as a good area to live in?** Please tick *one* box.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

I: Your hobbies and social involvement

1. Do you join in the activities of any of these organisations and how often?

Please, ***tick*** as appropriate

	Never	At least **once a week**	At least **once a month**	At least every **three months**	Less often
Political groups (e.g. trade unions or environmental organisations)					

School associations					
Neighbourhood watch					
Voluntary work					
Lunch club					
Working men’s club					
Sports or exercise groups, including taking part, coaching or going to watch					
Social club/ hobbies					
Groups for children or young people					
Adult education groups					
Groups for older people					
Health, disability and welfare groups					
Religious groups, including going to a place of worship or belonging to a religious group					
Other local community or neighbourhood groups					

2. I am satisfied with my opportunities as they are at the moment to participate in the above mentioned activities

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

3. In the last 12 months have you, or someone else acting on your behalf, taken any of the following actions in an attempt to solve a problem affecting people in your local area?
For example someone else complained to the council about rubbish collection in your area when you yourself were unable or uncomfortable to do so

Please ***tick*** all that apply

	Myself	**Someone else**
Contacted a local radio station, television station or newspaper		
Contacted the appropriate organisation to deal with the problem, such as the council		
Contacted a local councillor or MP		

Attended a public meeting or neighbourhood forum to discuss local issues		
Attended a tenants or local residents. Group		
Attended a protest meeting or joined an action group		
Helped organise a petition on a local issue		
None of these		

4. In the past month have you given any unpaid help in any of the ways shown below. Please do not count any help you gave through a group, club or organisation.

Please ***tick*** all that apply

Domestic work, home maintenance or gardening	
Provision of transport or running errands	
Help with childcare or babysitting	
Teaching, coaching or giving practical advice	
Giving emotional support	
Help with pet walking or feeding/ looking after whilst away	
Other	

5. Do you currently have access to someone who…?

Please ***tick*** all types of access that apply e.g. If you have a friend and neighbour that you have access to for repairing a car, please tick 'Friend' and 'Neighbour'.

	No	If '**Yes**', access through:					
		Immediate family	Wider family	Friend	Neighbour	Colleague	Acquaintance
Can repair a broken-down car							
Is a reliable tradesman							
Can speak another language fluently							
Knows how to fix problems with computers							

Is good at gardening							
Has a professional occupation							
Is a local councillor							
Works for your local council							
Can sometimes employ people							
Knows a lot about government regulations							
Has good contacts with local newspaper, radio or TV							
Knows a lot about health and fitness							
Knows a lot about DIY							

6. Do you currently know anyone who would…?

Please ***tick*** all that apply e.g. if you know a colleague and an acquaintance that would give you advice about money problems, please tick ‘Colleague’ and ‘Acquaintance’.

	No	If ‘**Yes**’, access through:					
		Immediate family	Wider family	Friend	Neighbour	Colleague	Acquaintance
Give you some advice about money problems							
Give you sound advice about problems at work							
Help you to move or dispose of bulky items							
Help you with small jobs around the house							
Do your shopping if you are ill							
Lend you a small amount of money							
Give you career advice							
Discuss politics with you							

Give you sound legal advice							
Give you a good reference for a job							
Get you cheap goods or 'bargains'							
Help you to find somewhere to live if you had to move home							
Lend you a large amount of money							
Look after your home or pets if you go away							

J: Your health and other people

Who do you believe <u>should be</u> responsible for the management of your condition? Please ***<u>tick</u>*** as appropriate

	Very responsible	Somewhat responsible	Not responsible at all	Don't know
Friends	☐	☐	☐	☐
Employer	☐	☐	☐	☐
Yourself (the person with the condition)	☐	☐	☐	☐
Your GP	☐	☐	☐	☐
Your specialist	☐	☐	☐	☐
Partner/ Spouse	☐	☐	☐	☐
Family	☐	☐	☐	☐
Other (please specify) ______________________ ______________________	☐	☐	☐	☐

K: Time you spend on managing your illness

1. Over the last 6 months, how much time do you spend every day on activities that are related to managing your condition?

Please ***tick*** as appropriate

Up to 30 min a day	30 min - 1 hour a day	1-2 hours a day	More than 2 hours a day
☐	☐	☐	☐

2. Over the last 6 months, please estimate the total number of times you have used each of the services below, during the last 6 months

Please enter '0' if a particular service was not used

	Total number of times
Accident and Emergency department	
Outpatient or day hospital	
General Practitioner (at the surgery)	
General Practitioner (at your home)	
General Practitioner (clinic in Supermarket or Pharmacy)	
Practice nurse	

3. Please list each overnight stay you have had in hospital over the last 6 months (number of times and nights)

	Ward/Specialty	Number of nights
Hospital stay 1		
Hospital stay 2		
Hospital stay 3		
Hospital stay 4		

L: Your background

For each of the following questions, please ***tick*** or fill in as appropriate.

1. Are you:

Male	Female
☐	☐

2. What is your date of birth?

Please write here your date of birth (Date/Month/Year) ……./……../……..

3. What is your legal marital status?

Never married or formed a civil partnership	Married or in a civil partnership	Separated	Divorced	Widowed
☐	☐	☐	☐	☐

4. Who do you live with in your current home?

Live alone	☐		
Spouse/partner	☐		
Parent(s)	☐		
Children under 18	☐	If yes, how many?	………………..
Children over 18	☐	If yes, how many?	………………..
Other family	☐	If yes, how many?	………………..
Friends	☐	If yes, how many?	………………..
Tenants	☐	If yes, how many?	………………..
Pets	☐	If yes, how many?	………………..

5. How long have you lived in your current home?

Please write here the number of years ……………………

6. How many rooms do you have for use only by your household? Please, do not count bathrooms, toilets, halls or landings, or rooms that can only be used for storage.

