

**Evaluating Type 2 Diabetes Risk Perception in the British South Asian
General Population: A mixed methodology approach for intervention development**

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Abstract

Type 2 Diabetes (T2D) is a significant public health concern with a high prevalence within the UK South Asian (SA) population. The prevalence of T2D is predicted to increase if the current trend continues. Previous research has highlighted that SA people 's behaviour might be influenced by culture and genetic factors. However, studies are still on-going to find out why the SA ethnic group has a higher prevalence compared to other ethnic groups. There is minimal research exploring Risk Perception (RP) of T2D in the SA community. Previous research and interventions have predominately focussed on encouraging individuals to change health-related behaviours. However, there is a lack of research understanding cognition and RP; before behaviour change, there is a need to focus on how people's RP and cognitions affect their behaviour. The overall PhD aim was to understand the complexities of RP in the SA community and to develop and test an intervention to change RP and hence improve T2D prevention behaviours for the SA general population.

This PhD thesis presents a number of studies which each explored specific aspects of the influences of RP and preventative behaviours in the SA population. New understanding has been created through the completion of a literature review evaluating the previous literature on T2D RP and prevention. In addition to this, a combination of quantitative and qualitative studies (mixed methods) explored multiple perspectives of RP and prevention behaviours in the SA population. Each study offered a unique contribution to the evidence-base and presented new knowledge, to develop a thorough and comprehensive understanding of the overall PhD aim.

The studies within this PhD explored a range of psychological and behavioural variables, and these were subsequently used in the development of a RP intervention for the SA population.

Overall, preventative behaviours are influenced by various dimensions of RP, predominantly Locus of Control (LoC). In the SA community, there is a tendency of external LoC whereby, each behaviour is influenced by external factors. The findings are discussed with reference to psychological theories. Based on these findings, and in collaboration with a range of stakeholders, an intervention was developed using the Medical Research Council (MRC) framework and the ‘person-based’ approach. Subsequently, this intervention was evaluated through a proof-of-concept study, which demonstrated preliminary effectiveness of the intervention, and also an acceptability and feasibility study, which suggested the intervention was appropriate and relevant to the SA population and could be implemented within the real-world as a T2D prevention intervention.

Strengths and weaknesses of the PhD are acknowledged, and the relevance of this research to the real world applied to T2D prevention settings is highlighted, alongside a call for further research to roll-out the intervention within a real-world context.

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Vaja, I. & Newson, L. M. Reducing T2D RP in SA community: Working together for better practice. INVITED SPEAKER. Diabetes UK, Glasgow, UK 18 – 20 March 2020.

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Oral Presentation

List of Abbreviations

ADA – American Diabetes Association

AR – Actual Risk

BAME – Black and Minority Ethnic

BCOM – Bolton Council Of Mosque

BCT – Behaviour Change Taxonomy

BCW – Behaviour Change Wheel

BMI – Body Mass Index

C-HLoC – Chance Health Locus of Control

CMO – Chief Minister Officer

CVD – Cardiovascular Disease

D-HLoC – Doctor Health Locus of Control

DIAB-Q – Diabetes, Intention, Attitude and Behaviour Questionnaire

DoH – Department of Health

DPP – Diabetes Prevention Programme

DPS – Diabetes Prevention Study

DUK – Diabetes UK

DV – Dependent Variable

GT – Grounded Theory

HbA1c – Haemoglobin A1c

HBM – Health Belief Model

HLoC – Health Locus of Control

IDF – International Diabetes Federation

IGT – Impaired Glucose Tolerance

I-HLoC – Internal Health Locus of Control

IV – Independent Variable

LH – Learned Helplessness

LoC – Locus of Control

M- Mean

MANOVA – Multivariate Analysis of Variance

MHLC – Multidimensional Health Locus of Control

MPA – Moderate Physical Activity

MRC – Medical Research Council

NDH – Non-Diabetic Hyperglycaemia

NDPP – National Diabetes Prevention Programme

NHS – National Health Service

NICE – National Institute Centre of Excellence

ONS – Office of National Statistics

OP-HLoC – Other People Health Locus of Control

PA – Physical Activity

PBC – Perceived Behavioural Control

PHE – Public Health England

P-HLoC – Powerful Health Locus of Control

PIS – Participant Information Sheet

PPI – Patient and Public Involvement

PR – Perceived Risk

RCT – Randomised Control Trial

RP – Risk Perception

RPS-DD – Risk Perception for Developing Diabetes

SA – South Asian

SCT – Social Comparison Theory

SD – Standard Deviation

SLT – Social Learning Theory

SRR – Standard Risk Ratio

T1D – Type 1 Diabetes

T2D – Type 2 Diabetes

TPB – Theory of Planned Behaviour

TRP – Total Risk Perception

UK – United Kingdom

UKPDS – The UK Prospective Diabetes Study

US – United States

VIF – Variance Inflation Factor

VPA – Vigorous Physical Activity

WHO – World Health Organisation

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Research Team

Throughout this thesis, the term ‘research team’ refers to:

Ishfaq Vaja (PhD Researcher)

A postgraduate researcher with research interests in long-term conditions and Black and Minority Ethnic Groups.

Dr Lisa Newson (Director of Studies (DoS))

A HCPC Registered and Chartered Health Psychologist with applied diabetes research experience and a portfolio of healthcare research expertise.

Dr Kanayo Umeh (Supervisor)

A Chartered Psychologist with interest in bio-psych-social interactions of diabetes research.

Dr Julie Abayomi (Supervisor)

A Reader in Dietetics with an interest long term conditions and diabetes research.

PhD Overview

This PhD reviews and explores preventative behaviours in lay individuals, who live in the UK and are from a South Asian (SA) descent, with a view to developing a comprehensive theoretical understanding of the topic of Risk Perception (RP) and using this new evidence to develop and test a new intervention to improve preventative behaviours in the SA community.

Aims and objectives of this thesis

The primary aims of this thesis were: (1) to understand the complexities of RP in the SA community and reasons for low uptake of prevention interventions in the UK and (2) to develop an intervention for SA general population to increase RP, based on identified needs and preferences

There were five objectives of this PhD:

- (1) Explore SA peoples understanding and assessment of T2D risk. (Chapter 1).
- (2) Identify potentially relevant theory and evidence based related to the role of Risk Perception on T2D preventative behaviour (Chapters 1, 4, 5, 6,).
- (3) Explore SA people's needs and preferences regarding an intervention to help them to meet their information needs and the reasons for these perceptions (Chapters 4, 5, 6, 8).
- (4) Design an intervention based on the identified needs and preferences of SAs (Chapter 9).
- (5) Conduct a Proof-of-Concept to test the intervention with SA people in the community to assess its acceptability and feasibility in practice (Chapter 10).

Thesis structure

Each phase of work presented in this thesis was guided by the Medical Research Council (MRC) framework (Craig et al., 2008). MRC guidance for developing and evaluating complex interventions advises that interventions should include three stages: 1) identify an existing evidence base; 2) identify or develop appropriate theory, and 3) model processes and outcomes (Craig et al., 2008). Moreover, the MRC outlines specific phases in the development and evaluation of interventions. During the first phase, 'Development', researchers are encouraged to identify the evidence base, relevant theories, model processes and outcomes of the intervention. In this PhD, Phase one included a review of the T2D, RP and SA health literature and current public health and prevention interventions in the UK and worldwide.

Subsequently, four empirical research studies, utilising mixed methods explored RP and health behaviours in the SA community. Specifically, the following studies are presented:

Chapter 4 - Study 1, Qualitative; Prevention of T2D in South Asians: A Qualitative Study Exploring Risk Perceptions, Health Beliefs, Values and Community Perspectives.

Chapter 5 - Study 2 Quantitative; Measuring Comparative Risk Perception of Developing T2D Amongst South Asian and White British Populations.

Chapter 6 - Study 3 - A Mixed-Method Study: Investigating the Dimensions of Locus of Control and Current Psychological State in SA Populations.

Chapter 10 – Study 4a – Proof-of-Concept Study

Chapter 10 – Study 4b - Exploring the Acceptability and Feasibility of the Intervention Utilising the new knowledge developed in Chapters (1,4,5,6), along with further discussions with stakeholders, an intervention was designed (Chapter 9)

The second phase of the MRC framework, ‘feasibility and piloting’, encourages initial testing of the acceptability and feasibility of the intervention, prior to a full-scale evaluation. For this PhD, the intervention was tested via a quantitative feasibility study (Chapter 10) and an acceptability PPI (qualitative) study (Chapter 10).

Thoroughly assessing the effectiveness and cost-effectiveness of the intervention via an RCT evaluation (MRC- third phase) were considered beyond the scope of this PhD. However, recommendations for refinement and future research to implement this new intervention at scale are discussed in detail (Chapter 10 & 11).

PhD Flow Chart

Phase 1	<p>Literature Review: Reviewed the previous evidence base on SA culture, RP and health behaviours in the SA population. The literature review highlighted the gaps in the current research literature around SA and T2D prevention behaviours.</p> <p>Methodology: Overviews the different qualitative and quantitative methodologies, followed by an explanation towards the orientation of a mixed-methods approach. A detailed account of mixed-methodology and analysis applied throughout this thesis is presented.</p>
Phase 2	<p>Study 1: Unique contribution to knowledge: Concepts such as destiny (believing life is written for you), lack of education and understanding, and lack of engagement in healthy lifestyle behaviours all significant impacted on participants RP.</p> <p>Study 2: Unique contribution to knowledge: This was the first study to investigate Risk Perception (RP) and Actual Risk (AR) of T2D in SA and White population in the UK. Individuals who were categorised as moderate to high AR of T2D, scored greater on their RP scores. However, SA participants RP scores were lower than the White participants. This was due to specific constructs of RP such as Personal Control.</p> <p>Study 3: Unique contribution to knowledge: This study was the first to adopt a mixed-methods approach to investigate psychological concepts such as Locus of Control and Depression, Anxiety and Stress as associated with T2D RP, in the UK lay SA population. SAs expressed a higher external Locus of Control which impacted their RP, and this was resembled in the qualitative findings.</p> <p>Intervention Design: An intervention was designed based on the Medical Research Council framework (MRC) and ‘Person-Based’ Approach, with key stakeholders’ part of the design of the intervention. The stakeholders were part of the whole intervention design and this was a unique contribution, as previous interventions have not taken a stakeholder involvement in the design.</p> <p>Study 4 (a&b): Unique contribution to knowledge: Proof-of-Concept 4a: This intervention was deemed successful in the SA community, there was higher scores on RP and increase in internal Locus of Control (See video message) Study 4b: The acceptability and feasibility study showed that the intervention was deemed suitable for the SA population and could be implemented in the real-world.</p>
	<p>This thesis interconnects new empirical findings; previous research and topics (prevention, behaviour change, T2D risk perception, interventions); and indeed, considered of a range of theoretical approaches towards the intervention content and delivery. A comprehensive approach has been applied for intervention development, which has included stakeholders throughout, and has the initial evaluation of this intervention suggests it has potential for effectiveness and acceptability within the real world.</p>

PhD Phase 1

Chapter 1: Introduction & Literature Review

Chapter 2: PhD Aims & Objectives

Chapter 3: Methodology

Chapter 4: Study 1

Chapter 5: Study 2

Chapter 6: Study 3

1 Chapter 1: Introduction

1.1 Introduction – Chapter Overview

This chapter introduces the concepts of ethnicity, culture and religion specific to the South Asian (SA) population. A brief overview of Type 2 Diabetes (T2D) is provided and considered in the context of the increasing occurrence within the United Kingdom (UK) SA population. Furthermore, Risk Perception is discussed and the importance of this relative to T2D prevention in the UK SA population. Finally, this chapter provides an overview of the current T2D prevention initiatives in the UK.

1.2 History of Diabetes

The earliest recorded description of ‘Diabetes’ as a metabolic disorder date back to 1550 BC (Lakhtakia, 2015). Sushruta and Charaka (400-500 A.D.) described two main types of diabetes – one that was prevalent in obese people and the other, a more serious condition that was difficult to treat and needed a nourishing diet (Frank, 1957; Lakhtakia, 2015). Over the last 50 years, there has been a better understanding of the epidemiology of diabetes, its classification and the causations of micro- and macrovascular complications (Beckman & Creager, 2016).

Simultaneously, there has been significant advances in the development of new drug delivery techniques, diabetes prevention initiatives and insulin analogues (Cefalu et al., 2015). Despite these developments, diabetes prevention remains a formidable challenge.

1.3 Diabetes Classification

In 1980, the World Health Organisation (WHO) published the first classification of diabetes mellitus, which was subsequently modified in 1985 (Alberti & Zimmet, 1998). In the 1980 classification, two primary classes of diabetes were named ‘Type 1 Diabetes Mellitus’ (T1D) and ‘Type 2 Diabetes Mellitus’ (T2D). The new classification of diabetes was proposed in 1998 following a collaboration between WHO and the American Diabetes Association (ADA) expert groups (Care, 2000). Diabetes currently is classified into four major groups – Type 1 Diabetes (T1D), Type 2 Diabetes (T2D), Other Specific Types and Gestational Diabetes (ADA, 2018). Of these T1D accounts for nearly 5-10% of cases, while a more significant proportion of the remainder (90-95%) is T2D (Wu, Ding, Tanaka & Zhang, 2014). The scope of this PhD focuses on T2D only.

T2D is characterised by beta-cell dysfunction and insulin resistance (Cerf, 2013). This is the most common form of diabetes mellitus and is highly associated with a family

history of diabetes, older age, obesity and lack of exercise (Joseph et al., 2016). The aetiology of T2D is complex and involves both genetic and environmental factors.

1.4 Global Prevalence of Diabetes

Diabetes is one of the global public health emergencies of the twenty-first century (Zimmet, 2017). About 12% of global expenditure is spent on diabetes and related issues (Arugu & Maduka, 2017). In 2015, 415 million people were estimated to be living with diabetes globally, and this is expected to increase to about 642 million in 2040 (Ogurtsova et al., 2017). According to the WHO, diabetes was the seventh leading cause of global death in 2016 (WHO, 2018).

1.5 Complications of Type 2 Diabetes

Those diagnosed with T2D have a high risk of developing microvascular and macrovascular complications as a result of chronic hyperglycaemia. Microvascular complications affect the blood vessels in the eyes, kidneys and nerves leading to retinopathy, macular degeneration, blindness, nephropathy, end-stage renal disease and neuropathy. Macrovascular complications take the shape of cardiovascular and cerebrovascular diseases such as coronary artery disease, myocardial infarction and stroke (Einarson, Acs, Ludwig & Panton, 2018). Hospitalisations due to cardiovascular disease are two to four times more likely in people with diabetes (Hippisley-Cox & Coupland, 2016). Likewise, admissions for the end-stage renal disease are 12 times more likely for non-traumatic lower-limb amputations are over 20 times more likely in those with diabetes compared to the general population (Franz et al., 2018).

One well known, high-quality Randomised Controlled Trial (RCT) has highlighted essential findings regarding the relationship between the level of diabetes control and the development of diabetes-related complications. The United Kingdom Prospective Diabetes Study (UKPDS) (Klonoff, 2008) focused on participants with newly

diagnosed T2D and aimed to ascertain the effects of intensive therapy on the development of microvascular and macrovascular complications of diabetes. Intensive treatment was referred to as achieving and maintaining fasting plasma glucose less than 6 mmol/L, with the addition of insulin-treated participants to achieve pre-meal glucose concentrations between 4 to 7 mmol/L. This group was followed every three to four months in clinic, with additional follow-ups in between as necessary to maintain the specified blood glucose targets. The study population in the UKPDS consisted of participants with T2D, with the mean age of participants being 53 years in both intensive and conventional therapy groups. The majority of participants were of White ethnicity. The results of the UKPDS revealed a statistically significant reduction in median A1C in the intensive therapy groups at 7.0%. Furthermore, there was a 25% reduction in microvascular endpoints in participants in the intensive therapy compared to standard treatment. The results of the UKPDS demonstrate the importance of maintaining blood glucose concentrations as close to a normal range to prevent the development and progression of microvascular complications of diabetes.

1.6 Type 2 Diabetes

In the UK, the overall prevalence of diabetes increased from 2.8% to 4.3% between 1996 to 2005 (Gonzalez, Johansson, Wallander & Rodriquez, 2009). The estimated number of people with diabetes in the UK has risen from 1.4 to 2.9 million between 1996 and 2011, and an estimated 90% of these people have T2D (Piper, Marossy, Griffiths & Adegbeye, 2017). There are an estimated million people with diabetes who were unaware of their condition or undiagnosed (Diabetes UK, 2018). The prevalence of T2D is predicted to increase to 5 million by 2025 if the current trend continues (Diabetes UK, 2018). T2D is a major cause of premature mortality, with around 22,000 people with diabetes dying early each year in England (Diabetes, UK, 2018). It is often not T2D itself

that causes death, but complications of the disease, including Cardiovascular Disease (CVD) (Petrie, Guzik & Touyz, 2018). Worldwide, it was estimated that 500 million people had T2D in (Kaiser, Zhang & Pluijm, 2018). T2D is the most common non-communicable disease globally with low and middle-income countries now dealing with the greatest burden (Islam et al., 2014). Due to changes in life expectancy, diet and lifestyle, around 80% of people with diabetes live in low to middle-income countries. T2D traditionally affected older people and used to be known as adult-onset diabetes (Hu, 2011). However, the prevalence of T2D in children and young adults has increased due to higher levels of obesity and sedentary lifestyles (Sahoo et al., 2015).