Please write here the number of rooms ……………………

7. How many cars or vans are owned, or available for use, by one or more members of your household?

Please write here the number of cars and vans……………………

8. Does your household own or rent the accommodation?

Owns outright	Owns with mortgage or loan	Part rent and part mortgage	Rents	Lives here rent free
☐	☐	☐	☐	☐

9. Which ethnic group do you consider you belong to?

White

British	☐
Irish	☐
Other white background. Please specify	☐

Black or Black British

Caribbean	☐
African	☐
Other black background. Please specify	☐

Asian or Asian British

Indian	☐
Pakistani	☐
Bangladeshi	☐
Other Asian background. Please specify	☐

Chinese or other ethnic group

Chinese	☐
Other ethnic background. Please specify	☐

Mixed

White and Black Caribbean	☐
White and Black African	☐
White and Asian	☐
Other mixed background. Please specify	☐

Other Background

Please specify	☐

10. Which of these qualifications do you have?

1 to 4 O levels/ CSEs/ GCSEs (any grade)	☐
5 or more O levels/ CSEs/ GCSEs (any grade), School Certificate	☐
1 or more A levels/ AS levels	☐
First Degree (e.g. BA, BSc)	☐
Higher Degree (e.g. MA, PhD, PGCE, post-graduate certificate diplomas)	☐
NVQ, HNC or HND	☐
Professional qualification	☐
Other Qualifications (e.g. City and Guilds, RSA /OCR, BTEC/ Edexcel)	☐
No qualifications	☐

M: Your work and your health

1. Have you ever worked?

	You	**Your partner**
Yes	☐	☐
No	☐	☐

2. Which of these best describes <u>YOUR</u> current work situation? Please tick <u>ONE</u> main and any others as appropriate

	Main	**Other**
In paid work (full or part-time, including self-employed)	☐	☐
Retired from paid work	☐	☐
In full time education or training	☐	☐
Currently seeking employment	☐	☐

Voluntary work	☐	☐
Looking after home/family	☐	☐
Long-term sick/disabled	☐	☐
None of the above	☐	☐

3. Which of these best describes YOUR PARTNER'S current work situation? Please tick ONE main and any others as appropriate

	Main	Other
In paid work (full or part-time, including self-employed)	☐	☐
Retired from paid work	☐	☐
In full time education or training	☐	☐
Currently seeking employment	☐	☐
Voluntary work	☐	☐
Looking after home/family	☐	☐
Long-term sick/disabled	☐	☐
None of the above	☐	☐

4. Do you work as an employee or are you self-employed?

	You	Your partner
Employee	☐	☐
Self-employed with employees	☐	☐
Self-employed without employees	☐	☐

5. What is the full title of your main job? (if not employed at present what was the full title of your main job when you were employed)

	You	Your partner
Title	…………	…………

6. Do/ did you supervise any other employees?

	You	Your partner
Yes	☐	☐

No ☐ ☐

7. How many hours a week do/did you usually work in your *main* job?

	You	**Your partner**
Number	…………	…………

8. What is your household's total income from all sources, e.g. employment, benefits, pensions, investments, savings, maintenance payments, grants?

Please **do not** deduct: taxes, national insurance contributions, Health insurance payments

Per week	OR		Per year (approximately)
Nil	☐	☐	Nil
Up to £99	☐	☐	Up to £5,199
£100 to £199	☐	☐	£5,200 to £10,399
£200 to £299	☐	☐	£10,400 to £15,599
£300 to £399	☐	☐	£15,600 to £20,799
£400 to £499	☐	☐	£20,800 to £25,999
£500 to £599	☐	☐	£26,000 to £31,999
£600 to £999	☐	☐	£32,000 to £51,999
£1000 or more	☐	☐	£52,000 or more

Please write in today's date below

Day: **Month:** **ar:**

Please fill in your details below:

Name:	
Contact phone number:	

If you have any comments on the survey or any other aspects of the research, please write them here.

The researcher will collect this questionnaire from you when they come to interview you. If you have any difficulty in completing the questionnaire, please ask the researcher at the interview. Alternatively, please phone the U-NET Research Team on freephone **0800 0270661** and we will be happy to assist you.

Thank you for your time in completing this survey.

END OF QUESTIONNAIRE

FOR OFFICE USE ONLY					
GP Practice ID					
Patient ID					

Appendix 16: Social Networks survey interview

A: Social network diagram

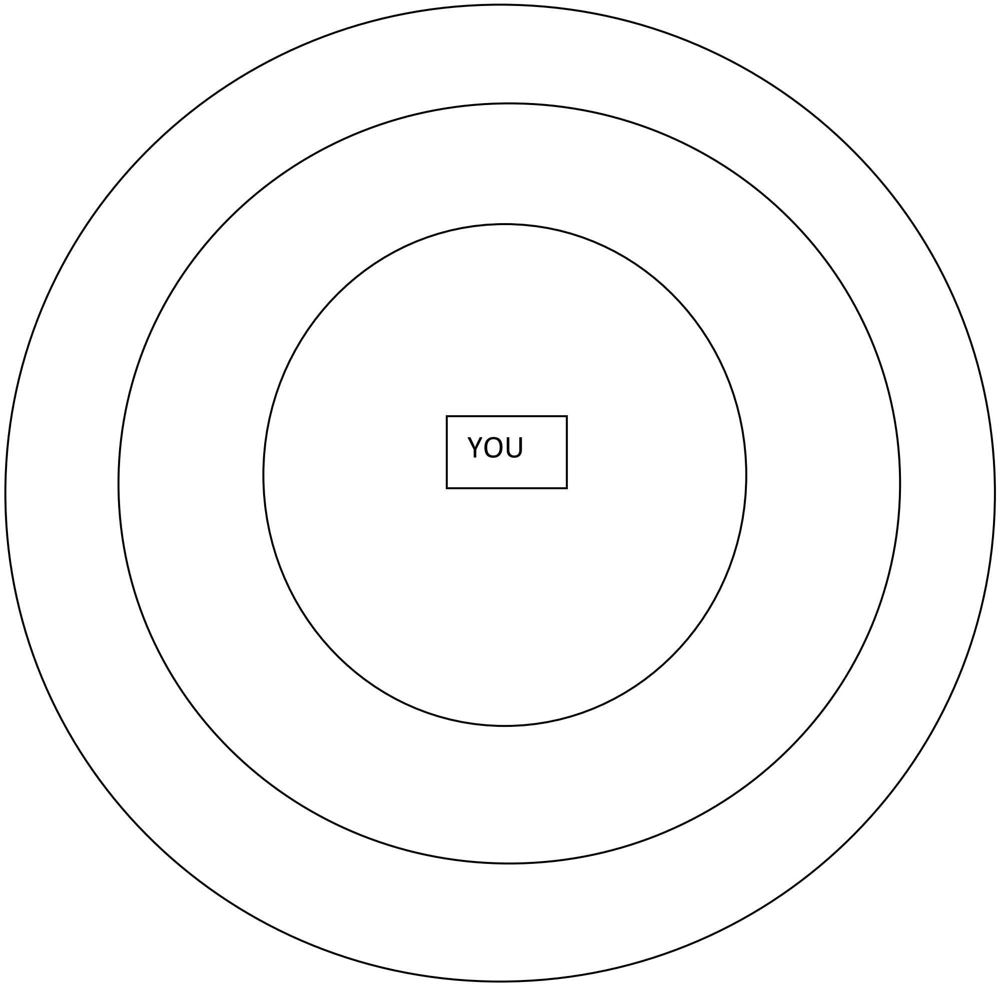
[Start audio recording]

[Give leaflet 1 and explain that the inner circle symbolizes people, groups or service providers who the respondent considers <u>most important</u> in relation to managing their condition, in the middle circle people, groups, service providers who they consider <u>less important</u> (if compared to the first group), and in the outer circle people, groups, service providers who they consider <u>important</u> (but less so compared to the other two groups).]

[Show the table with the list of people, groups and service providers that might be involved with different types of support.]

Types of support

Relationships	a) Spouse/Partner b) Son/Daughter c) Grandchildren (female/male) d) Mother/Father e) Brothers/Sisters f) Relatives (female/male) g) Friends (female/male) [types of friends, be specific] h) Pets i) Neighbours (female/male) j) Colleagues/Classmates (female/male)
Local and voluntary groups	Support group Lunch/Tea club Internet-based discussion group Religious group Ethnic group Sports groups Other social groups
Alternative medical	Traditional healers (faith healers, spiritualists, herbalists)
Non medical professionals	Social workers Legal agents (Police, lawyers) Religious or spiritual leaders Supervisors (Bosses, teachers) Community wardens Carers Volunteer [individuals]
Modern medical	GP Nurse Specialists (physicians, psychiatrists, podiatrists) Pharmacist


YOU

1. For the interviewer only – mark on the grid below which circle each network member is placed in:

a) central
b) middle
c) outer

[After the respondent completes the diagram ask:]

2. **What relationship is each of the people in the diagram to you?** [Choose from the list and mark in the grid below]

a) Spouse/ partner	i) Supervisor/ boss	r) Alternative medical
b) Mother/ father/ other parent	j) Carer	s) Son-in-law/ daughter-in-law
c) Son/ daughter	k) Volunteer	t) Grandchild
d) Brother/ sister	l) Pet	u) Internet support group
e) Other relative	m) Voluntary/ community group	v) NHS group
f) Friend	n) Religious group	w) Work (as a whole)
g) Neighbour	p) Medical professional (GP-**p1**, nurses-**p2**, pharmacist-**p3,** other-**p4**)	x) Food delivery
h) Colleague	q) Non-medical professional	z) **Other**

3. What is roughly the distance from where you live and each one of the people/groups/pets in the diagram? Choose from the list below [Mark in the grid below]
a) co-habiting
b) short walk
c) short drive or bus journey (up to 1 hour)
d) longer journey (that will take more than one hour)

4. How often do you see (or talk on the phone, text, or via internet) each of them and for how long? [Mark in the grid below]
a) every day
b) at least once a week
c) at least once a month
d) at least once every couple of months
e) less often

5. How much time do you spend with each one of them when you meet (or talk on the phone, text, or via internet)? [Mark in the grid below]
a) up to 30 minutes
b) between 30 minutes and 1 hour
c) between 1 and 2 hours
d) more then 2 hours

6. My contact with this member of my networks [person/group/pet] is mostly: [Mark in the grid below]
a) Face-to-face
b) by telephone
c) by e-mail
d) other internet resource (e.g. chat room or facebook).

Question numbers		Network Members																			
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
	1																				
	2																				
	3																				
	4																				
	5																				
	6																				

7. Who among these people/<u>pets</u> know each other? [mark with different colour markers]

8. How close is the relationship between people/<u>pets</u> who know each other? [Ask this for those people that have been highlighted on the map, in response to the previous question. Mark responses in the grid below]

a) not very close
b) close
c) very close

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1	■																			
2	■	■																		
3	■	■	■																	
4	■	■	■	■																
5	■	■	■	■	■															
6	■	■	■	■	■	■														
7	■	■	■	■	■	■	■													
8	■	■	■	■	■	■	■	■												
9	■	■	■	■	■	■	■	■	■											
10	■	■	■	■	■	■	■	■	■	■										
11	■	■	■	■	■	■	■	■	■	■	■									
12	■	■	■	■	■	■	■	■	■	■	■	■								
13	■	■	■	■	■	■	■	■	■	■	■	■	■							
14	■	■	■	■	■	■	■	■	■	■	■	■	■	■						
15	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■					
16	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■				
17	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■			
18	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■		
19	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	
20	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■

B: Changes in your network over time

Looking at this diagram and thinking about the time when you were first diagnosed with this condition, and up to a year after diagnosis, can you tell me in what ways was this diagram different? [only to be asked if the person has been diagnosed with the illness more than 1 year ago] Can you tell me:

1. Who among these people/pets/groups/services that are currently on the diagram were [mark on the grid below]

a) more important than they are at present?
b) less important than they are at present?
c) of same importance?

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

2. Were there other people/pets/groups/services that used to be in your network but are not now? [interviewer to list members below]

Network Member name	Relationship	Relationship code (use codes from question 2 above)	Which circle? (a – central; b – middle; c- outer)

C: How are others involved in managing your illness

Many of the questions in this section are related to mundane tasks and activities that we take for granted. However, living with a long term condition we often rely on other people to perform some tasks that we would otherwise do ourselves.

1. What helps you manage your condition day to day?

2. What do people/pets do to help you cope with your illness?

3. Where or who do you go to find out more about your illness?

4. Do you use the internet in relation to your illness? How?

5. Is there anything else that you find useful to help you cope with your illness?

6. When you need advice about, or help with, your diet who do you go to?

[Note for interviewer: Who does the cooking and shopping? Who helps with finding new recipes? Who knows about sugar, salt and fat content of ingredients? In ready meals or take away food?]