Assigning a type of diabetes to an individual often depends on the circumstances present at the time of diagnosis. The risk of being diagnosed with diabetes, among other factors increase with age, Body Mass Index (BMI), obesity and family history. Studies have shown that first degree relatives have three times greater risk of developing T2D, than unrelated individuals of a population (Ali, 2013; Unnikrishnan, Pradeepa, Joshi & Mohan, 2017). Furthermore, some racial and ethnic groups are likely to have higher risk and prevalence due to genetic or environmental predispositions associated mainly to them such as access to healthy food sources and places to exercise (Spanakis & Golden, 2013). From a public health perspective, the impact of diabetes and its complications is likely to place a huge demand on health care resources, and a greater emphasis on preventive measures is required to tackle this problem (Bergman et al., 2012).

Research has shown that T2D and obesity are significantly associated (Van Gaal & Scheen, 2015; Wilding, 2014). Both conditions are increasing at a concerning rate, with T2D being one of the primary consequences of obesity in the world today. Most of the T2D cases are hard to detect because symptoms develop slowly, and many cases develop

undiagnosed until complications start (Wu et al., 2014). Therefore, screening for T2D is encouraged for persons who are at high risk; which include persons who are overweight or obese, persons who have first-generation relatives with diabetes and those who come from an ethnic background where diabetes risk is high (Savill, 2012).

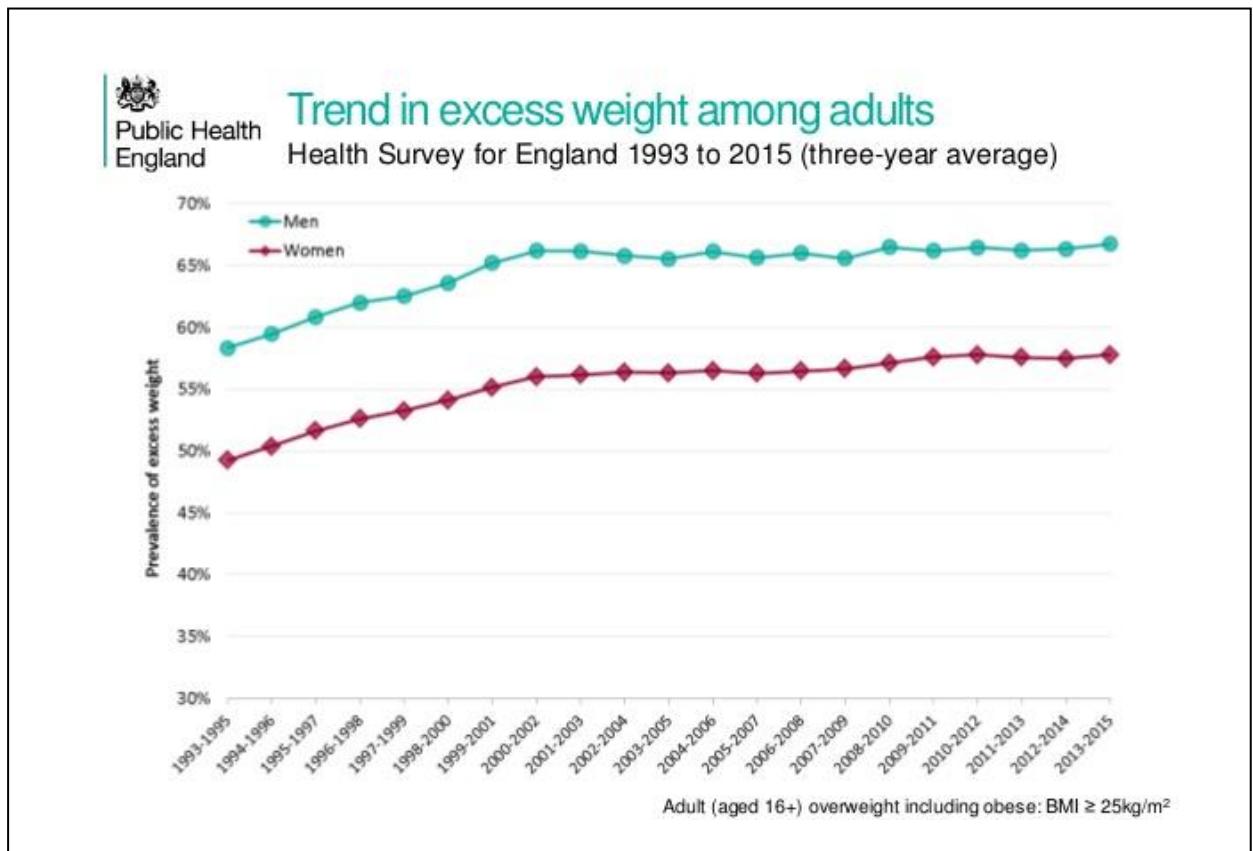


Figure 1.1: Trends of Excess Weight Among Adults in the UK

1.7 Ethnicity & Health

1.8 Section Overview

This section briefly discusses the current concepts of ethnicity and the critical mechanisms by which ethnicity can influence health outcomes. In addition to this, a description of the progress in ethnicity data collection in the UK is provided.

1.9 Definition and Concepts of Ethnicity

Ethnicity is a multi-dimensional concept that reflects an expression of belonging based on one or more shared characteristics (Ford & Harawa, 2010). The issue of what constitutes ethnicity is heavily debated, but the characteristics often associated with ethnic identification include common ancestry, country of birth, nationality, religion, culture, colour or language (Connelly, Gayle & Lambert, 2016). The importance of each of these characteristics is subjective and vary from individual to another (Evandrou, Falkingham, Feng & Vlachantoni, 2016).

Currently, the UK Department of Health (DoH) states that ethnicity is:

“Complex, multifaceted and subjective, and defined by [:] a shared history, a common cultural tradition; a common geographical origin; descent from common ancestors; a common language; a common religion; and a distinct group within a larger community.” (Department of Health, 2005) (P.18)

Ethnic identification is also constructed from externally imposed social identities. External factors such as stereotypes, social-economic inequality, discrimination enforce a sense of belonging to a particular group (Jetten et al., 2017). For example, experiencing racism can enforce the individual to belong to a particular ethnic group. Ethnicity is a fluid concept that changes over time and within different contexts, rather than something fixed in biological or genetic terms (Schwartz-Marin & Wade, 2015).

Modood & Khattab (2016) argue that ethnic group should be used as an explanatory factor for outcomes or behaviour because ethnic identification involves groups which bring with its community and cultural norms and structures. They argue that although ethnicity is partially shaped by external factors such as social and structural inequality, it is also shaped by culture in the form of past experiences, current motivations

and trajectories (Modood & Khattab, 2016). Using employment as an example, they argue that ethnic differences in employment are associated with social and structural inequality but also with ethnicity and culture. For example, members of an ethnic group form culturally informed strategic responses to prevailing circumstances such as high levels of unemployment. Therefore, they argue that ethnicity and culture should be used as additional explanatory factors for differences in outcomes alongside social and structural inequality (Modood & Khattab, 2016). This is an essential way of thinking about the different ways that underlie ethnic differences and emphasises the importance of the interplay between social and structural inequality and cultural factors.

1.10 The Measurement of Ethnicity

Due to its subjective and multidimensional nature, ethnicity is difficult to measure (Connelly et al., 2016). The concept of ethnicity is often reduced to a number of fixed categories in order to make data analysis feasible. Previous studies have used a range of different methods to measure and categorise ethnicity, including place of birth and surname analysis (Connelly et al., 2016; Smith et al., 2017). These markers are not synonymous with the concept of ethnicity in its entirety. Although many have acknowledged the benefits of including multiple measures to capture its multidimensional nature, self-definition (the evaluation by oneself of one's worth as an individual in distinction from one's interpersonal or social roles) has been referred to as the gold standard and is for many in health research, which is the currently preferred method of assessing ethnicity (Hull, Mathur, Badrick, Robson & Boomla, 2011).

Within the UK, the population Census has been instrumental in standardising the measurement of ethnicity via the use of fixed categories (Office of National Statistics (ONS), 2012). The Census ethnic group categories are used as the official measure of ethnicity and are used in many government surveys and research (Thompson, 2015).

Within the last three Censuses (1991, 2011 and 2011), each respondent was asked to self-identify their ethnicity from a number of main categories and 2001, and 2011 Census then asked the respondent to choose from a number of sub-categories. The categories reflect a number of dimensions of ethnicity – country of birth, nationality and skin colour (Thompson, 2015). Figure 1.2 shows the 2011 Census categories used in England and Wales.

White

- *White English/Welsh/Scottish/Northern Irish/British; White Irish; White Gypsy or Irish Traveller; Any other White Background*

Mixed/multiple ethnic groups

- *Mixed White and Black Caribbean; Mixed White and Black African; Mixed White and Asian; Any other Mixed background*

Asian/Asian British

- *Indian; Pakistani; Bangladeshi; Chinese; Any other Asian background*

Black African/Caribbean/Black British

- *Black African; Black Caribbean; Any other Black/African/Caribbean background*

Other ethnic group

- *Arab; Any other ethnic group*

Figure 1.2: Ethnic group categories from the 2011 Census of England and Wales (ONS, 2011):

1.11 History of Ethnicity Data Collection in the UK

The UK is one of the few countries in Europe that highlights the need for decisive action to encourage ethnic equality via the collection of official ethnic group statistics (Wrench & Modood, 2001). In a recent review of practices of data collection in censuses across Europe, only 5 out of 35 countries surveyed collected ethnicity data, of which the UK is one. Since the Race Relations Act of 1968 (Thompson, 2015), the official collection of ethnic groups has been mandated as an essential step towards actively reducing ethnic inequalities. One of the conceptual challenges of disaggregating populations by ethnicity is the way in which ethnic groups are defined and understood (Ford & Harawa, 2010).

Senior & Bhopal (1994) suggested that, when utilising ethnicity as an epidemiological variable, it should be defined so as to allow the differentiation of populations in a way that is relevant to health and facilitates the generation of hypotheses about the aetiology of disease or explains observed differences in healthcare. However, there is no way to create a classification scheme that is valid and meaningful across all settings, as the relevance and validity of ethnic categories depend upon the context in which they are used (Mathur et al., 2013).

In both the US and the UK, it has been acknowledged that the ethnic categories used in official statistics are, to some extent, arbitrary and have been selected for pragmatic reasons (Mathur et al., 2013). Just as individuals can change their ethnic identity over time, so too does the classification of ethnicity evolve. This is of particular importance in countries such as the UK, where historical changes in migration patterns have increased the ethnic diversity of the country as well as creating new ethnic categories (Kirk, Stein & Fisher, 2018). Provided that researchers recognise the limitations of

categories and approach them critically, the study of ethnic differences can nonetheless offer vital information about patterns of health and social indicators.

1.12 Migration

Economic changes, political turmoil and demand for skilled labour have caused in-migration of people from more impoverished and developing countries (Czaika & Haas, 2014). Over the last 60 years, the English population has become more ethnically diverse; the population of non-White people in England and Wales grew from approximately 100,000 in 1951, to 7.8 million in 2011 (ONS, 2011). The majority of non-White migration to England occurred after the Second World War. The 1948 British Nationality Act was introduced to address a labour shortage. Therefore, the post-war period (1950s and 1960s) witnessed a large-scale economic migration of people from the Caribbean and the Indian sub-continent (India, Pakistan and Bangladesh) (Peach, 1998).

Migration of SAs to the UK has typically occurred in two phases. The first wave occurred in the post-second war era, following increased labour demands (Peach 1998). A further wave of migration occurred in the 1960s and 70s because of the political chaos in East Africa (Frenz 2013). The first wave can roughly be divided along religious lines into Muslims from Pakistan, mostly Sikhs from India, and people from Sylhet were mainly Bangladeshi Muslims. During emigration from their home countries to the UK, emigrants were not well educated, and their knowledge of English was poor. These immigrants were typically blue-collar workers who lived and worked in factories in inner-city areas of the UK (Delaney, Fernihough & Smith, 2013). The main concentrations of these population groups are still found around the West Midlands, Manchester, Bradford and London (ONS, 2018). Many still live in poor, socially deprived inner-city areas. The education and earnings of this group of immigrants are often low, and there are still communication difficulties, and the level of understanding of English is commonly

inadequate. Over the last 50 years, there have been at least two generations of South Asian born and educated in the UK (Bhatnagar, Shaw & Foster, 2015), the population make-up of UK SAs is therefore changing.

The second mass migration occurred in the mid-1970s due to political disturbances in East Africa. SAs living there emigrated to the UK. These people were mostly Gujarati: they were well educated, and most had been established business people in East Africa. They settled around Leicester and London, and most were Hindus (Religion Media Centre, 2018). Other than the above, many others from the subcontinent have come to settle in the UK. These are usually highly skilled, White-collar workers and, about 30 per cent of doctors working in the NHS are from the Indian subcontinent (Jayaweera, 2015). In addition, technological progress and skilled labour have caused migration to different parts of the world, including Canada and the United States. The term ‘South Asian’ (SA) broadly refers to people of Indian, Pakistani and Bangladeshi origin, but those from Sri Lanka and Nepal are also included. Although there is considerable heterogeneity between these subgroups, they share many socio-cultural factors and characteristically are high susceptibility to T2D.

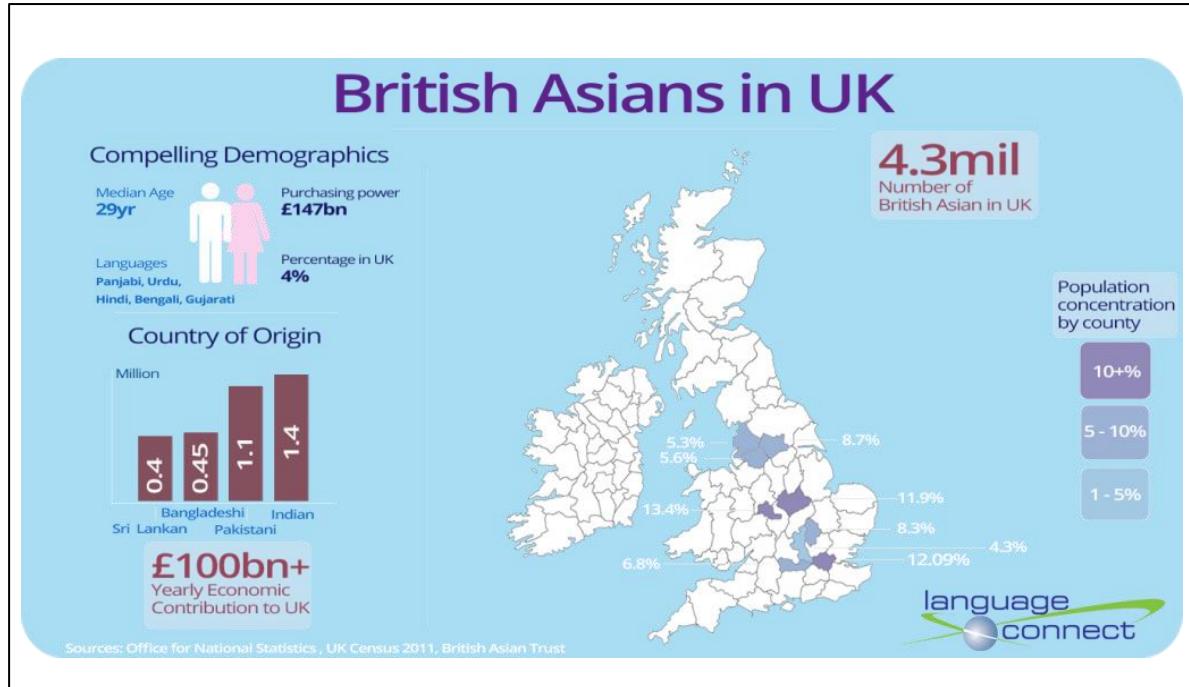


Figure 1.3: Illustration of British SAs

1.13 North-West England

In the North-West of England, 9.8% of the population is Black, Asian and Minority Ethnic group (BAME) (UK Government, 2018). A closer review of the individual ethnic minority groups reveals that people of Pakistan origin are by far the largest BAME group in this region accounting for 2.7% of the UK total population (UK Government, 2018). The broader Asian/Asian British ethnic minority group make up 6.3% of the population, and the combined mixed/multiple ethnic groups make up 1.6%, as does the combined Arab/other ethnic groups. In the North West of England, the highest proportions of SAs reside in Manchester and Blackburn with Darwen (UK Government, 2018).

Table 1.1: The highest percentage of SAs in the North-West

Local Authorities/Districts with the highest proportion of South Asians	
Manchester	33.5%
Blackburn with Darwen	30.7%
Oldham	22.5%
Pendle	20.4%

ONS (2015) revealed that 67.3% of the residents in the North-West of England reported their religion as Christianity. However, there is a notable Muslim community in the North-West, 5.1% of its resident population are followers of Islam. In Manchester, the Muslim community is significant; 79,496 followers equates to 15.8% of the resident population. In addition to this, the prevalence of specific health conditions, such as diabetes is higher than the national average alongside diabetes hospitalisation (Quality and Outcomes Framework, 2016-2017).