7. When you need advice about, or help with, exercises who do you go to?

[Note for the interviewer: Who encourages you, accompanies you, gives you ideas and information about things like running, swimming, walking, going to the gym]

8. Where would you go, or who would you go to, for advice or help with relieving stress?

[Who encourages you to try not to worry, to do breathing exercises, take more short breaks and more regularly]

9. When you need advice about, or help with, medications who would you turn to?

[Note for the interviewer: Noticing or managing symptoms, worries related to medications, help/advice about performing difficult, inconvenient and painful tests.]

10.

a) Living with a long term condition often means that you need to do things more slowly, take on additional tasks and other people may need to make compromises that are good for your health. Who in your diagram does these things

b) Using the map can you please describe in detail what would you do on a typical day starting from getting up in the morning? Please include tasks and activities that are not related to managing your condition, such as cooking, cleaning, making repairs, etc. Can you tell us how different people/pets on your diagram are involved with different activities?

- Can you look at the map and tell me what you did and where you went yesterday?
- Do you have any ….(refer to list)… in the area? Are there any other places where you go?

a) Library b) Place of worship c) Health club d) GP surgery/NHS centre e) Community centre f) Public toilets g) Pubs/Cafes h) Local shops i) Park

b) Can you also mark where your friends and relatives live?

- When or how often would you go there?
- Can you mark on the map where you normally go for a walk? (mark with a marker pen; indicate who with)

11. Who do you turn to when you are worried about your illness?

12. a) Looking at your diagram who do you think you would like to be more involved in helping you with your illness than they are at present?

b) What and who helps or hinders your care (related to diet/exercise/medication)? Can you think of examples?

13. Who or what (e.g. pet) in your diagram gives you emotional support and encouragement? Can you think of examples?

14. Who in your diagram would step in/stand up for you when you do not feel well enough to stand up for yourself?

[Note to the interviewer: Sometimes people around you may not understand how you feel due to your condition and you may not always feel comfortable explaining and defending yourself. Ask the question in relation to home and to work if relevant]

15. Who among the people or pets in your diagram do you help? How?

D: Who is involved in managing your illness

1. How many years have you known this person?

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

Now I will ask you a couple of questions about each person in your diagram and will ask you to rate each of them in terms of their contribution on a scale between 1 and 5, where 1 is not at all and 5 is a lot. Please start with the people in the centre of the diagram.

2. This person helps me with the day-to-day management of my long-term condition. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

3. This person makes the day-to-day management of my long-term condition more difficult for me. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

4. This person helps me with the day-to-day running of my household. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

5. This person helps me value and enjoy life. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

6. This person helps me achieve personal goals. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

7. This person helps me when I need to re-arrange things due to health problems. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

8. This person helps me understand advice so I know what I have to do to manage my condition. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

9. This person helps me organise tasks related to my condition, including arranging appointments with health care staff, getting prescriptions etc. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

10. This person stands in for me or stands up for me when I am unwell or unable to stand up for myself. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

11. This person comforts me when I am worried or anxious about my health problems. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

12. This person makes me feel good about myself.

[Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

13. This person makes me feel bad about myself.

[Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

14. This person helps me with things related to my diet. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

15. This person can have a negative influence on my diet. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

16. This person helps me with things related to physical activities and exercise. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot.]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

17. This person discourages me from doing physical activities and exercise. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot.]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

18. This person helps me with things related to medications. [Rate this between 1 and 5 where 1 is not at all and 5 is a lot. Please mark N.A. if not applicable]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
P																				
R																				

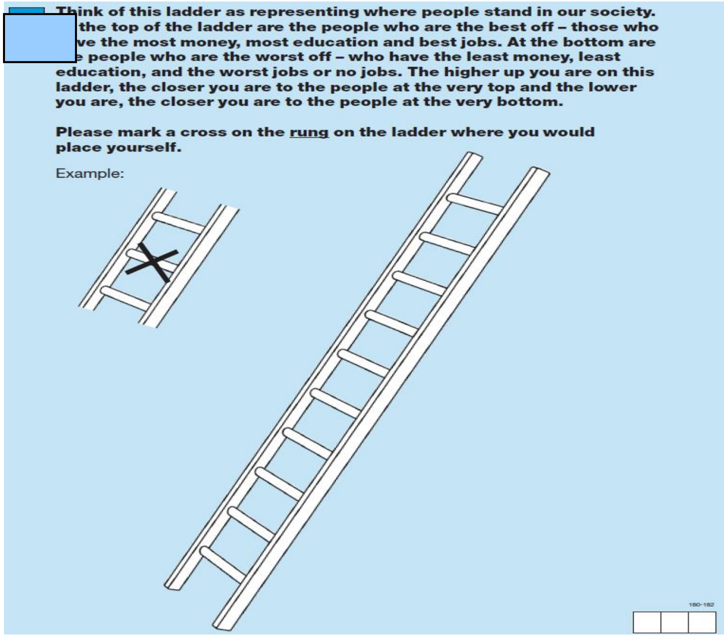
E: What is most important for you in managing your illness

1. Which of these activities or types of support are most important to you? [Please select the three most important ones and rank them from 1 to 3, 1 being most important and 3 least important]

Day-to-day management of your long-term condition	
Day-to-day work in running your household.	
Enjoying life and achieving personal goals.	
Re-arranging things due to health problems	
Understanding information and advice for managing your condition.	
Organising tasks related to your condition, including arranging appointments with health care staff, getting prescriptions etc?	
Someone to stand up for you when you are unwell or unable to stand up for yourself	
Reassurance when you are worried or anxious about your health problems	

2. Which one is least important? [Please mark with ‘0’]

F: Where do you think you stand in society?



Think of this ladder as representing where people stand in our society. the top of the ladder are the people who are the best off – those who ve the most money, most education and best jobs. At the bottom are e people who are the worst off – who have the least money, least education, and the worst jobs or no jobs. The higher up you are on this ladder, the closer you are to the people at the very top and the lower you are, the closer you are to the people at the very bottom.

Please mark a cross on the rung on the ladder where you would place yourself.

Example:

180-182

G: About other people around you

Please assess all members of your network in relation to the following statements:

1. This person's diet is: [Please mark as appropriate]

1) very healthy 2) healthy 3) neither healthy nor unhealthy 4) unhealthy 5) very unhealthy

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

2. This person does exercise and physical activities: [Please mark as appropriate]

1) Never 2) Sometimes 3) Often 4) Very often 5) All the time

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

3. Who among the people on your diagram have diabetes, heart disease or kidney disease? [Please tick as appropriate]

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
D																				
CHD																				
CKD																				

4. Where does this person stand in society compared to you (think about the ladder question earlier)? [Please mark as appropriate]

1) much lower than myself 2) a bit lower than myself 3) same as myself 4) a bit higher than myself 5) much higher than myself

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

5. What is the age of this person? They are:

a) 10 or under b) 11-17 c) 18-24 d) 25-29 e) 30-39 f) 40-49 g) 50-64 h) 65-74 i) 75 or over [Please mark as appropriate]

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

H: Coping with your illness

Please mark as appropriate

1. I find that managing my illness is making life difficult for me.

Never	Sometimes	Often	Very often	All the time
☐	☐	☐	☐	☐

2. I am so used to living with my condition that I can manage it without much thinking.

Never	Sometimes	Often	Very often	All the time
☐	☐	☐	☐	☐

3. I find that managing my illness is making life difficult for other people.

Never	Sometimes	Often	Very often	All the time
☐	☐	☐	☐	☐

4. Other people around me are so used to my condition that it has become a normal part of their everyday life.

Never	Sometimes	Often	Very often	All the time
☐	☐	☐	☐	☐

I: Neighbourhood, family, and work

I feel settled and strongly attached to:

My residential area

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

My working place/school

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

Organizations and/or community groups to which I belong (e.g. voluntary groups, church, union, clubs, etc.)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

My family (in a broad sense)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

Appendix 17: Qualitative Study Interview guide

Category	Questions	Prompts
General introduction, warm up	Tell me about yourself	How are you feeling today
Migration and Demographics	How long have you lived in the area? How many people live with you? Do you work locally? Where were you born? How long have you lived in the UK?	Intermediate or extended family? Out of the UK, native country?
Travel and Diabetes	How often do you visit – native country? What do you do when your there? How long do you tend to stay for? Who do you stay with? How do you manage your diabetes during your holiday?	Do people give you different advice to that you've been given in the UK? If so – what do you do, do you make any changes while you are with them? Medication, time zone, diet, exercise
Perceptions and myths of the causes of diabetes.	How did you find out you had diabetes? Where were you diagnosed? Can you tell me what diabetes means to you in your own words? What do you think was the cause? What were you told to do after diagnosis? How did you feel about it? How do these changes affect your life/your family?	Worried, upset, anxious, surprised? Out of the UK, native country? Any family members who have diabetes? Foods - sugar, genetics, family history, migration, work, fatalism? Eat healthy, exercise?
Use of alternative medication	Do you take any medication? How do you feel about taking medication? Are there occasions when you don't feel like taking your medication? What happens then? Do you use any medicines or treatments that are not prescribed by your GP?	Anxiety about taking drugs vs. herbal medications. Religious days / or festivals or on holiday? Do not understand why take medication?
Diet and Domestics	Thinking back to when you were diagnosed to NOW what type of changes have you had to make because of your diabetes? Who does the cooking and food shopping in your house and why? Thinking back to yesterday's meal, how did you decide what to eat?	Changes to meal times, diet, more or less use of certain foods, and day to day life? Who helps you plan your meals? How do you access information on the foods to eat?

Fasting	How do you decide whether or not to fast? Have you ever had any advice about fasting and diabetes? Does your GP know you fast? Has anyone ever told you not to fast? Do you know anyone that has been advised not to fast? How do you decide what to eat at the break of the fast? What changes do you have to make to your daily routine?	What do you think fasting does to your body? If not, why? Fear or concerns about refusal GP, PN, Dietician, other HCP, family, friends, religious leader. Adherence to medication, day off work, types of food, social visits, attend place of worship
Self-Management Resources	Have you used any information concerning your diabetes? How did/do you access these (if any)? What do you think about information that is translated? What do you use it for? What do other people you know that have diabetes do?	Leaflets, DVDs, Media, Magazines, Newspapers? GP, PN, via post, friends or family? How useful are translated resources? Able to read native language? Relevant? Preference? Do you think they manage their diabetes well or badly?
Information and Advice	Who in your family or circle of friends locally do you talk to about diabetes? What and when do you talk about? What do other people you know that have diabetes do for information? Do you prefer getting information from your GP or family and friends or other sources? How do you access new information on diabetes? What do you do with the advice you are given? What does your GP mean to you?	Partner, siblings, dependants, neighbours? Is this different from when you were first diagnosed? What's changed? House visits, place of worship, shopping centre, doctors surgery, social gatherings, community centre, via telephone? Powerful other, God, expert How does this compare to other health professionals?
Responsibility Attribution	Who do you think is responsible for the management of your diabetes? Who do you think should be responsible?	
Stigma & Beliefs of illness	How do you feel about telling people you have diabetes? How do you feel about people finding out if you have diabetes? Are there occasions when you don't want to say you have diabetes? When and why do you feel like this?	Friends, family, work, insurance companies, job applications? Weddings, place of worship, social gatherings, eating out?

Normalising and Seriousness of Diabetes	How many people do you know have diabetes? Why do you think a lot of Asians have diabetes? How do you feel about having diabetes?	Diet, migration, lifestyle, type of work. Normal? Serious? Concerned?
Lay beliefs and attitudes	Have you had any health problems or concerns related to diabetes? How do you feel about the future of your health? Do you have any other health concerns? Are you concerned about the changes in your health?	Foot, eyes, kidney, heart? When did you start to notice these? Who have you talked to about your concerns? Uncertain? Worries about life? What are your main concerns in life?