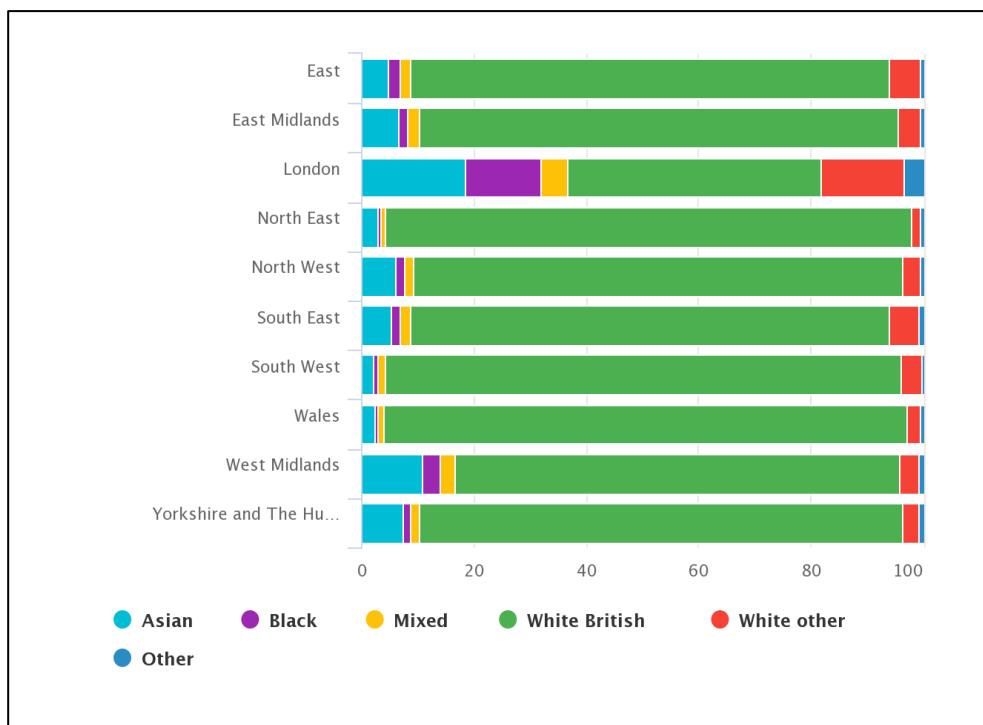


Figure 1.4: Areas of England and Wales by Ethnicity.

1.14 South Asian Culture

The term culture is defined as “the lifeways of a particular group with its values, beliefs, norms, patterns and practices that are learned, shared and transmitted intergenerationally” (Leininger, 1996). Although SAs are identified as one cultural group (Dey, Balmer, Pandit, Saren & Binsardi, 2017), there is ethnic diversity present in terms of geographical, religious and linguistic variability amongst this group. Despite the diversity across SAs from different geographical and linguistic backgrounds, one similarity that most share is a strong sense of kinship and family belonging. Family households usually comprise of parents, children and other relatives such as grandparents (Tran, Kaddatz & Allard, 2005). The family thus becomes a medium through which cultural values, languages and religious customs and traditions are passed down between generations (Tran et al., 2005).

Religious diversity among SAs takes the form of three major religions which are practised by this population: Islam, Hinduism and Sikhism. According to the 2011 Census, Muslims form 4.8% of the total population in England and Wales (ONS, 2011). This population had increased from 1.55 million in 2001 to 2.71 million in 2011. From a very recent statistic from the ONS (2018), there are currently 3.37 million Muslims in Great Britain (ONS, 2018). Furthermore, there are 816,633 Hindus in England and Wales (1.5% of the total population). In 2011, Hinduism was the fourth largest religious group after Christianity (59%), No Religion (25%), and Islam (5%). Finally, there are almost 500,000 Sikhs across the UK, approaching 1% of the total population (ONS, 2018).

1.15 Diabetes Prevalence in South Asians

It is estimated there are over 25 million people of SA origin living outside the Indian subcontinent (Mahal & Matsoukas, 2018). In the UK, the prevalence of diabetes in this community is particularly high and is rising at a faster rate than in any other ethnic group (Oldroyd, Banerjee, Heald & Cruickshank, 2005). This is evident where T2D diagnosis is 2.5-5 times more common in SAs (Khunti et al., 2013). Specifically, parts of Oldham, Rochdale, Blackburn, Bolton and Ashton-under-Lyne have a high estimated prevalence of T2D and a higher than average proportion of Asian ethnic groups. On average, diabetes prevalence in North-West England is around 18% higher than in the South East of England (Quality and Outcomes Framework, 2016-2017).

One of the ethnic groups that have been of concern to researchers in recent years has been the SA population. SAs are a subgroup of people who have a particular predisposition to diabetes (Gujral, Pradeepa, Weber, Narayan & Mohan, 2013). The SA continent consists mostly of low- and middle-income developing countries representing about one-quarter of the world's population. According to the IDF, more than 70 million individuals in the sub-continent are living with diabetes, and approximately 7.9 million

of its people die every year from this condition (Ogurtsova et al., 2017). India has had a steady increase in the disease over the last 40 years. According to the ADA, it is expected to lead the world with 101.2 million people living with T2D by the year 2030 (Whiting, Guariguata, Weil & Shaw, 2011). T2D among this group differs from other races because it occurs at an earlier age, at a lower BMI and complications develop earlier (Gujral et al., 2013). This makes the incidence of T2D among SAs a case for urgent attention.

One of the first indications for the high prevalence of T2D in SAs was the publication of the Southall Diabetes Survey in 1985 (Mather, 1985). This revealed that the incidence of T2D in SAs was three times that in White Europeans, and five times more in those aged between 40 and 69 years. More recently, this has been reinforced by Waisundara & Shiomi (2017), who indicate that SAs have the highest risk of developing T2D, and around four times higher than in any other ethnic group.

Studies are still on-going to find out why the SA ethnic group has a higher prevalence compared to other groups, for example, the White population. Some studies have gone ahead to find out that SAs have this predisposition because of a combination of genetic and socio-cultural factors (Greenhalgh et al., 2015; Murea, Ma & Freedman, 2012). The phenotypes of SAs make them more susceptible to T2D than other populations. Some of the genetic factors include fetal programming, insulin resistance, pancreatic beta-cell capacity, capacity for safe fat storage and lean body mass (Wells, Pomeroy, Walimbe, Popkin & Yajnik, 2016). Even though these genetic factors play a role in the development of the disease, unhealthy lifestyles contribute significantly to its development.

1.15.1 Physical Activity (PA)

Several studies have shown that increased PA can reduce the risk of T2D (Colberg et al., 2010; Colberg et al., 2016; Yang & Yang, 2019). However, physical inactivity is

the fourth leading cause of global mortality, and data shows that 31% of the world's adult population is physically inactive (Gichu et al., 2018). Evidence shows that physical inactivity increases the risk of coronary heart disease, T2D and breast and colon cancer and shortens life expectancy (Lee et al., 2012). Worldwide, it was estimated that physical inactivity causes 7% of the burden of disease from T2D (Lee et al., 2012). Prolonged television watching as a surrogate marker of a sedentary lifestyle, was reported to be positively associated with diabetes risk in both men and women (Hamilton, Hamilton & Zderic, 2014). Evidence from clinical trials which included PA as an integral part of lifestyle interventions suggested that onset of T2D can be prevented or delayed as a result of successful lifestyle interventions that included PA as a part of this intervention (Galaviz, Narayan, Lobelo & Weber, 2018; Kahn & Davidson, 2014; Mutie, Giordano & Franks, 2017). SAs are generally less physically active in their entire life course than, for example, the general British populations, particularly women and older people (Jepson et al., 2012).

In 2011, the CMO's of the four UK countries introduced revised guidelines for PA that reflected current evidence on what is needed to benefit health and what are the incremental benefits from undertaking PA (Department of Health, 2011). The current UK guidelines for PA recommends adults engage in at least 150 minutes of moderate-intensity PA (e.g. brisk walking) or vigorous activity (e.g. running/swimming) per week. In addition to this, strength activities (muscle training) on two or more days per week (PHE, 2016). However, despite these recommendations, statistics show there are still large numbers of people across the UK who are failing to engage in PA at this level. Specifically, around 40% of adults are not meeting government guidelines for PA (Weed, 2016). The proportion of adults meeting the aerobic activity guidelines was lowest in the West Midlands (53%) and highest in London (65%) (Scholes & Neave, 2013).

Whilst it is important to be physically active for the prevention of disease, to our knowledge, there are no studies that solely examine the link between T2D RP and PA. Several studies have examined PA as a behaviour that could delay or prevent chronic disease (Booth, Roberts & Laye, 2012; Knight, 2012). A study done by Peltzer (2000) examined risk awareness of five different health problems (heart disease, lung cancer, mental illness, breast cancer, high blood pressure) and four health behaviours, one of which was PA. Findings revealed that risk awareness was not associated with exercise as a health behaviour.

It has been identified that the UK SA population have shown not to partake in as much PA as the general population (Bhatnagar, Townsend, Shaw & Foster 2015; Lawton, Ahmad, Hanna, Douglas & Hallowell, 2005). Overall, the SA population have the highest rates of physical inactivity in the UK by ethnicity (31%) compared to the rest of the population (UK Government, 2019). The studies so far have been based on self-reported PA levels and suggest that PA levels are lower in SA adults compared with other ethnic groups (Khunti, 2007). Most studies have identified particularly low levels of PA in SA women, and it is thought that, among this group, it may be easiest to intervene in low leisure-time PA (Babakus & Thompson, 2012). Data from the Health Survey for England found that SAs were 60% less likely than native White's to meet government recommendations for PA (Williams, Stamatakis, Chandola & Hamer, 2011). Likewise, a systematic review by Fischbacher, Hunt & Alexander (2004) examined PA levels among SAs and compared it to the general UK population and noted that rates were 50-75% less in SAs. Low PA is one of the contributing risk factors for the higher obesity levels seen in SAs (Lucas, Murray & Kinra, 2013). A qualitative study conducted among SA living in the UK found that understanding external motivators and social context of their lives is very crucial for developing successful PA interventions (Jepson et al., 2012). Hence,

although exercise is promoted in public health campaigns to increase the overall PA level of a population, it is also important to understand socioeconomic factors associated with different populations in order to deliver effective PA interventions. Therefore, research in this field has suggested that tailored PA interventions for SA may be useful to increase PA. Although there is a need for further quantitative and qualitative research on this topic.

Table 1.2: The physical activity levels and definition

Activity Level	Definition
Meets aerobic guidelines	Reported 150 minutes/week of Moderate Physical Activity (MPA), 75 minutes/week of Vigorous Physical Activity (VPA), or an equivalent combination of the two.
Some activity	Reported 60-149 minutes/week of MPA, 30-74 minutes/week of VPA, or an equivalent combination of these.
Low activity	Reported 30-59 minutes/week of MPA, 15-29 minutes/week of VPA, or an equivalent combination of these.
Inactive	Reported less than 30 minutes/week of MPA, less than 15 minutes/week of VPA, or an equivalent combination of these.

1.15.2 Diet

The composition of diet seems to be an essential factor in the prevention of T2D (Sami, Ansari, Butt & Ab Hamid, 2017). International guidelines (WHO, 2018) recommend a diet with increased dietary fibre and whole grains intake and reduced calorie

and saturated fat intake. A diet high in carbohydrates can have adverse metabolic consequences by raising triglycerides and reducing High-Density Lipoprotein (HDL) cholesterol (Siri & Krauss, 2005). Several prospective studies showed a reduced risk for high intake of dietary fibre from grains on the development of T2D (Forouhi, Misra, Mohan, Taylor & Yancy, 2018; Weickert & Pfeiffer, 2018). A review which included 19 studies, “On diet and risk of T2D: the role of fat and carbohydrate” concluded that a higher intake of polyunsaturated fat and long-chain n.3 fatty acid is beneficial, whereas higher intake of saturated fat and trans-fat adversely affect glucose metabolism and insulin resistance (Hu, Van Dam & Liu, 2001). Another prospective study found higher consumption of butter, potatoes and whole milk to be associated with increased risk of T2D. Higher consumption of fruits and vegetable was associated with reduced risk of T2D (Villegas et al., 2007).

SAs are also likely to acculturate their diet to that of the host countries. Asian Indians in the United States consume diets that are high in calories and saturated fats, which increase their risk of T2D. In the Oslo Health Study (Mellin-Olsen & Wandel, 2005), it was reported that the majority of the Pakistani immigrants, after migration consumed more milk, meat and butter. They consumed fewer beans, lentils and their traditional meals, which contain products that increase metabolism and reduce the risk of getting T2D. In addition to this, Surinamese-Indian immigrants were known to consume meals with less fibre, less fruit and vegetables and little breakfast compared to the Dutch population (Raza, Snijder, Seidell, Peters & Nicolaou, 2017).

Among SA immigrants to western countries, dietary acculturation takes the shape of increased consumption of sugar-sweetened beverages, processed foods and convenience foods that contain increased fat and sodium content (Shah & Kanaya, 2014).

For example, Asian Indians in the United States consume diets that are high in calories and saturated fats (Martyn-Nemeth et al., 2017).

In the Oslo Immigrant Health Study (2001), it was reported that the majority of the Sri Lankans and Pakistani immigrants, after migration, consumed more meat, milk and butter. They consumed fewer beans and lentils, which contain products that increase metabolism and reduce the risk of getting T2D (Holmboe-Ottesen & Wandel, 2012). Nevertheless, SAs seem to change their diet after migration and all of these factors, in turn, contribute to weight gain and obesity, which in turn translates to an increased risk of prediabetes and T2D.

A study carried out in the UK (Simmons & Williams, 1997) explored the dietary practices of Europeans and SA populations. The study showed that the SA Gujarati group consumed higher amounts of fried food, white flour and rice. The SA Muslim cohort were least likely to be vegetarians and made food with ghee. This evidence highlights that the SA diet has been a causal factor in increased blood glucose levels and increase the risk of T2D. Furthermore, studies have found that SAs are at higher risk of consuming more of foods that are high in salt, sugar and fat as they tend to consume both traditional SA cuisines alongside western food (Lawton et al., 2008). Consequently, second and subsequent generation migrants are becoming increasingly at risk due to their consumption of a high-fat diet through consumption of both traditional SA diet and the western diet. Evidence shows that the typical SA diet is high in fat, especially ghee which is used in traditional Indian cooking (Mani & Kurpad, 2016). Amongst SAs fat intake, it was found that the average amount consumed was 37% which is higher than the recommended 30% allowance (Ellahi, Chow, Fitzgerald & Dikmen, 2014). Food frequency data shows that SAs, predominately Punjabi Muslims, eat more butter and meat and are more likely to drink full-fat cream and milk. Although there is evidence to suggest

that diet plays a role in ensuring effective management of T2D, the research specifically in the SA population and the effects food has on T2D is under-investigated. The majority of the research predominately focuses on the management of T2D (Forouhi et al., 2018; Sami et al., 2017) and there is minimal research which investigates the prevention of T2D and the role of food and diet in individuals, not already diagnosed with T2D.

1.15.3 Obesity

Overweight, and especially obesity, is a significant risk factor for the development of T2D, primarily when the excess adiposity is centrally distributed (Schuster, 2010). In obese individuals, adipose tissue releases increased amounts of fatty acids, glycerol, hormones, pro-inflammatory cytokines, and other factors that are involved in the development of insulin resistance. There is convincing evidence for an association, which has been shown in several studies in different populations, with a striking increase in risk apparent with increasing levels of BMI, waist circumference or waist-to-hip ratio (Tran et al., 2018; Van der Merwe, 2004). The risk of developing T2D is almost three times higher for those overweight, and seven times higher for those obese compared with healthy weight people (Wilding, 2014).

A combination of biological and lifestyle factors predisposes SAs to their increased risk of developing T2D (Kolb & Martin, 2017). From a biological standpoint, insulin resistance is one of the predisposing factors to the early diagnosis and onset of T2D among SAs (Gujral et al., 2013). People of SAs descent are reported to have higher levels of subcutaneous fat and visceral fat, both of which contribute to an increased percentage of overall body fat. It is the higher level of visceral fat in particular which contributes to central abdominal and adiposity and can, in turn, lead to the development of insulin resistance (Hall, Sattar & Gill, 2008). The increased percentage of overall body fat among SAs is reflective in the comparison of BMI between SAs and White's. For a

given identical BMI calculated in both of these populations, SAs will have a significantly increased percentage of body fat that is primarily situated in the abdominal area (Bodicoat et al., 2014; Gujral et al., 2013). For this reason, WHO (2008) has identified specific cut-off points for what is considered to be “normal” waist circumference and waist-to-hip ratio within the SA population, to account for their increased risk. The pathophysiological effects of increased visceral adiposity in SAs are why many health organisations now utilise adjusted BMI categories for SAs for example, The National Institute for Care Excellence (NICE) (Abdullah, Attia, Oldmeadow, Scott & Holliday, 2014). In combination with biological risk factors, lifestyle risk factors also put the SA community living in the UK at even greater risk of developing T2D (Muilwijk et al., 2018).

In order to ensure that healthcare serves a diverse population and the population needs, it is vital that all ethnic groups participate in health research (Redwood & Gill, 2013). Researchers need to devote time to address the challenges of recruiting and retaining participants, as to date, very few quality studies in the UK have included SAs. Hussain-Gambles and colleagues (2006) investigated the reasons for non-participation in clinical trials, including motivation and deterrents. Professional views included a lack of time and resources and inadequate support. It has also been highlighted that SAs are often explicitly excluded due to perceived cultural and language difficulties. This was further supported by Lloyd and colleagues (2008). However, this study addressed some of these difficulties by developing audio-recorded methods of obtaining informed consent and recording data (Lloyd et al., 2008)

1.15.4 Health Beliefs

SAs living in the UK tend to have little knowledge about T2D and lack understanding of the relationship between lifestyle choices and T2D (Lucas et al., 2013). Evidence shows that personal models of illness can determine an individual’s response to

illness (Wade & Halligan, 2004), which is vital to diabetes care when health beliefs about diabetes can affect self-care, wellbeing and medical outcomes. In addition to this, it has been shown that lay individuals and healthcare professionals have different beliefs and attitudes about chronic disease management (Sadler, Wolfe & Mckevitt, 2014). Knowing about lay health beliefs is particularly important in T2D care as it has been shown that if health education complies with people's lay epidemiology, it is more likely to be successful in facilitating behaviour change. Studies conducted on the SA population have shown their health beliefs to be different from those of European populations (Lucas et al., 2013). For example, majority of the SAs tend not to follow biomedical models when explaining the cause of their T2D (Wells et al., 2016).