Appendix 18: BIPQ Causal Dimension Ranks

Rank 1 - Cause

No	No of ranks	Types of cause
1	15	Genetics
2	12	Stress
3	15	Diet
4	6	Lifestyle
5	5	Lack of exercise
6	4	Personal issues
7	5	Other inc weight, other conditions
8	9	Missing

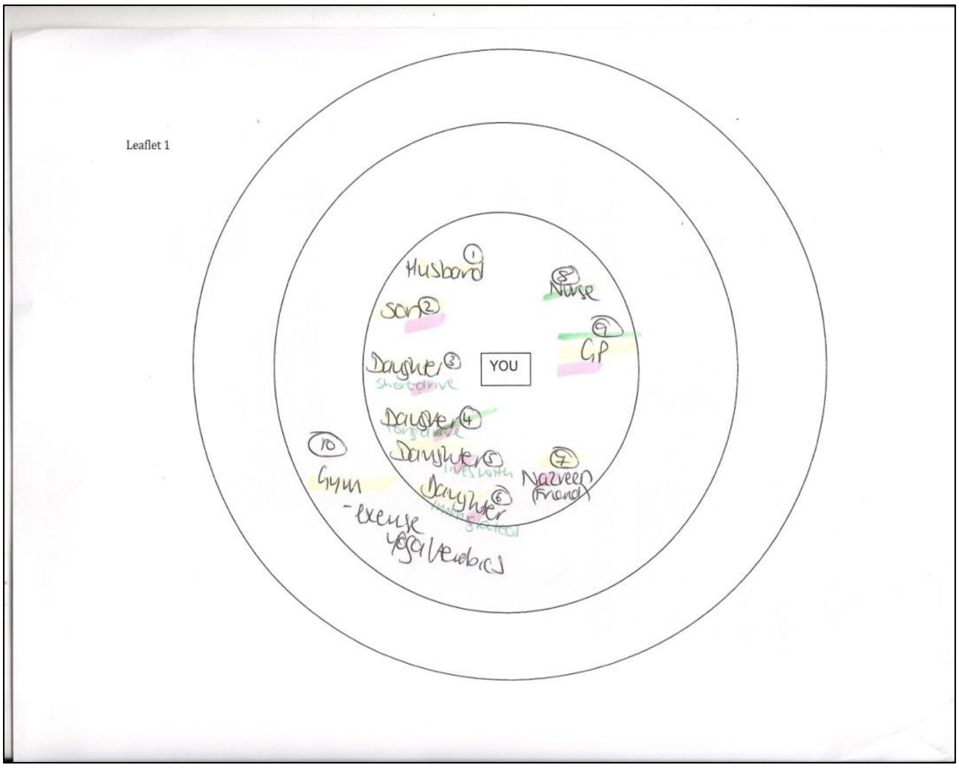
Rank 2 - Cause

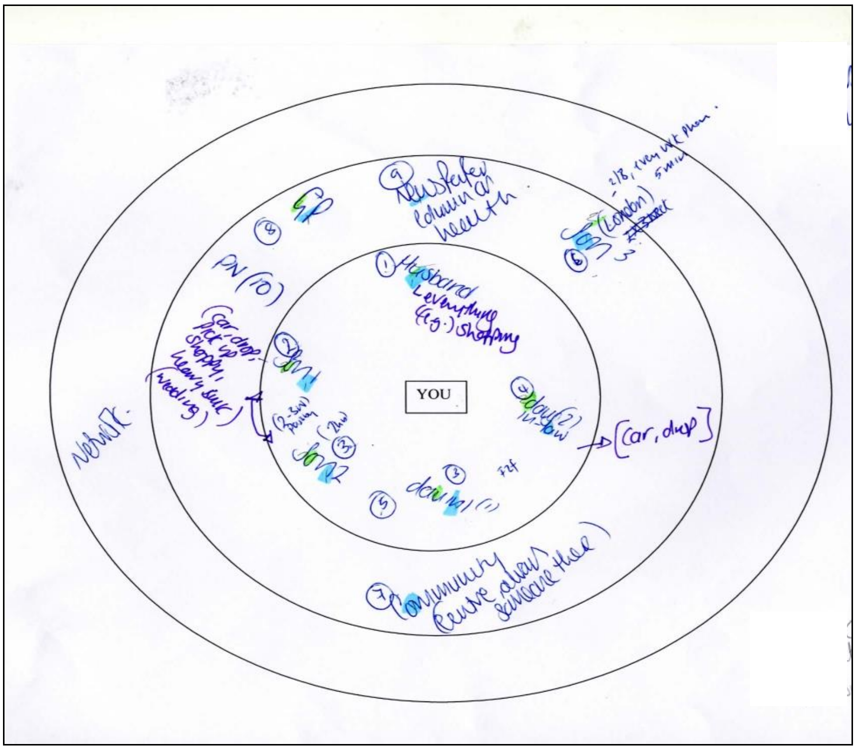
No	No of ranks	Types of cause
1	6	Genetics
2	3	Stress
3	13	Diet
4	4	Lifestyle
5	6	Lack of exercise
6	5	Personal issues
7	7	Other inc weight, other conditions
8	24	Missing

Rank 3 - Cause

No	No of ranks	Types of cause
1	3	Genetics
2	2	Stress
3	10	Diet
4	2	Lifestyle
5	7	Lack of exercise
6	0	Personal issues
7	7	Other inc weight, other conditions
8	37	Missing

Appendix 19: Example of a completed social network diagram





Appendix 20: Demographics for the random and community South Asian sub-groups

	Random sample	Community sample
Total N	**30**	**37**
Gender	**N (%)**	
Male	17 (57)	19 (51)
Female	13 (43)	18 (49)
Employment		
In paid work	9 (30)	9 (24)
Retired	12 (40)	16 (43)
Other	9 (30)	12 (32)
Marital status		
Married or in civil partnership	26 (87)	28 (76)
Other	4 (13)	9 (24)
Accommodation		
Own	26 (87)	35 (95)
Rent	4 (13)	2 (5)
Number of cohabitants*		
No cohabitants	2 (7)	0 (0)
One of more cohabitants	28 (93)	7 (100)
Duration of diabetes		
0 to 5 years	7 (23.3)	7 (19)
5 to 10 years	9 (30.0)	10 (27)
10 years or more	14 (46.7)	20 (54)
	Mean, (SD)	
Total number of conditions	2.70 (1.37)	2.80 (1.06)
Age	57 (15)	64 (9.6)
Education (highest)	4.10 (3.02)	4.62 (2.90)
Income	3.10 (1.65)	4.16 (1.56)
Index of Multiple Deprivation	40.0 (13.4)	30.3 (18.4)

Appendix 21: Outlier detection

Table 8.8 Spearman's correlation for demographic characteristics (continuous variables), BIPQ and fatalism items

VARIABLE PAIR		Max Mahalanobis distance observed[1]	N of Mahalanobis distance > critical value[1]	Results with outlier	Results without outlier
Consequences (n=36)	Total number of conditions	5.45	0		
Personal control (n=37)	Age	6.46	0		
	Income	6.05	0		
Understanding Income		**9.26**	**1, GP400**	**-.210** **p=.087**	**-.271** **p=.110**
Fate 2 Index of Multiple deprivation		8.40	0		

[1] Chi-square with 2 df and alpha0.01 = 9.21

Table 8.9 Kruskal Wallis test for BIPQ, Fatalism and demographics (categorical variables)

VARIABLE PAIR		MAX Mahalanobis distance Observed[1]	N OF Mahalanobis distance > critical value	PATIENT ID	Results with outlier	Results without outlier
Fate 2	Accommodation (rent, own)	8.11	0	n/a		
Identity	Employment (paid work, retired, other)	7.85	0	n/a		
Concern	Employment (paid work, retired, other)	6.58	0	n/a		
Treatment beliefs	**No of cohabitants**	**10.7**	**1**	**GP400**	**P=.059** **3.56**	**P=.061** **3.51**

[1] Chi-square with 2 df and alpha0.01 = 9.21

Table 8.10a: Spearman’s Correlation for Social Network Variables BIPQ and Fatalism

VARIABLE PAIR		MAX Mahalanobis distance Observed	N of Mahalanobis distance > critical value[1]	PATIENT ID	Results with outlier	Results without outlier
Concern Beliefs	No of supportive females	4.79	0	n/a	n/a	n/a
	Frequency of contact	8.11	0	n/a	n/a	n/a
	Emotional work	**9.34**	**0**	**GP131**	**-.599 p=.000**	**-.461 P=.005**
	Practical work	8.08	0	n/a	n/a	n/a
	Size of support network	8.76	0	n/a	n/a	n/a
Consequences	Size of support network	4.90	0	n/a	n/a	n/a
	Proximate number of children	6.19	0	n/a	n/a	n/a
Understanding	**Emotional work**	**9.96**	**1**	**GP387**	**-.306 p=.065**	**-.368 P=.027**
Emotional Representations	**Frequency of contact**	**9.36**	**1**	**GP079**	**-.352 p=.004**	**-.352 P=.032**
	Emotional work	8.04	0	n/a	n/a	n/a
	Size of support network	**9.70**	**1**	**GP079**	**-.373 p=.023**	**-.373 P=.023**
Fate 2	Frequency of contact	6.23	0	n/a	n/a	n/a
	Size of support network	7.70	0	n/a	n/a	n/a
	Practical work	7.95	0	n/a	n/a	n/a
	Mix of agents	**11.19**	**1**	**GP296**	**-.294 p=.082**	**-.358 P=.035**

[1] **Chi-square with 2 df and alpha 0.01 = 9.21**

Table 8.11 Multiple regressions

VARIABLES IN REGRESSION MODEL PAIR	MAX of Mahalanobis distance observed	N of Mahalanobis distance > critical value[1]
Stepwise 1* **CONCERN** Number of supportive females Frequency of contact Practical work Emotional work Size of support network	15.62	0
[1]**Chi-square with 6 df and alpha 0.01 = 16.81**		
VARIABLES IN REGRESSION MODEL PAIR	**MAX of Mahalanobis distance observed**	**N of Mahalanobis distance > critical value[2]**
Stepwise 2** **EMOTIONAL REPRESENTATION** Frequency of contact Size of the support network Emotional work	12.22	0
[2]**Chi-square with 4 df and alpha 0.01 = 13.28**		

Table 8.11 Spearman correlations between illness and fatalistic beliefs and other health outcomes in South Asians

VARIABLE PAIR		MAX Mahalanobis distance Observed[1]	N of Mahalanobis distance > critical value[1]	PATIENT ID	Results with outlier	Results without outlier
CONCEQUENCES	SF-12	5.97	0	n/a		**-.568** **p=.000**
	HEIQ	8.62	0	n/a		
	SDSCA	5.70	0	n/a		
CONTROL	SF-12	5.73	0	n/a		
	NORMALISATION	6.42	0	n/a		
TREATMENT CONTROL	**SF-12**	**9.33**	**1**	**GP400**	**-.378** **p=.002**	
	SDSCA	7.29	0	n/a		
IDENTITY	SF-12	5.19	0			
	HEIQ	**10.12**	**1**	**GP387**	**-.249** **p=.044**	**-.353** **p=.038**
CONCERN	**SF-12**	**10.83**	**1**	**GP339**	**-.278** **p=.024**	**-.508** **p=.002**
UNDERSTANDING	SDSCA	7.90	0	N/A		
EMOTIONAL RESPONSE	SF-12	5.66	0	N/A		
	HEIQ	**10.84**	**1**	**GP387**	**-209** **(*p*=.089)**	**-.352** **p=.036**

[1] **Chi-square with 2df and alpha0.01 = 9.21**

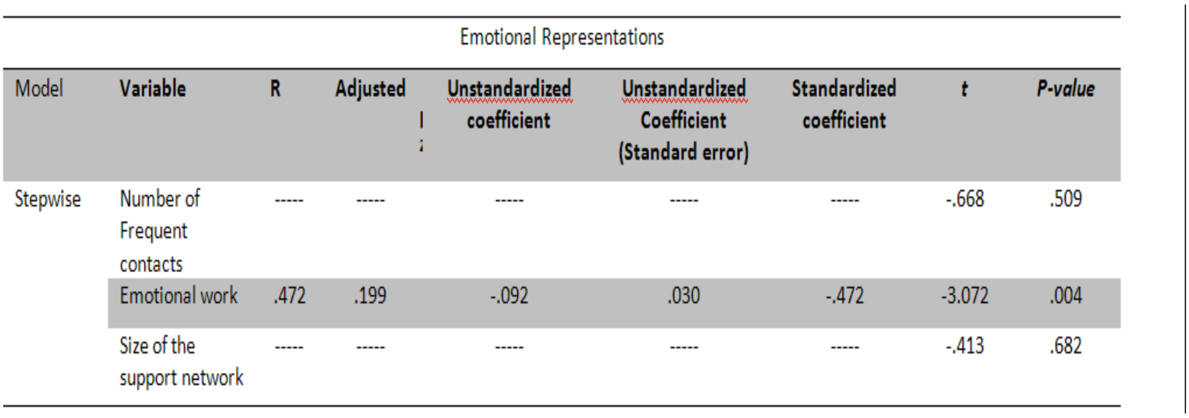
Appendix 22: Comparison of BIPQ and Fatalism items between the random and community samples