Within the Bangladeshi community, the onset of T2D is attributed to a range of external influences including heredity and having family history (Stone, Pound, Pancholi, Farooqi & Khunti, 2005) and dietary factors such as the intake of sugar and a western diet (Choudhury, Furbish & Chowdhury, 2016; Rankin & Bhopal, 2001). The onset of T2D is also associated with social isolation, as people with diabetes are labelled as 'out of control' in terms of their lifestyle choices (Grace, Begum, Subhani, Kopleman & Greenhalgh, 2008). However, one study found that participant's awareness about risk factors increased due to family and friend's diagnosis and the perceived threat was enough to inspire preventative action in others (Grace et al., 2008). However, not all SAs draw upon the same factors when explaining T2D causation. Studies show that Hindu Gujaratis have a biomedical understanding of chronic diseases and recognise the importance of lifestyle modifications and are familiar with T2D through family and friends (Keval, 2009). Furthermore, many SA individual's understanding of illness and disease are bound to cultural explanations which do not match traditional 'western medicine' health concepts. One of the key studies from Macaden & Clarke (2006) examined the

experiences of SA people with diabetes in the UK, and their influences on the perception and understanding of risk. They found that a number of issues influenced the RP among SA older people with diabetes. For example, the beliefs about its cause, perceived severity, food and its social function and external control over their lifespan. People weighed up the risks in making decisions about issues such as dietary management. Whilst these studies provide some insight into how SAs perceive their risk for T2D, overall, there is little evidence to show that can draw meaningful conclusions to lower this community's risk.

1.16 Risk Perception

The next section discusses the concept of risk and the main approaches used to examine Risk Perception (RP). Furthermore, the literature is reviewed to gain a broad understanding of what is known to be important in influencing T2D RPs in the SA community.

1.17 Risk

The term ‘risk’ originated in the mid-17th century from the French word risqué, meaning danger (Engemann, 2018). According to Jacobs (2000), it initially related to the probability or mathematical likelihood of an event occurring, combined with the magnitude of the losses or gains that would likely result. However, others argue that risk is not a definitive entity because people do not merely respond to the physical impact of measurable and quantifiable risk (Burns and Slovic, 2012; Waters, Hay, Orom, Kiviniemi & Drake, 2013). Others emphasise the need for a focus to be placed on the significance of psychological, social and cultural contexts associated with risk (Chan, Yang, Gu, Wang & Tai, 2015; Taylor-Gooby, 2004). Slovic and Weber (2002, p.4) assert:

"It does not exist "out there," independent of our minds and cultures, waiting to be measured. Instead, risk is seen as a concept that human beings have invented to help them understand and cope with the dangers and uncertainties of life. Although these dangers are real, there is no such thing as "real risk" or "objective risk."

This view is supported by arguing that while the risk is recognised by threats and danger, it closely relates to uncertainty in terms of situations with unknown outcomes (Brewer et al., 2007; Sjöberg, Moen & Rundmo, 2004). An evaluation or judgement about risk varies from person to person because it is learned by socially and contextually structured conceptions and evaluations in terms of what it looks like and what it should or should not be (Hampel, 2006; Zinn, 2009). Van Nuffelen (2004) argues that individuals

are never separated from their social and cultural background and as a result, uncontested or accurate perception of any risk does not exist. Instead, it is the social, cultural and contextual biases that condition them. Due to these reasons, to manage and communicate risks, an understanding of how and why people perceive and respond to risks within specific contexts is vital (Seale et al., 2010; Setbon and Raude, 2010).

One of the main focus in health risk research is risk from an epidemiological perspective. Epidemiological research evaluates the probability that certain events will occur in a given population, which is particularly important in highlighting what risk exists and who they are likely to affect (Fuster & Kelly, 2010). For example, the discovery of the link between cigarette smoking and lung cancer, showed that the rates of lung cancer are much higher in smokers. From this angle, there has been a growing interest in research which explores an individual's beliefs about the likelihood of a risk occurring.

1.18 Diabetes Risk

NICE (2012) introduced guidelines to identify those individuals at 'high risk' of developing T2D (NICE, 2012). In addition to this, Diabetes UK (2018) introduced a validated risk assessment to identify any individuals at high risk across the UK. Diabetes risk is assessed by the use of validated risk-assessment tools (CANRISK), self-assessment questionnaires (Diabetes UK assessment/Leicester Risk assessment) and blood sugar test (HbA1c). Furthermore, NICE (2012) guidelines recommend using validated risk scores that take account of routinely collected data in primary care such as QDiabetes risk calculator (Hippisley-Cox, Coupland, Robson, Sheikh & Brindle, 2009) or the Cambridge Risk Score (Griffin, Little, Hales, Kinmonth & Wareham, 2000).

According to the Diabetes UK Risk Assessment tool (DUK), there are various risk categories that can define an individual to whether they are at high risk of developing

T2D. Within this risk assessment tool, there are 4 categories: Low Risk, Increased Risk, Moderate Risk and High Risk. Based on specific information provided by the individual, the risk assessment tool will calculate the risk score (See figure 1.5).

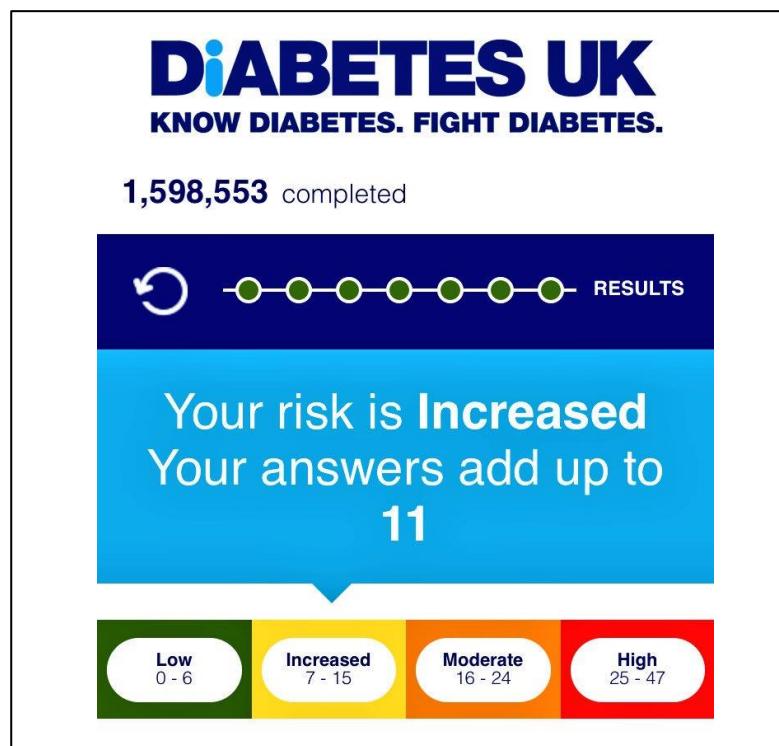


Figure 1.5: Screenshot of the DUK Risk Assessment Tool

1.19 Risk Perception

Risk perception (RP) is a term used to describe the attitudes and judgements individuals have about risk (Ferrer & Klein, 2015). Lay risk perceptions are influenced by some factors, including the severity of the risk occurring as well as individual differences and personal beliefs (Ferrer & Klein, 2015). The physical consequences of risks such as death and harm are objective facts, yet how people assess and understand them are subjective and based solely on individuals' beliefs and attitudes. Therefore, risk has different meanings to different people (Slovic, 1987).

According to Wachinger et al. (2013), through this process, risks are internalised by social and contextual learning, which is continuously reinforced, modified, or attenuated through the continual communication process. It is for this reason that people often make judgements and evaluations about risks and make behaviour decisions which may not align with scientific evidence (Heo et al., 2013). For example, research demonstrates that immunisation is one of the most effective ways of controlling illness from the flu (Nowak, Sheedy, Bursey, Smith & Basket, 2015). Despite, the availability of a safe and effective vaccine, a key predictor of poor uptake is found to be a result of evolving subjective perceptions of risks of the vaccine. People do not accept the vaccine despite knowing the risks of illness (Gidengil, Parker & Zikmund-Fisher, 2012). To address misconceptions and encourage behaviour change, is it, therefore, crucial that we understand why and how people perceive the risks and consequences of their actions (Rubin, 2009).

RP plays a significant part in the clinical care and self-management of diabetes (Shreck, Gonzalez, Cohen & Walker, 2014). Self-management includes the modification of the significant four lifestyles risk, which includes: alcohol consumption, PA levels, diet and smoking (Ng, Sutradhar, Yao, Wodchis & Rosella, 2019). Those who are identified as at high clinical risk are encouraged to monitor their behaviours, engage in improvements to lifestyle and manage their own risks (Adams, 2010).

Past research has found that an individual's RP of T2D is a crucial part of whether or not individuals take steps to prevent or treat symptoms (Shrivastava, Shrivastava & Ramasamy, 2013). Perceiving one's risk of acquiring diabetes is crucial because it serves as an indicator as to whether or not the individual is aware that action needs to be taken to control his or her health outcomes. On the one hand, if an individual underestimate the severity of their risk (Kowall et al., 2017), they are unlikely to engage in behaviours that

improve their health, while, the other hand, overestimating risks can lead to unnecessary stress and anxiety (Kowall et al., 2017).

One of the biggest misconceptions of RP is that it is not merely a mathematical probability that can be measured accurately and assessed outright (Botzen, Kunreuther & Michel-Kerjan, 2015). RP is, in reality, complex and multidimensional, with several different facets that support an overall picture of one's perception of a given risk. In general, RP can be classified into three categories, which are absolute, comparative or conditional risks (Rouyard, Kent, Baskerville, Leal & Gray, 2017). First, absolute risk refers to the difference between one's RP and actual outcomes (Eiser et al., 2012). Second, comparative risk refers to one's RP relative to another individual or relative to an average member of the population. Lastly, conditional risk refers to RPs that outcomes will occur if specific behaviour is adopted over the time period being studied (Glenn et al., 2011).

Another important concept that creates a challenge for researchers attempting to measure RP is the concept of 'optimistic bias'. Primarily, optimistic bias also referred to as the 'illusion of invulnerability', reflects the tendency that most people have to underestimate their own likelihood of experiencing adverse events in their life, while at the same time overestimating the probability that more positive events would occur (Rouyard et al., 2017). The optimistic bias tends to be familiar with younger groups; adolescents are unlikely to fully understand the long-term consequences of their on-going health-related behaviours (Popova et al., 2016). The formation of accurate or inaccurate RP may have significant consequences for health, for example, having inaccurate RPs around developing T2D (Ferrer & Klein, 2015). Although low-risk perception is by definition optimistic, if an individual is indeed at low clinical risk for a disease threat, those RPs are also realistic. The accuracy of RPs depends on measurement; an

individual's RP regarding the same disease can be simultaneously pessimistic and optimistic when assessed with absolute and comparative measures (Ferrer & Klein, 2015). For example, a woman with an objectively high risk of breast cancer can estimate she has a 70% chance of breast cancer, but simultaneously report she is at lower risk than other women her age. Some studies suggest that unrealistic optimism yields lower motivation to engage in health-protective behaviours that would mitigate risk and unrealistic optimism has been linked to objective adverse health outcomes. However, other studies have linked unrealistic optimism for positive health outcomes (Conversano et al., 2010; Joshi & Carter, 2013). Despite, mixed evidence regarding implications, the literature suggests that RPs can be unrealistically optimistic and that this is a fairly common bias across population groups (Ferrer & Klein, 2015).

1.20 Risk Perception Literature

The notion of RP and how people respond or react to risk has been a topic of interest for many researchers over recent years. Sociological (Spink, Menegon, Bernardes & Coelho, 2007), anthropological (Stellmach, Beshar, Bedford, du Cros & Stringer, 2018) and psychological literature has contributed to gain an understanding of how risk is constructed (Zinn, 2019) perceived and responded to by the public and experts from a broad perspective. However, considerably less is known about RPs and responses related to T2D prevention in SAs.

The majority of published research in this area focuses upon RP in adults. Although the research on perceptions regarding T2D is still in its early stages, several studies that have established the research directions of the subject (Amuta, Barry, & McKyer, 2015; Skot, Nielsen & Leppin, 2018). It has been demonstrated that adults who perceive themselves at risk for developing a disease are more likely to participate in risk-

reducing behaviours to reduce the risk of developing the disease (Kim, Sargent-Cox, Cherbuin & Anstey, 2014).

The HBM has been the most widely used theory to study RP (Jones et al., 2015). Perceived risk for illness and disease in adults has been researched extensively. Relationships between chronic diseases and perceived risk have been demonstrated in breast cancer (Orom, Kiviniemi, Shavers, Ross & Underwood, 2013) and colon cancer (Choi et al., 2018). However, there are very few studies found that solely examine RP for developing T2D (Godino, van Sluis, Sutton & Griffin., 2014; Kowall et al., 2017) and there are currently no studies which examine RP for developing T2D for UK lay SA population.

In 2016, a group of researchers from the Health Economics Research Centre at the University of Oxford published a systematic review of studies that explored the perceptions of risk for diabetes-related complications in T2D (Rouyard et al., 2017). The review included a total of 18 total studies in which a mix of qualitative and quantitative methods was used. Out of the 18 studies, 12 studies focused only on cardiovascular risk of T2D, while the remaining six included microvascular risks. Overall, the findings were mixed, but there was a common tendency among individuals towards overestimation of possible heart attack and stroke. In terms of optimistic bias, one study showed that outcomes were higher among minority ethnic populations and among those with lower levels of education. Additionally, one study indicated that women tended to exhibit a higher perceived risk for cardiovascular disease compared to men (Azahar, Krishnapillai, Zaini & Yusoff, 2017).

In addition to this, another study conducted in 2003 by researchers from the Diabetes research training centre at the Albert Einstein College of medicine was designed

to explore the comparative risk judgements for diabetes of physicians in the United States and Canada (Walker, Mertz, Kalten & Flynn, 2003). In this study, 535 non-diabetic individuals were surveyed using the instrument of the Risk Perception Survey for Developing Diabetes (RPS-DD). At the beginning of the study, the sample was split into two groups, one containing higher-risk subjects and other containing lower-risk individuals. The findings of the study indicated that the level of the self-reported higher risk groups was significantly different from the level of the lower-risk groups. The findings included a lower sense of personal control, higher worry about developing diabetes and a greater overall RP across multiple other diseases. In terms of optimistic bias, the lower risk groups showed higher levels of optimistic bias, but 50% of the higher risk group members reported they were less likely than others of the same age and gender to develop diabetes. Overall, the study provided important evidence that optimistic bias can exist in any population or community and that a better understanding of lay-groups attitudes toward developing diabetes is an important step in helping overcome barriers.

In addition to this, there was another study examining the RP of T2D within adolescents (Fischetti, 2015). This study used a cross-sectional design to survey a group of high school students. The total sample included 80 participants, with ages 13-18 years old and comprised 35 male and 45 females. The study was designed to test the hypothesised relationship between perceived T2D and diet and exercise regimen. Fischetti (2015) pointed out that the findings indicate that not only did participants seem to have a false understanding of the role of carbohydrates in one's diet but also that participants that exercised more, even in moderate amounts, were less likely to perceive T2D as a risk.

Furthermore, Reyes-Velazquez and Sealey-Potts (2015) surveyed university students to compare their actual T2D risks to their RP. A total of 660 students participated

in the study, including 63.2% female participants and 36.8% male participants. The results supported the hypothesis that those who reported themselves to be at ‘some’ or ‘great’ risk for developing T2D score much higher on their actual risk compared to the lower-risk groups. In addition to this, findings also suggest that both the high and low-risk groups had a significant number of individuals that we’re unaware of their personal risks, and therefore were probably more likely to underestimate their risk of developing diabetes. Furthermore, the findings showed that over 40% of the participants were classified as overweight or obese, which is known as one of the leading contributors to the development of diabetes.

Certain psychological factors have also been linked to engagement in these health-protective behaviours generally, with at least some research on their relation to health-protective behaviours in individuals at risk for T2D. One such psychological variable is health locus of control (HLoC), which refers to the degree an individual believes his or her health is due to his or her own behaviour, luck or chance, or powerful others (e.g. doctors, religious leaders) (Berglund, Lytsy & Westerling, 2014). If an individual has a high internal locus of control, he or she is more likely to modify behaviour, due to the belief that he or she has greater control over possible outcomes. For example, the 1970 British Cohort Study, an ongoing longitudinal study of 17,198 live births, found that individuals with a propensity towards a more internal locus of control at age 10 had a significantly reduced risk of multiple health conditions at age 30, including obesity and being overweight, even after adjusting for possible covariates including education, social class and current income (Gale, Batty & Deary, 2008).

In addition to this, Steptoe & Wardle (2001) conducted a cross-sectional study of 4,358 female and 2,757 male university students from 18 European countries. Steptoe and Colleagues examined the relationship between the three orientations of locus of

control (internal, powerful others, and chance) and ten health-related behaviours (physical exercise, diet intake, alcohol consumption, breakfast, tooth-brushing, seat belt use and consumption of fruit, fat, fibre and salt) on the general population. Results suggested that those with the highest levels of internal locus of control conducted more (positive) healthy activities compared to those with lower levels of internal locus of control.