BIPQ ITEM TOTAL N	Random n, Mean (SD) n=30	Community n, Mean (SD) n=37	NON-PARAMETRIC (Mann-Whitney U
Consequences	n=29 4.79 (2.84)	n=37 4.68 (.327)	.938
Timeline	n=28 8.50 (2.74)	n= 37 9.22 (1.63)	.269
Personal control	n=30 4.96 (2.96)	n=37 3.62 (2.44)	.051*
Treatment control	n=29 2.96 (2.58)	n=37 2.83 (2.33)	.875
Identity	n=29 5.34 (2.84)	n=37 5.35 (3.02)	.969
Concern	n=29 6.48 (3.48)	n=37 7.00 (2.84)	.759
Understanding	n=30 2.60 (2.63)	n=37 1.72 (1.75)	.231
Emotional response	n=30 5.17 (3.05)	n=37 6.19 (3.09)	.139
FATALISM			
Chance or fate	N=28 3.29 (1.41)	N=36 3.42 (1.55)	.636
Little personally do to improve health status	N=30 3.10 (1.29)	N=36 2.89 (1.58)	.617

Appendix 23: Multiple regressions

Variables identified by stepwise regression analysis as predicting concern beliefs

				Concern beliefs				
Model	**Variable**	**R**	**Adjusted**	**Unstandardized coefficient**	**Unstandardized Coefficient (Standard error)**	**Standardized coefficient**	***t***	***P-value***
Stepwise	Number of Frequent contacts	-----	-----	-----	-----	-----	-1.417	.167
	Total number of Supportive females	-----	-----	-----	-----	-----	-1.149	.259
	Emotional work	.558	.290	-.128	.034	-.558	-3.807	.001
	Size of the support network	-----	-----	-----	-----	-----	-1.149	.259



				Emotional Representations				
Model	**Variable**	**R**	**Adjusted**	**Unstandardized coefficient**	**Unstandardized Coefficient (Standard error)**	**Standardized coefficient**	***t***	***P-value***
Stepwise	Number of Frequent contacts	-----	-----	-----	-----	-----	-.668	.509
	Emotional work	.472	.199	-.092	.030	-.472	-3.072	.004
	Size of the support network	-----	-----	-----	-----	-----	-.413	.682

***Significant at the 0.05 level (two tailed)**
**** Significant at the level (two tailed)**

Appendix 24: Reflexive notes - examples

Interviewer notes
Date: 15.06.11
Participant CM19, Female (Pakistani), Location: Eccles
Very friendly; gave me a glass of mango juice and biscuits on a plate. I felt obliged to accept. Her house was situated at the back of Trafford Park, industrial estate in a rundown cul-de-sac. She was very welcoming but seemed to be cautious of time which was understandable as she is currently revising for her Islamic studies exams next week. The SN interview tricky even though she was very fluent in English – some of the questions are worded very badly and do not make sense and make me look silly! She has had diabetes for the past 4-5 years and admits that she has a very bad sweet tooth and before her diagnosis she ate a lot of sweets. I forgot to ask to give me an example of how many but by the sounds of it, it was a lot. However, she has now turned to dates as a substitute for sweets and tells people not to eat sweets and really look after their health to prevent diabetes because it's something she didn't do. Her mum who lives in Tunisia has diabetes and is suffering a lot and the GP there has told her not to fast anymore. She explained how she fasts and will continue to fast and enjoys the social aspects of fasting. Her husband and daughter seem to be very supportive of her condition and her children continuously remind her to take her medication and are central to her network. Overall this was my first interview with young Pakistani women with diabetes and it wasn't as different as the others.

Date: 20.12.10
Participant GP329, Female (Pakistani), Location: Rusholme
The patient does not seem to have had much education into diabetes management. She believes that whatever happens to her is in the hands of Allah. The patient was much more pleasant during the follow but seemed more interested in receiving the vouchers and asked the interpreter several times if she will be getting the vouchers for her time. Of course she was paid for her time. The patient just seems really fed but is comfortable sitting at home and it seems that she spends a lot of time minding her grandson. She admits that when she was diagnosed she changed her diet as advised by her GP but once she was told her sugar levels were good she went back to her normal diet/routine mainly because she had to look after 6 children, go to work and says that her life was too hectic for her to be then looking after herself and her diet. She wishes somebody had told her the consequences of what would happen if she did not look after herself at a young age.
I felt frustrated because she was not co-operating properly. Made me feel like I was a nuisance and kept asking how long it will take. The interpreter was also annoying me because she was not translating the questions properly. I could see that was answering for the patient and at times I had to ask her to ask the patient. I understand why she was doing that because the questions are repetitive and sound the same when they are being interpreted. I don't think the patient would have co-operated as much if the interpreter was not there.

Date: 09.03.11
Participant GP393, Male (Bangiadeshi), Location: Longsight
Patient was very nervous and sat at the edge of the sofa. He must have asked his friend nearby to come round and sit with him during the interview but I had to kindly explain to his friends that only the patient could answer the questions. So the friend moved away and sat on the table nearby. After a few minutes his wife came in and just stood there before she went to college. It seemed like the patient hadn't received much information about diabetes. He had a small network; wife the main person who helps manages his diabetes e.g. cooking. He is currently unemployed and is seeking employment. Said he goes to job centre every 15 days and is undertaking English classes. They seemed quite suspicious of us and think they felt that we were from social security or something.