There have been several studies suggesting internal locus of control is associated with greater dedication to a diabetes regimen in individuals already diagnosed with T2D (Morowatisharifabad, Mahmoodabad, Baghianimoghadam & Tonekaboni, 2010; Trento et al., 2008). There has been very little research in individuals at risk for T2D (not already diagnosed). Further studies are necessary to examine how the unique experience of increased risk for T2D among SA individuals may be related to health locus of control and this influence the likelihood to engage in health-protective behaviours.

Diabetes self-management depends largely on an individual's knowledge of diabetes and their behavioural self-regulation (Baghbanian & Tol, 2012). However, T2D management is a complex process, influenced by a broad range of contextual factors including reciprocally interacting individual, socio-economic and cultural factors (Baghbanian & Tol, 2012).

Regulation of metabolic pathways includes regulation of an enzyme in a pathway by increasing or decreasing its response to signals. Metabolic control involves monitoring the effects that these changes in an enzyme's activity have on the overall rate on the pathway (Hoey et al., 2001). Metabolic control in T2D is a critical component in diabetes care (Huayanay- Espinoza et al., 2016). Without well-established metabolic control, complications can arise increasing mortality rates and lowering quality of life. Several comorbidities are related to poor metabolic control including dyslipidemia, hypertension

and obesity, increasing the risk of long-term macro and micro-vascular complications. It has been reported that more than 80% of deaths associated with T2D occur due to poor metabolic control (Wu et al., 2014). HbA1C test results are an indicator of metabolic control and this can be influenced by various factors including age, cultural background, economic status and health facilities (Ebrahimi, Sadeghi, Amanpour & Vahedi, 2016).

1.21 Theories of Risk Perception

Two major RP theories have dominated RP research since the 1970s: The Psychometric paradigm (Fischhoff, Slovic, Lichtenstein, Read & Combs, 1978) and Cultural Theory (Tansey & O’riordan, 1999). However, more specific to RPs and healthcare, the Health Belief Model (HBM) (Becker, 1974), first developed in the 1950s is one of the most widely used theoretical frameworks. These theories provide a context in understanding factors that impact on how people perceive and respond to risk (Silverman, 2011).

1.21.1 Psychometric Pattern

This theory was first developed in the 1970s to investigate lay perceptions of the risk towards nuclear power, natural hazard and chemicals (Slovic, Fischhoff & Lichtenstein, 1982). More recent risk research adopting this theory has explored a range of risk-related phenomena such as flooding (Reynaud, Aubert & Nguyen, 2013). This framework uses psychophysical scaling methods and multivariate analysis to produce a quantitative representation of the way people judge a specific set of risk or hazards (Dohle, Keller & Siegrist, 2010). The critical element of this theory is to isolate experts and public risk perceptions on the understanding that these two groups do not perceive or respond to risks in the same way.

While this model helps acknowledge that people can understand and rate risks, there are some limitations. Firstly, this theory assumes that all individuals assess risks in

a quantifiable manner and ignores the importance of social, cultural and institutional factors. Therefore, it does not help to understand in any depth how and why people perceive risks and why RPs differ among groups (Sjoberg et al., 2004).

1.21.2 Cultural Theory

Cultural Theory recognises that peoples RPs are the outcome of complex and diverse socio-cultural processes and are not merely accepted as an unproblematic fact (Taylor-Gooby, 2004). This approach assumes that there are four specific viable ways of life defined by the ‘grid’ and ‘group’ characteristics (Marris et al., 1998). A grid-group approach was developed as a tool to understand different logics of risk as they expressed in social groups (Douglas, 2002). For example, a specific culture will always correspond with a particular pattern of social relations.

In this theory, the grid-group ideal type is characterised as hierarchists, egalitarians, fatalists and individualists. Groups is defined as how strongly people are bonded together and grid describes how different people are in the group and how they take on different roles. Hierarchists (high group, high grid) have a strong group boundary. They have hierarchical views and great respect for authority (Pursglove, 2010). These types of individuals believe that disease occurs when rules are broken, especially those derived from higher sources such as doctors. Egalitarians (high group, low grid) have a powerful sense of social connectedness. They often exercise their control over one another by claiming to speak in the name of the group. Fatalists (low group, high grid) have a strong sense of social distinction and believe that their autonomy is controlled by their own interpretations of social institutions. They have the ‘can’t do anything about it’ attitude towards health risks and that ‘it will happen anyway’. For that reason, they often ignore health advice (Langford, 2002). Finally, individualists (low group, low grid) are known by no group incorporation or roles. They regard the allocation of power and

resources as their own responsibility not influenced by power or status; they tend to blame themselves and their behaviour for ill health.

Similar to the Psychometric paradigm, although Cultural Theory provided useful insight into RPs, limitations are evident. For example, an element such as personal and social identity and influences from various forms of social organisation can impact on people beliefs and values. Therefore positions may change over time due to circumstance (Vandermoere, 2008). However, the typology (grid-group) does not account for this. The lack of interaction between these groupings fails to capture the reality of people's RPs. This view seems to support the notion that there is a single perspective of risk, thus ignoring the fundamental concept that people are ambivalent, and RPs are socially constructed and subjective (Gaskell and Allum, 2001).

Although the psychometric paradigm and cultural theory have dominated general RP research. However, to my knowledge, there is very little or no research investigating specific RP within the SA population and T2D. Therefore, it is useful to consider health psychology theories in this context.

The goal of research in health psychology is to determine the cause and process of change in health behaviour. Empirically testing health behaviour theories has been heralded as the fundamental basis of understanding health behaviour (Michie & Prestwich, 2010) because of the stated importance of approaching health behaviour questions from a perspective of theory. Theory serves two principal functions in research: (1) it facilitates a better understanding of the determinants of health behaviour and (2) it aids researchers in developing effective interventions to increase health behaviour (Noar & Zimmerman, 2005). The MRC process evaluation guidance (Craig et al., 2008) recommends using a theory-based approach, in which underpinning theory provides a

structure for the process evaluation design, data collection and analysis. Given, the limitations identified with the general RP theories, it is useful to consider this topic by considering specific health psychology theories that have been developed in order to explain, predict and change health-related behaviour. For example, the Health Belief Model (HBM) (Becker, 1974), Theory of Planned Behaviour (TPB) (Ajzen, 1991) and Social Learning Theory (SLT) (Rotter, 1966).

1.21.3 Health Belief Model

The HBM is the most dominant and widely used theory in health-related RP research (Herrmann, Hall & Proietto, 2018; Jones et al., 2015). The concept of this theory is to distinguish personal beliefs and perceptions about a disease or health condition to enable an in-depth understanding of how health behaviour can be determined or understood (Becker, 1974).

RP is a crucial determinant of the HBM as it derives from threat appraisal and is considered a major motivating factor in understanding prevention and protective health behaviours. The model comprises of six primary constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy.

Perceived susceptibility is concerned with people's perceptions about the likelihood of getting a disease or developing a health problem and is understood to be one of the most powerful factors in the promotion of preventative health behaviours. This model hypothesises that the greater the RP, the more likely that the person will engage in preventative behaviours (Bond & Nolan, 2011). Perceived severity related to a person's perception of how serious a disease or health problem and its consequence are. If a person perceived the health problem to have serious consequences, then they more likely to take protective behaviour. Perceived benefits refer to a person's perception of the value or usefulness of adopting preventative behaviour in decreasing the risk of developing a

disease. Therefore, if a person doesn't think their actions will benefit them, they are unlikely to take precautions. Perceived barriers refer to the assessment and evaluation of an obstacle that may be associated with adopting preventative behaviour. Cues to action are the presence of stimuli in the form of events, people, reminders or prompts that may influence a person to adopt a healthy behaviour. When a person has little or no knowledge about something, they tend to seek guidance and advice. These social influences can initiate change in perceptions, therefore motivating a person to alter their behaviour (Orji, Vassileva & Mandryk, 2012). Finally, self-efficacy was later added to the HBM to enable the understanding of a person's belief in their ability to make a health-related change (Jones et al., 2015). The notion that if a person has faith in his or her ability to do something, they are more likely to do it. Likewise, if they believe they cannot do something, they are less likely to make the change (Kaiser et al., 2013).

Since its development, the HBM has been employed in a variety of public health settings over the years. For example, HBM has been applied to help increase voluntary screening rates for cervical cancer (Aldohaian, Alshammary & Arafah, 2019), breast self-examination (Umeh & Rogan-Gibson, 2001), smoking cessation (Upadhyay, Lord & Gakh, 2019) and healthy eating (Deshpande, Basil & Basil, 2009). The model's ability to explain and predict a variety of health-related behaviours has been validated across various domains and among wide range populations. The model has also been used in designing many successful health interventions (Orji, Vassileva & Mandryk, 2012).

However, to my knowledge, there are few studies that have investigated RP in the field of diabetes using the HBM (Al-Mutairi, Bawazir, Ahmed & Jradi, 2015; Gallivan, Brown, Greenberg & Clark, 2009; Shabibi et al., 2017). Each of the research has shown the value of the HBM and the benefits of using this model to predict and change health

behaviour. Although there is research in RP and diabetes using the HBM, there is no research which has investigated RP in T2D within the SA population.

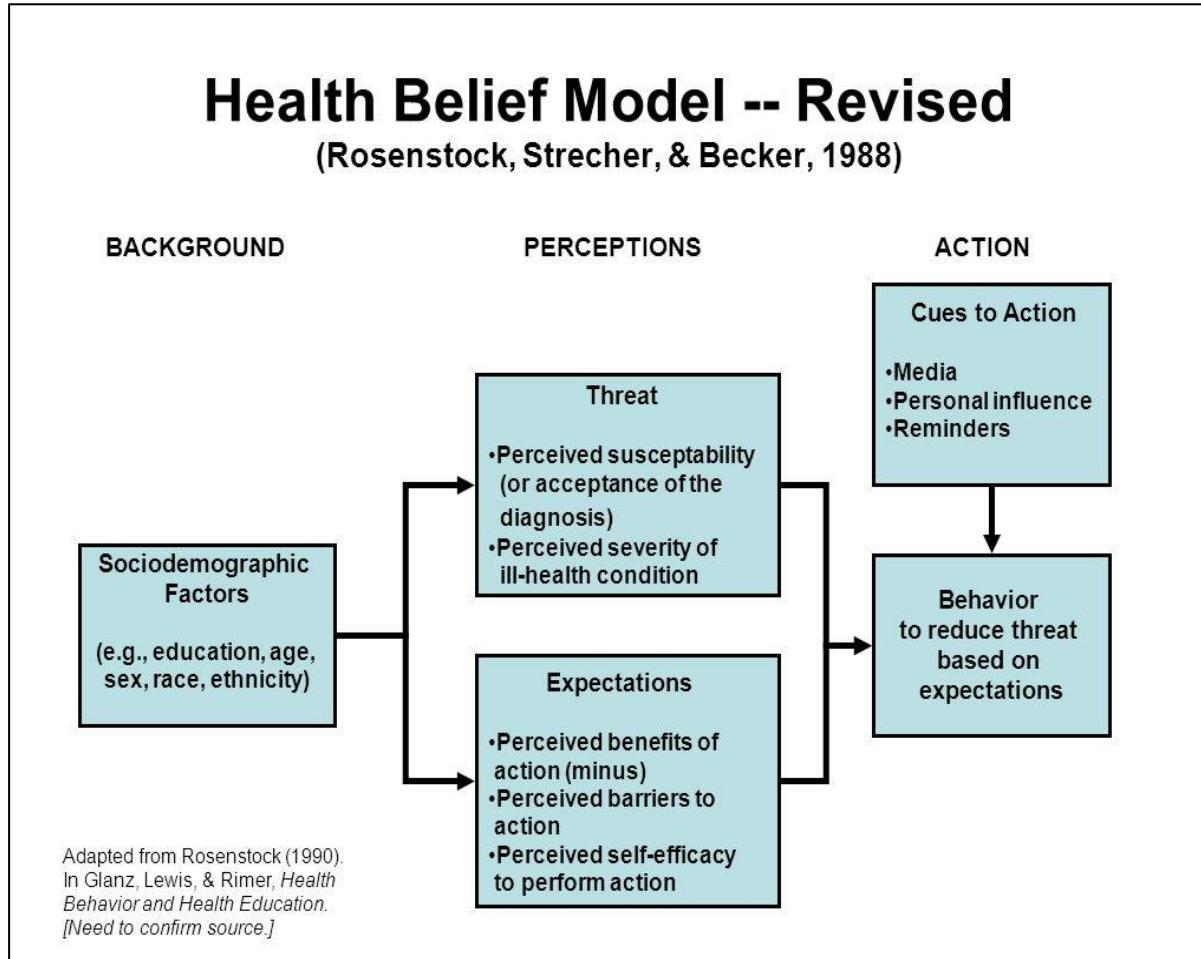


Figure 1.6: Diagram showing the HBM

1.21.4 Theory of Planned Behaviour

The Theory of Planned Behaviour (TPB) was developed by social psychologists and has been widely employed as a tool to aid our understanding of a variety of behaviours, including health behaviours (Ajzen, 1991). The TPB details how the influences upon an individual determine that individual's decision to follow a particular behaviour. Within the TPB, the determinants of behaviour are intentions to engage in that behaviour and perceived behavioural control (PBC) over that behaviour. Intentions represent a person's motivation. The construct is conceptualised as an individual's

conscious plan or decision to exert effort in order to engage in a particular behaviour. Perceived behavioural control is a person's expectancy that performance of the behaviour is within his/her control. Intentions are determined by three variables. The first is attitudes, which are an individual's overall evaluation of the behaviour. The second is subjective norms, which consist of a person's beliefs about whether significant others think he/she should engage in the behaviour. The third measures, the extent to which the individual perceives the behaviour is under their personal control.

According to the TPB, individuals are likely to engage in a health behaviour if they believe that the behaviour will lead to particular outcomes which they value and if they feel that they have the necessary resources and opportunities to perform the behaviour. Conversely, an individual who perceives that he or she does not have a significant degree of control over the performance of a behaviour will make little or no effort towards behaviour change.

The TPB has been used successfully to predict and explain a variety of health behaviours and intentions. These include smoking, contraceptive use, exercise, drinking and health care utilisation (Blanchard et al., 2003; French & Cooke, 2012; Topa & Moriano, 2010;). In addition, the TPB is a useful framework for designing behaviour change interventions and to explicate the mechanisms by which interventions are expected to exert their effects on behaviour (Steinmetz, Knappstein, Ajzen, Schmidt, & Kabst, 2016). In fact, the number of TPB-based behaviour change interventions has grown rapidly in recent years. Meta-analyses summarising the results of interventions in specific-behavioural domains have supported the use of the TPB (Tyson, Covey & Rosenthal, 2014).

However, the utilisation of this theory in the prevention of T2D within the SA population is significantly limited especially investigating RP. While diabetes prevention research using the TPB is lacking in the scientific literature, many studies (mentioned above) have been conducted using this theory to explain and predict behaviour change. Within these studies, the TPB has been proposed as a promising framework for investigating behaviour change.

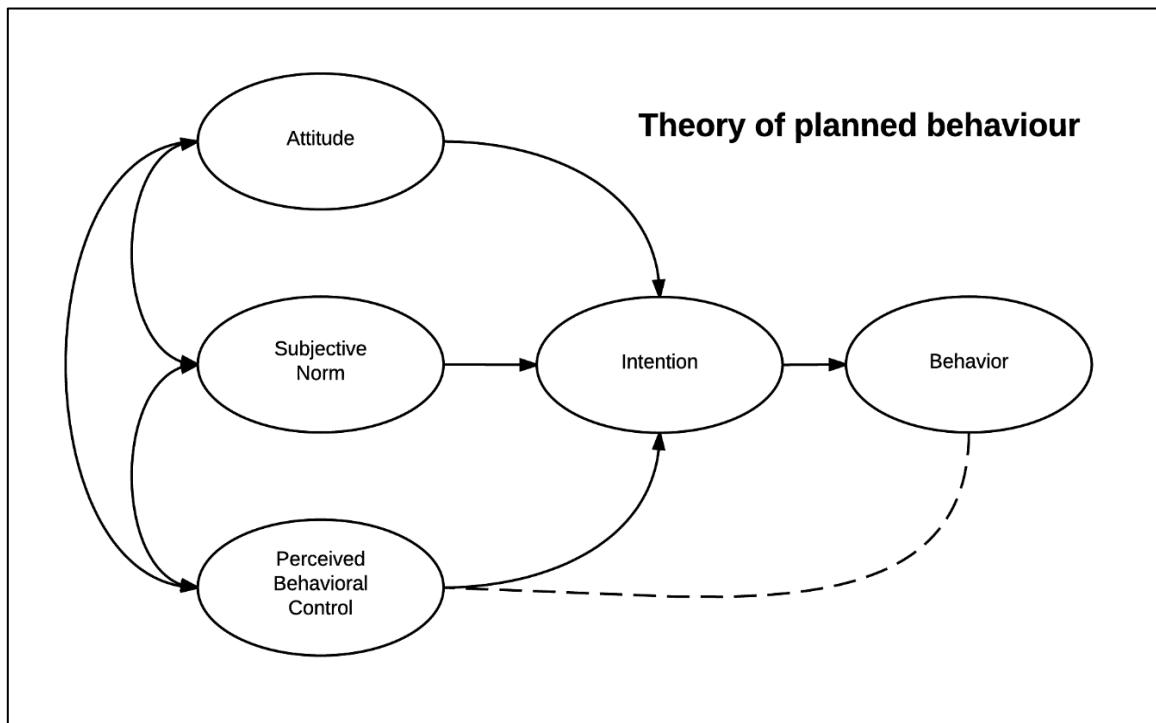


Figure 1.7: Diagram showing the TPB

1.21.5 Rotter's Social Learning Theory

Rotter's Social Learning Theory (SLT) states that an individual's behaviour is a function of their behaviour potential, their expectations and the reinforcement value of that behaviour (Kwasnicka, Dombrowski, White & Sniehotta, 2016). Behaviour potential is the likelihood that an individual will perform a particular behaviour in a given situation. For any situation, there are a variety of behaviours an individual could engage in, and

each behaviour has its own specific potential of occurrence. In other words, how strongly does the individual believe that the behaviour they engage in will lead to what they expect to happen. If an outcome has a low reinforcement value and the individual has a low expectancy, the likelihood that this individual chooses to engage in this behaviour is low, or the behaviour potential is low. However, if an outcome has a high reinforcement value and the individual has a high expectancy that this particular behaviour will lead to the desired outcome, then the likelihood that this individual chooses to engage in this behaviour is high, or the behaviour potential is high.

Rotter defined Locus of Control (LoC) as people's general, cross-sectional beliefs about what determines whether or not they reinforced in life (Kwasnicka et al., 2016). Individuals with an internal locus of control believe that the outcome of a situation is within their own personal control more than it is in the control of external factors. Hence an individual with an internal locus of control is more likely to have a higher expectancy that their particular behaviour will lead to a particular outcome. An individual with an external locus of control believes external factors play a more significant role in the outcome of a situation than internal factors such as their own decisions and actions. Therefore, individuals with an external locus of control are more likely to have a lower expectancy that their behaviour will lead to a particular outcome. In other words, an individual's behaviour outcome could be predicted based on their locus of control, since the degree to which an individual feel that they have control of a situation is related to their expectancy that a particular behaviour will lead to a particular outcome.

Rotter believed that SLT could operate on two specific levels. The first level is situation-specific. The second level is broader in context, in that an individual's behaviour potential could be generalised across situations. Rotter stated that an individual's LoC operated on the latter, broader level, context and could be generalised across situations

(Kwasnicka et al., 2016). An individual's LoC can be classified along a spectrum of internality and externality. In 1966, Rotter developed the I-E (Internality-Externality) Scale, which is used to assess different levels of LoC. Since then, there have been numerous LoC scales that have been developed and have been used in multiple studies worldwide as a predictor of behaviour (Besen et al., 2016; Helmer et al., 2012).

Similar to the HBM and TPB, SLT has been widely used in various research. However, there is limited research on RP (Trujillo, Suarez, Lema & Londono, 2015). Currently, there is no research which investigates the prevention of T2D RP within the SA population.

1.22 Strengths and Limitations

The main strength of the HBM is its use of simplified health-related constructs that can make it easy to implement, apply and test (Connor, 2010). The HBM has provided a useful framework for investigating the cognitive determinants of a wide range of behaviours for over three decades. It has focused on researchers and health care professional's attention on variables that are prerequisites for health behaviour. Hence, it has formed a basis for many practical interventions across a range of behaviours.

The TPB has shown more utility in public health than the HBM. TPB is easy to understand for people with a causal understanding of social science. This occurs because the TPB is a parsimonious approach for understanding the complexity of human behaviour and offers a simple structure between behaviours and their antecedents (Miller, 2017). TPB is popular because it is easily understood and provides clear management implication in applied fields like human dimensions (Ajzen & Fishbein, 1980). Furthermore, TPB has successfully predicted behavioural intentions and informed management. Examples illustrate a strong relationship between the TPB components and

behavioural intentions (Miller, 2017). Collectively, TPB's flexibility, face validity and proven utility show the theory's value.

One of the strengths of SLT is that it offers the ability to relate to real-life examples. It also has the ability to quickly and easily put to use. Furthermore, this theory is very comprehensive. It takes human behaviour, cognition and the environment into consideration as a whole. It addresses reinforcement and punishment along with self-efficacy, motivation and the ways in which an individual works towards obtaining their goal.

All of the theories discussed have a variety of limitations. For example, the predictive capability of the HBM. Results from quantitative reviews of the HBM suggest that the primary variables were significant predictors of health-related behaviour in most cases. However, their effect sizes are usually very small (Abraham & Sheeran, 2005). This suggests that there are other important variables that determine healthy behaviour that has not been accounted for by the HBM. Another limitation of the HBM is that it does not account for normative or cultural factors and because of this, the ability to explain health behaviours in different cultural settings has been questioned.

There are notable reservations about the TPB. For instance, doubt has been cast on the relationships among the components (McCleery, 2009). In TPB, behavioural intentions are immediate antecedents of actual behaviours. Although we often assume this and rely on theory to make the connection, there is a notable paucity of research relating behavioural intentions and behaviours, or even simply measuring behaviours. Without evidence of this relationship, we cannot be confident in the assumption that behavioural intentions lead to behaviours.

Finally, there are limitations for SLT. The theory assumes that changes in the environment will automatically lead to changes in the person, when this may not always be true. The theory is loosely organised, based solely on the dynamic interplay between person, behaviour and environment. It is unclear the extent to which each of these factors into actual behaviour and if one is more influential than another. Therefore, this theory can be broad reaching, so can be difficult to operationalise in entirety.

The HBM, TPB and SLT all provide a logical framework for explaining, predicting and facilitating behavioural change. As discussed in this section, all have also been systematically tested and applied to a variety of preventative and illness-related behaviours. However, they have had limited use in the research concerning the prevention of T2D RP in the SA population. While the intent of this section is not to prove that one model is superior to another, a multi theory approach will be taken using various components from each of these theories to gain a better understanding of prevention of T2D RP within the SA population and certain constructs of these theories will be used in the intervention design. Considering, there has been limited use of these theories in T2D RP in SA population, it is also important to generate a new theory within this PhD, which incorporates the cultural and environmental elements which the HBM, TPB and SLT have been criticised.

1.23 Summary

Recent concerns about the high prevalence of T2D, more specifically in the SA population has led to concerns which require further exploration on how to engage this community in more preventative behaviour

Together the studies reviewed thus far provide important insight into factors that influence RP within the SA population. The current literature helps to understand the

factors that are relevant to the SA population who may be at high risk of developing the condition. However, the evidence base is inconclusive with regards to making recommendations when it comes to health promotion in the UK SA population. Furthermore, simply identifying the factors is not enough, to implement behaviour change it is important to look at the concept of RP in the whole SA population to understand which specific constructs influence their behaviour and then implement strategies for successful behaviour change.

1.3 Prevention of Type 2 Diabetes

This section provides an overview of Public Health Prevention initiatives and considers the role of the various intervention approaches. A specific focus on prevention for T2D is presented with careful consideration given to the current National Diabetes Prevention Programme (NDPP).

1.4 Introduction

The National Health Service (NHS) Five Year Forward View (2014), a strategic document set out a clear direction for the NHS, showing change is needed across healthcare management and delivery. It is proposed that successful delivery of the vision contained within the report required the input of the NHS, local communities, local authorities and employers across the UK. Moreover, the report highlighted the role of health promotion and illness prevention and emphasised the need for effective public health interventions. In particular, this document called for national action on obesity; smoking; diabetes; and workplace health incentives. The aphorism that ‘prevention is better than cure’ (Maruthappu, 2016) continues to grow in relevance. As populations become progressively plagued by multimorbidity and avoidable long-term disorders, the need to prevent illness is increasing. In the UK, almost one in five adults smoke, a third of men and half of the women do not meet the recommended levels of PA, and almost two-thirds are overweight or obese (NHS, 2016). As policymakers and administrators attempt to achieve fiscal sustainability for health systems, drastic changes in prevention to improve population health and moderate service demand are essential. The NHS has launched a triple prevention strategy, which includes initiatives for patients, staff and the public (NHS, 2016). This strategy aims to set an example for other sectors in England as well as for other health systems worldwide.

Many people working in the fields of medical care and public health believe that “prevention has broken down” too often, sometimes because modern science has insufficient knowledge to prevent disease (Grumbach & Bodenheimer, 2005), but more often because society has dedicated insufficient resources and commitment to prevention. However, it appears that prevention has gained momentum in research, application and (for some topics) financial attention.

Primary prevention seeks to avert the occurrence of a disease or injury (e.g. taxes on the sale of cigarettes to reduce their affordability) (Grumbach & Bodenheimer, 2005). Secondary prevention refers to early detection of a disease process and intervention to reverse the condition from progressing (e.g. mammograms for early detection of breast cancer).

The promotion of good health and the prevention of illness encompass three distinct levels or strategies (Grumbach & Bodenheimer, 2005)

1. The first and broadest level includes measures to address the fundamental social determinants of illness; lower income is associated with higher morbidity and mortality rates. Improvement in the standard of living and social equity (through job creations) may have a more significant impact on preventing disease than specific public health programmes or medical services.
2. The second level of prevention involves public health interventions to reduce the incidence of illness in the population as a whole, e.g. the banning of cigarette smoking in the workplace and public health education on HIV prevention in the schools. These strategies generally consist of primary prevention.

3. The third level of prevention involves activities aimed at reducing the incidence of chronic incapacity or recurrences in a population, and thus to reduce the functional consequences of illness, including therapy, rehabilitation techniques or interventions designed to help the patient return to their education, social and cultural life.

1.5 Public Health Prevention Intervention

The following section outlines the overall role of public health preventative intervention, broadly across topics.

Lifestyle-related disease refers to health conditions that are predominately caused by health-risk behaviours, such as poor diet, smoking, high consumption of alcohol, or lack of exercise. The consequences of lifestyle-related disease represent a significant challenge for the individual as well as for society at large (WHO, 2018). In light of these trends, there is a substantial need to advance and implement evidence-based health strategies and interventions that facilitate the identification and management of people at risk of developing health diseases (Larsen et al., 2018).

Public health interventions attempt to improve mental and physical health on a population level. Common types of prevention interventions include screening programmes such as NHS breast screening, NHS bowel cancer screening and NHS diabetic eye screening, vaccinations and health promotion (NHS, 2015). Health interventions run by a variety of organisations, such as NHS and Public Health England (PHE). Such interventions can operate at various scales, such as on a global, country or community level. The whole population can be reached via websites, video messages, and other mass media.

Most health prevention intervention includes one or more of the following components (Hopewell., 2018): education and knowledge building, motivation and community-based techniques to encourage to a change in behaviour (Jepson Harris, Platt & Tannahill, 2010). These interventions can be delivered on three different levels: individuals, community and population-level interventions. Individually targeted interventions are usually aimed at those with an existing ‘risky’ behaviour such as smoking cessation services. Community-level interventions focus on particular population groups such as particular workplace or schools. Finally, population levels tend to rely on the use of mass media activities, policies and legislation such as NHS diabetes screening adverts.

All three levels of prevention interventions are aimed at achieving changes in lifestyle, as well as improving knowledge and influencing attitudes towards positively healthy behaviours. However, there is a need to consider the socio-economic and cultural contexts within which they are located. For instance, an intervention to promote healthy eating within a diverse locality might involve a somewhat different approach from one undertaken in an area of non-diversity.

Jepson & Colleagues (2010) conducted a review of reviews of behaviour change interventions. Although they found the effectiveness of health prevention intervention, this review provided valuable information for future research. They argue that it is not clear whether current health prevention initiatives have absorbed and embedded the ‘determinants’ approach in order to improve the health of those who may benefit the most. For instance, those who are more affluent and have a higher level of formal education are more likely to modify their diets, give up smoking and increase PA than are the less affluent (Vetter, 2005). A mass media campaign to increase walking in Scotland found that it had less appeal for those in the lower socio-economic groups, despite higher

awareness levels among those groups (Wimbush, Macgregor & Fraser, 1998). Furthermore, despite the importance of socio-economic status as a determinant of health, few reviews explored whether interventions had targeted those from a different ethnic background, education, poorest health and gender are only some of the complex factors to the determinants of health. These interventions do not include the most recent psychosocial approaches (Martikainen, Bartley, & Lahelma (2002). In addition to this, the importance of primary prevention interventions, which take account of the context of the lives that an intervention seeks to improve, rather than simply to take a ‘one size fits all’ approach (Jepson et al., 2010). However, there is little evidence at systematic review level that interventions to effect changes in behaviour are tackling the more complex interplay of health, illness and the broader determinants of health.

Some public health interventions focus on changing beliefs using psychological theories such as the HBM. Jones, Smith & Llewellyn (2014) conducted a systematic review to identify studies, which used the HBM as a theoretical basis for intervention design. They found 78% of the studies reported significant improvement in adherence to health promotion. However, there is minimal research that used psychological theories in intervention design. Alageel, Guiliford, McDermott & Wright (2017) conducted a systematic review on multiple behaviour change interventions on CVD, targeting specific behaviours such as diet, PA, weight and smoking, and CVD risk. Out of all the studies included, only 29% used some of the psychological theory, predominately the Transtheoretical Model (Prochaska & Norcross, 2001). Furthermore, the links between the psychological dominants specified by theory and the Behaviour Change Techniques (BCTs) employed in interventions were poorly articulated, with little evidence cited to justify the choice of BCTs to change specific constructs. It was not clear which BCTs were being used to target which behaviours as part of the interventions. This review and

previous reviews (Michie, Jochelson, Markham, & Bridle, 2009; Prestwich et al., 2014) found that reported theory use in intervention design was not as extensive as it could be. Therefore, it is possible that interventions based on other theories or that more explicitly link theoretical constructs to select BCTs might be more effective.

Many interventions may profit from a multi-theories approach for intervention design (Baban & Craciun, 2007). For example, one theory can be used to identify cognitions related to health, while another describes psychological change processes (Kok, Schaalma, Ruiter, Van Empelen & Brug, 2004).

1.6 Targeted Type 2 Diabetes Prevention Programmes

Although broad lifestyle recommendations such as sensible diet, ideal body weight, frequent exercise, and not smoking are helpful, targeted approaches for at-risk patients with specific long-term disorders can yield the most significant results. For example, targeted efforts to prevent T2D have been widely supported. In 2002, a RCT by the US-based Diabetes Prevention Program Research Group showed that lifestyle modification could reduce the incidence of T2D by 58%, compared with a 31% reduction with metformin, over an average follow-up of 2·8 years (Diabetes Prevention Program (DPP), 2002). The intervention was shown to be both safe and cost-effective, and RCT's of similar interventions in several other countries have shown similar results (Sheng et al., 2019).

NHS Five Year Forward View had enabled a National Diabetes Prevention Programme (NDPP) to be established, which enrolled 10,000 people in 2016 and has been scaled upwards since then.

1.6.1 National Diabetes Prevention Programme (NDPP)

The NDPP is a joint commitment from NHS England, PHE and Diabetes UK, to deliver at scale, evidence-based behavioural interventions for individuals identified as being clinically at high risk of developing T2D. The NHS NDPP is being implemented in phases, with plans for 100 000 treated across England by 2020 (NHS, 2016).

Many cases of T2D are preventable, and there is strong evidence that behavioural interventions can significantly reduce the risk of developing diabetes, through weight loss, increasing PA and improve diet (Katz & Meller, 2014). Diabetes treatment currently accounts for around 10% of the annual NHS budget. Therefore, a requirement for the NDPP was needed.

The NDPP is underpinned by three core goals for individuals to achieve: a healthy weight, the achievement of dietary recommendations, and the achievement of Chief Medical Officer (CMO) PA recommendations.

The NDPP is contracted to be made up of at least 13 sessions, with at least 16 hours face-to-face contact time, spread across a minimum of 9 months, with each session lasting between 1 and 2 hours (Penn et al., 2018). People are supported to set and achieve goals and make positive changes to their lifestyle, in order to reduce their risk of developing T2D. Individuals eligible for inclusion have ‘Non-Diabetic Hyperglycaemia’ (NDH), defined as having an HbA1c 42-47 mmol/mol. The blood test result indicating NDH must be within the last 12 months to be eligible for referral. Only individuals aged 18 years or over are eligible for the NDPP.

1.7 Type 2 Diabetes Lifestyle Interventions

This section summarises evidence on diabetes prevention via lifestyle behaviours and reviews both experimental and real-world research and their effects on long term health.

Tackling the increase in T2D is vital to the sustainable future of the NHS. The effectiveness of complex behavioural interventions often referred to as lifestyle interventions to prevent or delay T2D onset was first demonstrated in an RCT in Finland (Finnish Diabetes Prevention Study DPS) (Lindstrom et al., 2003) and the USA (Diabetes Prevention Programme DPP) (Sepah, Jiang, Ellis, McDermott & Peters, 2017). These RCTs were conducted in adults with Impaired Glucose Tolerance (IGT) between 7.8 mmol/L and 11 mmol/L.

The first T2D prevention RCT in England was based on the Finnish (DPS) (Lindstrom et al., 2003). The DPS was aimed to evaluate whether an intensive diet plus exercise programme could prevent or delay T2D. In this large trial, 522 subjects with obesity and IGT were randomised to either the lifestyle intervention group or the control group. The lifestyle intervention involved tailored advice aimed at weight reduction, total and saturated fat intake reduction and increased fibre intake and PA. After four years of intensive intervention, the relative risk reduction was 58%. Seven years after baseline, a 43% reduction in the relative risk and after 13 years from baseline, there was a 38% risk reduction. The US DPP was developed to evaluate the efficacy of both an intensive lifestyle intervention and standard lifestyle recommendation combined with metformin in preventing T2D. A total of 3,234 subjects with elevated fasting plasma glucose concentrations were randomised into one of the three groups: lifestyle modification group, metformin or control group. The lifestyle modification consisted of a 16-lesson curriculum covering diet, exercise and behaviour modification and was aimed to achieve

and maintain a weight reduction of at least 7% of initial body weight. At the end of the study period, the lifestyle intervention reduced diabetes incidence by 58% and metformin by 31% compared to the control group.

Furthermore, in the Netherlands, the study on lifestyle intervention was designed to evaluate the effect of a combined diet and PA intervention programme on glucose tolerance in subjects with IGT (Mensink et al., 2003). A total of 147 subjects were randomised to the lifestyle intervention group or control group. The lifestyle intervention consisted of personal advice on dietary intake, and PA and participants were encouraged to participate in a combined aerobic and resistance exercise programme. This study has shown a 58% reduction in diabetes risk after three years of intervention and a 47% reduction at the end of the intervention.

1.8 Lifestyle Interventions in Real-World Settings

The evidence from studies in experimental settings calls for translation and implementation of DPP in real-world settings to guide diabetes prevention policies (Dunkley et al., 2014). As real-world settings are complex and limited in finances and resources, it is a challenge to implement cost-effective and sustainable interventions. Multiple reviews showed significant reductions in weight but inconclusive results for metabolic indicators of diabetes risk such as blood glucose or HbA1c (Duijzer et al., 2017; Kahn & Davidson, 2014). In 2003-2008, the Finnish National Programme for the prevention of T2D was one of the first large-scale nationwide diabetes prevention programmes in the world. Altogether, 10,149 individuals at high risk of T2D were identified and followed up for one year. The lifestyle intervention consisted of either individual counselling visits or group sessions, focused on weight control, dietary intake and exercise. After a one-year follow-up, weight was on average 1.1kg, waist circumference reduced by 1.3cm, blood pressure decreased. Altogether, 17.5% of the

subjects lost >5% weight. Diabetes risk reduced by 69% in the group who lost >5% weight compared with the group who maintained.

The US NDPP has been translated and implemented in many real-world settings like community environments and health care facilities. Ali, Echouffo-Tcheugui & Williamson (2012) summarised 28 lifestyle interventions that were modelled on the NDPP. These programmes consisted of individual or group sessions, or a combination of both, and the median study duration as twelve months. Across all studies, mean weight change was -3.99% at 12-month follow-up.

To ensure prevention of T2D, lifestyle modifications need to be maintained in the long term (Galaviz et al., 2018). Lifestyle interventions that were conducted in experimental settings have shown that reduced diabetes risk can be sustained over the long term, up to 23 years after baseline (Kahn & Davidson, 2014). However, current evidence for sustainability and long-term benefits in real-world settings are limited (Ali et al., 2012). It has been shown that maintaining weight loss reduced diabetes incidence. However, it is well-known that weight regain is common, even in successful lifestyle interventions. Moreover, there is a range of factors that might facilitate maintenance of behaviour change which includes elements of social support, self-efficacy, comorbidities, lack of time and psychological stress are perceived as barriers for maintenance (Middleton, Anton & Perri, 2013).

Despite the development of preventative programmes such as the UK NDPP, US and Finland DPP, evidence shows that attendance at these programmes is variable (Khunti et al., 2013; Lawal, 2014) and those who attend are mainly referred by healthcare professionals (e.g. in the UK, GPs) (Penn et al., 2018), and as such identification of those at risk of T2D are those often already engaged in healthcare.

Moreover, SA people are less likely to engage in healthcare and preventative behaviours (Ali, Gilani & Patel, 2017; Patel, Phillips-Caeser & Boutin-Foster, 2012). It is plausible to suggest that those most in need of referral to such prevention initiatives are not targeted and aware of such interventions or indeed not aware of their own T2D risk.

There are numerous examples of effective educational programmes that have started to target specific vulnerable groups, such as to include British ethnic minorities (Leung & Stanner, 2011; Szczepura, 2005). However, there is still a gap between delivering these programmes to relevant populations, i.e. South Asians and preventing the onset of T2D. Finucane and McMullen (2008) emphasised some of the main barriers to diabetes interventions such as the teaching style, the design of the resources, strategies to recruit participants and mobility barriers. Furthermore, there are other factors that may influence diabetes care such as theoretical constructs, LoC (Grady & Geller, 2016), self-efficacy (Dehghan et al., 2017) and optimism bias (Rouyard et al., 2017).

Therefore, this PhD explores the gap by tackling perceptions, knowledge and health behaviours of SAs and risk of T2D.

2 Chapter 2: PhD Aims and Objectives

Aims and objectives of this thesis

The primary aims of this thesis were: (1) to understand the complexities of RP in the SA community and reasons for low uptake of prevention interventions in the UK and (2) to develop an intervention for SA general population to assess these complexities, based on identified needs and preferences

Table 2.1: Overall PhD aims and objectives of the thesis.

<u>Aims and objectives of this thesis</u>
Aim 1) To understand the complexities of RP in the SA community and reasons for low uptake of prevention interventions in the UK
Objective 1) Explore SA people's understanding and assessment of T2D risk (Chapter 1, 4, 5, 6).
Achieved through:
<ul style="list-style-type: none"> • Study 1: Grounded Theory (GT) aimed to explore RPs in the lay SAs to understand and recognise the complexity of risk perception. • Study 2: Aimed to examine the relationship between RP and AR among the SA community.
Objective 2) Identify potentially relevant theory and evidence-based related to the role of RP on T2D preventative behaviour (Chapter 1,4,5,6).
Achieved through:
<ul style="list-style-type: none"> • Study 2: Aimed to examine the relationship between RP and AR among the SA community. Study 3: Aimed to develop a GT framework to investigate HLoC and DASS further.
Aim 2) To develop an intervention for SA general population to assess these complexities, based on identified needs and preferences
Objective 3) Explore SA people's needs and preferences regarding an intervention to help them to meet their information needs and the reasons for these perceptions (Chapters 4, 5, 6, 8).
Achieved through:
<ul style="list-style-type: none"> • Study 1: Grounded Theory (GT) aimed to explore RPs in the lay SAs to understand and recognise the complexity of risk perception. • Study 3: Aimed to develop a GT framework to investigate HLoC and DASS further.

Objective 4) Design an intervention based on the identified needs and preferences of SAs (Chapter 9).

Achieved through:

- Study 4: Aimed to identify the preliminary effectiveness of the intervention, to improve RP of T2D in the SA population, with the objective of encouraging intent to engage in preventative behaviours.

Objective 5) Conduct a proof-of-concept to test the intervention with SA people in the community to assess its acceptability and feasibility in practice (Chapter 10).

Achieved through:

- Study 4: The overall aim of this study was to engage key stakeholders in the process of intervention validation, to consider future implications for the intervention, and to offer SA in the community an opportunity to comment on the relevance and acceptance of the intervention in plain English, not using 'NHS-speak' or research jargon.

3 Chapter 3: Methodology

3.1 Chapter Overview

This chapter provides an overview of what constitutes mixed methods research, followed by information on the methodology used within the empirical studies 1-3, detailing the recruitment strategies and analysis techniques implemented across the studies, which make up this PhD thesis:

Study 1 Qualitative; Prevention of T2D in South Asians: A Qualitative Study Exploring Risk Perceptions, Health Beliefs, Values and Community Perspectives.

Study 2 Quantitative; Measuring Comparative Risk Perception of Developing T2D Amongst South Asian and White British Populations.

Study 3: A Mixed-Method Study: Investigating the Dimensions of Locus of Control and Current Psychological State in SA Populations.

Additional information on specific methodological details is provided within each relevant chapter.

3.2 Mixed Methods Design

3.2.1 Theoretical framework

The theoretical framework that has been adopted for this PhD is pragmatism. Pragmatism is seen as ‘debunking concepts such as truth and reality and focuses instead on what works as the truth regarding the research questions under investigation (Tashakkori & Teddlie, 2003). The philosophical theory of pragmatism is seen as a means of bridging the gap between an empirical singular scientific approach to research and the newer ‘freewheeling’ inquiry of qualitative research theories. A theoretical framework such as pragmatism can be pivotal to the conduct of research as it focuses on the logical link between the two paradigms of inquiry; quantitative and qualitative.

Tashakkori and Teddlie (2003) defined mixed methods research simply as the research design in which qualitative and quantitative approaches are used in types of questions, research methods, data collection, analysis procedures and inferences within a single study. It is important to understand that there are different terms used in the literature to describe this approach, such as multimethod, mixed methodology (Azorin & Cameron, 2010). However, in recent literature, the term ‘mixed-methods’ is used and has been used in this thesis (Tariq & Woodman, 2013).

Mixed methods research is an emerging dominant paradigm in health care research (Rapport & Braithwaite, 2018). It has been described as the third paradigm, often called pragmatism (Johnson & Onwuegbuzie, 2004). Paradigm is defined by Morgan (2007) as the set of beliefs and practices that guide a field and most commonly associated with four distinct elements that are used to compare different paradigms. These elements include Epistemology (how we know what we know), Ontology (nature of reality), Axiology (values) and Methodology (the process of research). Traditionally, researchers proposed that constructivism and/or interpretivism (qualitative) and positivism

(quantitative) are paradigms that have different views, each with a distinct epistemological stance and framework (Morgan, 2007). Many believe that these paradigms cannot be mixed or combined because of those distinct difference (Holloway & Wheeler, 2010). According to Morgan (2007), the pragmatism approach offers a new framework that does not necessarily reject the two paradigms of positivism and constructivism. Instead, it shows how this approach offers opportunities for advancing our knowledge and research practice. Despite the debates about the issues surrounding mixed methods research, this had become a popular approach (Morgan, 2007) within the last decade, particularly in healthcare (Teddlie & Tashakkori, 2009).

It is believed that the problems that are addressed by social and health scientists are complex. The use of either quantitative or qualitative research individually is not adequate enough to address this complexity (Creswell, 2003). The combined use of methods provides a practical and outcome-oriented method of inquiry producing superior research compared to monomethod studies and an expanded understanding of research problems (Creswell, 2003). This has enormous potential in healthcare research where there are many different and complex factors that can influence health.

3.2.2 Justification for Methodology

A mixed methodology is widespread in health services research as it allows for the exploration of issues from a range of perspectives (Tariq & Woodman, 2013). Research that builds on the health needs expressed by a population group being studied, i.e. T2D prevention, is relevant when the objective is to evaluate or develop health services (Tritter, 2007). Health outcomes can no longer be understood by medical and/or pharmaceutical interventions alone; individual participation in health care decisions means that health can be managed better or more successfully (Tritter, 2007). Measuring an individual's health care outcomes as well as understanding their beliefs and

expectations about their health should enable the development of more effective healthcare service (NICE, 2012). As mentioned earlier, the use of either quantitative or qualitative research is inadequate to address the complex problems that social and health science encounter every day (Creswell, 2003). This is particularly true in complex conditions such as T2D. Clinical knowledge must be integrated with social science expertise and other disciplines in order to explore and understand contemporary health care (Tritter, 2007). Both qualitative and quantitative research, in mixed methods research, contribute to clinical practice (Holloway & Wheeler, 2010) and provide knowledge that could be used to determine health care policies (Rapport & Braithwaite, 2018).

Doyle et al. (2009) state that choosing an appropriate design for a mixed-methods study depends on a) which approach is best suited to answering the particular research question, b) the overall motivation for pursuing a mixed methods study and c) which typology is most appropriate to meet the aims and objectives of the research.

Taking the above into account, a mixed-methods approach was used in this thesis as it has the potential to harness the strengths and counterbalance the weaknesses of both approaches and can be especially powerful when addressing complex, multifaceted issues such as health services interventions.

3.3 Types of Mixed Methods Designs – Sequential Embedded Design

There is a range of mixed methods design to choose (For example, Triangulation, Embedded, Explanatory and Exploratory). Creswell & Plano-Clark (2017) have proposed four main types of mixed-method design. The studies in this thesis 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-Clark, 2017). The rationale for this design is that one single data set is not sufficient, that different questions need to be answered and that each type of question requires different types of data. One of the advantages of using this design is that it enables embedding a qualitative study within a larger quantitative design. This design is particularly useful for studies under time and resource constraints and where one method requires less data than the other method. For example, in some of the studies in this thesis, the data gathered using qualitative interviews, were based on a relatively small number of participants, to generate in-depth information in response to the questions on the interview topic guide. The purpose of the sequential embedded design is to keep the two sets of results separate in their reports. However, Creswell (2003) suggests that the conclusions and interpretation phase of the design should comment on how the qualitative findings have helped to elaborate on or extend the quantitative results.

For the purpose of this PhD Creswell's (2003) definition of mixed-method theory, an inquiry was utilised as it incorporates a philosophical worldview, pragmatism and accommodates the notion of mixed methods as a methodology whilst stressing the importance of method. The fundamental principle of mixed methods research is that the combination of qualitative and quantitative approaches provides a better understanding of the problem than either approach can achieve alone (Creswell & Plano Clark, 2017). Support of this central concept can be made in several areas. Firstly, mixed methods strengthen empirical research findings, addressing the weaknesses of both quantitative and qualitative methodology when conducted separately.

The aim of this PhD was to investigate the risk of T2D within the UK SA population and lead to the development of a new intervention. The MRC framework (Craig et al., 2008) was applied as a strategy across this PhD. The MRC framework provides guidance to researchers on the process for developing and evaluating

interventions that contain several components. The aim of the framework is to ensure that interventions are empirically and theoretically founded and that considerations are given both to the effectiveness of the intervention and how it works. Therefore, the following studies in this PhD attempt to follow this framework in developing a complex intervention.

This PhD ensured a thorough investigation of and offered a rigorous approach to evaluate the complex issues of T2D RP. The PhD consists of a significant contribution to new knowledge through the implementation of the sequential embedded design of mixed methods empirical studies.

Table 3.1: Titles of all the PhD studies

Study	Titles
Study 1	A Qualitative Study: Prevention of T2D in South Asians: A Qualitative Study Exploring Risk Perceptions, Health Beliefs, Values and Community Perspectives.
Study 2	A Quantitative Study: Measuring Comparative Risk Perception of Developing T2D Amongst South Asian and White Caucasian Populations.
Study 3	A Mixed-Method Study: Investigating the Dimensions of Locus of Control and Current Psychological State in South Asian Population.
Study 4 a & b	A Two-Part Study: 4A: A Proof-of-Concept Study investigating A Risk Perception Video Intervention Designed for Diabetes Prevention in South Asian Community. 4B: Exploring the Acceptability of a Risk Perception Video Intervention Designed for Diabetes Prevention in South Asian Community

3.4 Ethical Approval

Ethical approval was sought for all research studies conducted within this PhD. Approval was granted by Liverpool John Moores Ethical Committee. As a PhD student for Psychology, it is noteworthy that the British Psychological Society Code of Ethics and Conduct (2018) was adhered to throughout.

See Table 3.2 below detailing where further information on the ethical applications and approvals can be found in the relevant appendices.

Table 3.2: Liverpool John Moores University Ethical Approval

Empirical research	Chapter	Ethical Committee Reference No.	Appendix
Study 1	Chapter 4	16/NSP/005	3.1
Study 2	Chapter 5	17/NSP/022	3.5
Study 3	Chapter 6	18/NSP/070	3.10
Study 4 (a&b)	Chapter 10	19/NSP/012	3.13

The overall aim of research ethics is to protect the welfare of research participants. This section outlines the ethical considerations undertaken for this PhD. During this PhD, there were no ethical concerns or issues raised whilst conducting or following the studies.

Examples of ethical concepts adhered to:

3.4.1 Informed Consent

It is the duty of the researcher to protect their participants from any harm or loss (Willig, 2013). A crucial part of any study is to inform participants about the purpose of the study. All participants were provided with a Participant Information Sheet (PIS), fully informing them of the study they were about to take part in. Each PIS outlined the

purpose of the research study, the procedures involved and all foreseeable risks to the participant. Participants were asked to indicate informed consent. Consent was ascertained verbally prior to qualitative interviews, consent forms were signed if quantitative studies were conducted via paper version, or implied consent if conducted online (through agreement to continue with the questionnaire and submit upon completion). All paperwork (e.g. Signed consent forms) were initially retained and kept in a locked filing cabinet, prior to scanning and storing digitally (upon which hard copies were destroyed). All digital data/files (e.g. interview transcripts, were originally digitally recorded and subsequently transcribed verbatim), which were stored on a password-protected laptop and to protect the anonymity of participants pseudonyms replaced any real names provided.

3.4.2 Debrief

Upon completion of the study, participants were provided with debriefing information. For qualitative interviews, upon completion, the participants were also given the opportunity to ask questions or clarify any comments in relation to the interview.

3.4.3 Withdrawal

Participants had the right to withdraw from the research studies at any time during the data collection process without reason.

3.4.4 Confidentiality & Anonymity

For the quantitative studies, the researcher collected some demographic data such as postcode. However, to keep anonymity, participants were asked to give postcode areas instead of the whole postcode. Overall, the collection of demographic information was limited.

For qualitative research, distinguishing accurately between confidentiality and anonymity is an 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. Participants names and the data obtained was kept anonymous. Pseudonyms were given to the participants within the transcripts. The signed consent forms, audio recordings and transcribed interview remain with the research team for five years, and after that, they will be destroyed. The participants were made fully aware that the findings from the research were to be discussed within the research team, and anonymous quotes may be used as evidence in the PhD thesis or conference/publications.

3.5 Quantitative Methodology Overview

Quantitative research was conducted in studies 2, 3, and 4a. The following section outlines the main methodological information for each of these studies.

3.6 Participant Samples

The inclusion criteria for quantitative research was as follows:

- SA men and women from any of the sub-ethnic groups (as described in Chapter 1.7) who were over the age of 18 years old.
- No diagnosis of T2D (or any diabetes type)
- Residing in the UK
- Literate in English or any of the three main SA languages: Hindi, Urdu and Gujarati commonly spoken/used in this ethnic group.

Exclusion Criteria

- Those who were not mentally capable of consenting to participate and notable to read/write.
- Not currently diagnosed with any mental health conditions

3.7 Recruitment Procedures

Due to the nature of SA participation in research, it has been recommended that several methods of recruitment should be employed to maximise the chances of recruiting SAs into research (Lloyd et al., 2008).

3.7.1 Sampling

Purposive sampling (Palinkas, Horwitz & Hoagwood, 2015) involves selecting participants based on the researcher's judgement and knowledge about which population or participants will be most suitable for the phenomena under study. For this PhD, SAs and White participants living in the UK without T2D were purposively chosen with the

assumption that they are likely to have beliefs and experiences related to the research question. To ensure the data was representative of the UK population (Census, 2011), participants were recruited from a range of SA subgroups (e.g. Indian, Pakistani and Bangladeshi), locations which represented the main populations such as Manchester, Bolton, Blackburn and Preston and recruitment occurred through a variety of techniques (e.g. face to face, and online) to enhance variability of the sample.

Online search engines were used to search for local SA community groups. Direct contact with local businesses owned or managed by SAs for information on local community groups was also made. Informal contact was made with leaders of several community groups (e.g. exercise groups, lunch clubs, day centres, awareness days and places of worship; mosques and temples) in Greater Manchester and Lancashire (Bury, Wilmslow, Whalley Range, Blackburn, and Preston) to ask if they would be willing to introduce the researcher to their group members in order for the researcher to inform them about the studies. Copies of the PIS and a gatekeeper consent form was emailed to the group leaders or personally given during the initial meeting. Once the group leaders agreed, the group members were verbally informed about the study and those interested in taking part were handed a copy of the PIS.

A snowball technique (Johnson, 2014) was used whereby people, who had friends or family 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 SA population and other hard to reach groups (Rankin & Bhopal, 2001). Participants who completed Study 3, quantitative ($n = 99$) were given the opportunity to participate in the follow-up qualitative study ($n = 11$).

In addition, in line with person-based research approaches (Yardley et al., 2015), participants from Study 1 were invited to co-design and support the development and feasibility testing of the intervention development (as presented in Study 4, Chapter 10).

3.8 Study Participants

A total of 489 participants have been recruited to studies contained within this PhD thesis. Overall, the study sample is deemed representative of the UK SA and White populations, as described within the most recent UK Census data (2011).

Table 3.3: Overall PhD sample characteristics

		Study 1	Study 2	Study 3	Study 3 Qual	Study 4a	Study 4b	Total
Age								
	Mean	38 Years	37 Years	36 Years	45 Years	34 Years	43 Years	38 Years
Gender								
	Male	10	105	65	6	58	12	256
	Female	10	104	34	5	62	18	233
Ethnicity								
	SA Indian	11	42	60	6	58	12	189
	SA Pakistani	5	37	28	3	39	9	121
	SA Bangladeshi	4	35	11	2	23	9	84
	Whites	0	95	0	0	0	0	95
Religion								
	Christianity	0	76	0	0	0	0	76
	Islam	16	100	81	8	120	30	355
	Hinduism	4	14	18	3	0	0	39
	Atheism	0	16	0	0	0	0	16
	Prefer Not to Say	0	3	0	0	0	0	3

Details of specific participant information are provided within each of the individual study chapters.

3.9 Materials

3.9.1 Demographic Information.

Participants were asked some basic demographic questions: gender, age, ethnic background, religious beliefs and education levels.

3.9.2 Risk Perception Survey – Developing Diabetes (RPS-DD).

This questionnaire was used in Studies 2, 3 & 4a. RP was assessed using the validated Risk Perception Survey of Developing Diabetes (RPS-DD) questionnaire (Walker et al., 2003). The RPS-DD comprised 53 items, including five subscales: Personal Disease Risk scale subscale, Environmental Health Risk scale, Personal Control subscale, Optimistic Bias subscale and Worry subscale. A single item in the Personal Disease Risk scale measures perceived risk for developing diabetes. The remaining items in this scale measure RP of other chronic conditions. The Likert responses options to all items in this scale, assigned numerical values from 1 to 4 are levels of perceived risk. “Almost No Risk”, “Slight Risk”, “Moderate Risk”, and “High Risk”. The scale is scored as the average of the items. A higher score is interpreted as a higher perceived risk to developing a chronic condition such as T2D. In a similar manner, the Environmental Health Risk scale measures perceptions of risk to health, due to environmental health hazards.

Three subscales measure general attitudes that may modify RP for developing T2D: Personal Control subscale, Optimistic Bias subscale and Worry subscale. The Likert responses to these subscales, assigned numerical values from 1 to 4, are “Strongly Agree”, “Agree”, “Disagree”, and “Strongly Disagree”. Each subscale is scored as the average of

the items, and a higher score is interpreted as a higher level of agreement with the assessed factor.

The RPS-DD questionnaire has been the primary source of data collection in similar studies and demonstrates internal reliability (Pinelli et al., 2009; Walker et al., 2003). A total RP score was calculated by adding together each of the scores for the subscales. A high score on the internal consistency reliability for the five subscales was assessed in this new population via Cronbach α coefficients.

Table 3.4: Cronbach α coefficients for RPS-DD

Constructs	α
Personal Control	.67
Worry	.61
Optimistic Bias	.81
Personal Disease Risk	.91
Comparative Environmental Risk	.81

This questionnaire has been widely used across the field of RP, diabetes and health conditions (Joiner et al., 2017; Pinelli, Berlie, Slaughter & Jaber, 2009) (see appendix 3.20).

3.9.3 Diabetes UK Risk Assessment Tool for Diabetes (DUK).

This questionnaire was used in Study 2. The Diabetes UK Know Your Risk tool (Diabetes UK, 2016) aims to help individuals find out their risk of developing T2D. The NICE (2012) public health guidance “Preventing T2D: risk identification and interventions for individuals at high risk”, recommended that GP’s and other primary

health professionals use the tool for identifying people at risk of developing T2D. The “Know your Risk Tool” asked 7 questions on gender, age, ethnicity, family history, waist measurement, blood pressure, and BMI. BMI was calculated from self-reported height and weight and then categorised in accordance with BMI criteria as stated within NICE guidelines (NICE, 2014, p. 9-14). The AR scores categorised individuals as follows: 0-6 indicated Low Risk; 7-15 indicated Increased Risk; 16-24 indicated Moderate Risk, and 25-47 indicated High Risk.

This DUK risk assessment is currently used in health services. However, it is also used in various research (O’Dowd, 2015; Penn et al., 2018). This AR tool is evidence-based and has been used in research and clinical practice. It has been used to identify those at clinical risk of impaired glucose regulation and T2D in UK multi-ethnic populations (Gray et al., 2010; NICE, 2018).

3.9.4 Multidimensional Health Locus of Control (MHLC).

This questionnaire was used in Studies 3 & 4a. The MHLC scale (Wallston, Wallston & DeVellis, 1978) is designed to assess the degree to which an individual feel that they are in control of their own health. The MHLC gives individuals a series of 18 statements and asks them to rate how strongly they agree or disagree with these statements. The Health Locus of Control (HLoC) scale consisted of 18 items, split into the five dimensions, which were: 1) internal HLoC (I-HLoC); 2) Doctor (D-HLoC); 3) Powerful Others (P-HLoC); 4) Chance (C-HLoC); and 5) and Other People (OP-HLoC). The Internal subscale (I-HLoC) measured the strength of the belief that the respondent’s health was the result of their own behaviours. Higher scores on the internal subscale indicated a more Internal Health Locus of Control. Lower scores on the Internal subscale indicated a more External Health Locus of Control or stronger belief that the respondent’s health was determined by factors aside from themselves. The P-HLoC subscale measured

the degree to which the respondent believed health was controlled by individuals seen as “powerful others”, such as clinicians or a higher power (e.g. God). Higher scores on P-HLoC indicated a stronger belief in external control of health by such influential forces. The C-HLoC indicated the degree to which the respondent believed that health was out of his or her control. Higher scores on both the P-HLoC and C-HLoC subscales represented a more External Health Locus of Control, while lower scores on the P-HLoC and C-HLoC indicated a more Internal Health Locus of Control. Finally, the D-HLoC scales measured the degree to which the respondent believed health was controlled by their doctor and if they have any existing conditions then that would be managed by their doctor over themselves, which represented an external locus of control. This questionnaire is one of the effective tools to be used when assessing HLoC (Kassianos, Symeou & Loannou, 2016; Ross, Ross, Short & Cataldo, 2015) (see appendix 3.18). The MHLC has been shown to demonstrate high reliability; Internal ($\alpha = .70$); Doctor ($\alpha = .77$); Powerful Others ($\alpha = .88$); Chance ($\alpha = .85$) and Other People ($\alpha = .79$).

3.9.5 Depression and Anxiety Stress Scale 21 (DASS-21).

This questionnaire was used in Study 3. The DASS-21 (Lovibond & Lovibond, 1995) was used to measure depression, anxiety and stress among the SA participants. This tool has been widely used when assessing depression, anxiety and stress (Lu et al., 2018; Osman et al., 2012). The DASS-21 is a 21-item self-report scale that measures three dimensions: Depression, Anxiety and Stress. The Depression scale assessed dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The Anxiety scale assessed autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The Stress scale was sensitive to levels of chronic non-specific arousal. It assessed difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive and impatient.

Participants were asked to use 4-point severity/frequency scales to rate the extent to which they had experienced each state *over the past week*. Scores for Depression, Anxiety and Stress were calculated by summing the scores for the relevant items. The scales of the DASS have been shown to have high internal reliability; Stress ($\alpha = .87$); Anxiety ($\alpha = .80$) and Depression ($\alpha = .85$). This internal consistency shows that DASS-21 can distinguish between anxiety and depression relative to other existing measures (see appendix 3.19).

3.9.6 Diabetes, Intention, Attitude and Behaviour Questionnaire (DIAB-Q).

This questionnaire was used in Study 4a and has been widely used across healthy lifestyle behaviours (Traina, Mathias, Colwell, Crosby & Abraham, 2016). DIAB-Q (Traina et al., 2016) was developed as an instrument to evaluate T2D behaviours. The DIAB-Q was designed to assess six psychological constructs related to PA, dietary behaviour and weight loss, as well as assessing the following current behaviour patterns: 1) Subjective Norm (items 5, 11 and 16), 2) Attitude (items 4, 10 and 15), 3) Perceived Behavioural Control (PBC) (items 6, 12 and 17), 4) Intention (items 2, 8 and 13), 5) Planning (items 3, 9 and 14) and 6) Behaviour (items 1 and 7). The DIAB-Q includes 17 items covering six psychological constructs and the recall period includes the past week and responses are rated on a seven-point scales (e.g. strongly disagree to strongly agree). Raw scores are calculated as the sum of the individual item scores. Scores are then transformed to a 0-100 scale, with higher scores indicated higher levels of engagement in beneficial behaviours. All six scales met the 0.6 + criterion for Cronbach's alpha (range 0.71-0.90) (Taber, 2018) (see appendix 3.21).

3.10 Data Analysis

The quantitative data analysis occurred during and after the quantitative phase of the various studies. Quantitative data from survey instruments were individually scored

using the relevant scoring tool as instructed. Numerical data were described using Means (M) and Standard Deviations (SD) when approximately normally distributed and using Medium and Inter-Quartile Range (IQR) when skewed. Categorical variables were reported by percentages. Statistical analyses were conducted using Statistical Package for the Social Sciences (SPSS) (Version 25, IBM Corp, 2016). Comparisons between demographics and other characteristics were conducted using independent t-tests (Kim, 2015), analysis of variance (Kaufmann & Schering, 2014), Pearson's and Spearman's correlation coefficients (Schober, Boer & Schwarte, 2018), Manova and One-Way repeated Manova (Pillai, 2014). In statistical hypothesis testing, the p-value or probability value of 0.05 was used as a cut-off for significance. If the p-value is less than 0.05, we rejected the null hypothesis, that there was no difference between the means, and concluded that a significant difference did exist.

Cronbach's alpha is the most common measure of internal consistency (reliability). It is most commonly used when you have multiple Likert questions in a survey/questionnaire that form a scale and wish to determine if the scale is reliable. For each of the questionnaires in the studies, the relevant Cronbach's alpha is reported (see individual study methodology chapters).

3.11 Qualitative Methodology Overview

Qualitative research involves the collection, analysis and interpretation of data that are not easily reduced to numbers. The purpose of qualitative research is to explore and describe participants understanding and interpretation of a social phenomenon under research (Ritchie & 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 the health behaviours of the SA population in the UK.

There are many qualitative approaches; therefore, it was important to identify which approach was most suitable for the research question in line with the purpose of the qualitative research, the role of the researcher and the method of data analysis (Wright, O’Brien, Nimmon, Law & Mylopoulos, 2016).

Table 3.5: Different Qualitative approaches

Methods	Outline of approach	Strengths	Weaknesses
Narrative Summary	Narrative description and ordering of primary evidence with commentary and interpretation	Can cope with a large evidence base. Could be used for theory-building.	Lack of transparency. Many variants and the absence of procedures/standards.
Thematic Analysis (Braun & Clarke, 2006)	Identification of major recurrent themes in literature; summary of findings of primary studies under these thematic headings.	Flexible procedures for the reviewers. Copes well with diverse evidence types and could be used for theory-building.	Lack of transparency regarding process decisions. The largely descriptive basis to groupings, not necessarily developing theory.
Grounded Theory (Glaser & Strauss, 1968)	Constant comparison method identifies patterns and interrelations in primary data. Sampling responds to analysis until theoretical saturation is reached.	Seeks generalised explanations/theories. Development of theory from findings. Provides novel evidence in different areas.	A possible criticism of a lack of transparency. Time – consuming process.
Meta-ethnography (Atkins et al., 2008)	The reciprocal translational analysis identifies key themes in each study, then seeks to translate these into the context of each other study.	Seeks higher-order (generalised) theories. Use with a diverse evidence base.	Does not guide sampling. Maybe order-of-synthesis effects.

3.12 Qualitative Methodology Choice

Grounded Theory (GT) (Strauss & Corbin, 1990) was chosen as the methodology as it provides for the systematic generation of theory from data acquired by a rigorous research method (Glaser & Strauss, 1967). GT was attractive as in contrast to other methodologies, as it aims to move beyond detailed description to produce theory grounded in the data generated by participants. Like other qualitative methodologies, GT emphasises understanding the ‘voice’ of the participant but is distinct in that it then uses this to build a theory about phenomena. According to Strauss & Corbin (1990), GT is an approach for looking systematically at qualitative data to generate a theory, which consists of coding and theoretical sampling. It was considered that the appropriate research methodology needed to have processes for gathering, analysing and presenting data that agreed with the research questions. Therefore, this choice was also based on the research questions and aims, the viability of using such a methodology within a specific research context and the specific guidelines for data analysis it offers. Employing GT helped produce a framework that could explain RP in the SA population by exploring the participant's views and beliefs. GT was developed by Glaser and Strauss (1967) as a methodology to build theory from data in their studies. They reported that theory emerged from data following the careful utilisation of the GT method of analysis. However, Strauss and Corbin (1990) moved away from this emphasis on the emergence and argued instead that the theory is constructed by the researcher after close engagement with the data. Furthermore, the recent work of Charmaz (2006) who came up with the constructivist GT approach has also been influential. Despite the variations between grounded theorists over the years, the core principles of the method have remained unchanged. The constant comparison method is a significant characteristic of GT as it entails the text to be compared and contrasted systematically. Data is collected continuously, and analysis is done immediately until saturation of the data has occurred. According to Strauss and Corbin (1990), theoretical

saturation is the point at which no new insights are obtained, no new themes are identified, and no issues arise regarding a category of data. Once this has occurred, this develops a theoretical model from the data.

3.13 Theoretical Sample

Strauss & Corbin (1998) refers to theoretical sampling as the process of sampling participants that can contribute to the creation and selection of pertinent information related to the central phenomenon. Therefore, theoretical sampling procedures dictate the selection of participants based on the evolving patterns, categories and dimensions emerging from the data. In the present studies, the researcher used participants background/demographics to select participants that were able to confirm, extend and sharpen the analytical patterns, categories and dimensions. By doing so, the researcher has chosen ‘experts’ who were able to provide the best data available concerning the phenomenon (Strauss & Corbin, 1998). Theoretical sampling also guided the questions used to collect data from the semi-structured interviews. The data emerged from these discussions were used to develop further the explanatory framework detailing the central phenomenon.

Following the GT methodology, participants were sampled until theoretical saturation of all of the categories was achieved. According to Strauss and Corbin (1990), saturation is reached when further data collection and coding becomes redundant and fails to contribute any further dimensions to the studies categories. As a general guideline, sufficient sampling includes 20 to 30 individuals to form an in-depth theory (Corbin & Strauss, 2008). When the qualitative studies were proposed, estimated 20-25 interviews were initially planned. However, by the time the last interviews were completed and analysed, all of the data they contained could be accounted for by the existing codes and categories that had been developed. Therefore, data collection stopped after the completion of the 20th interview for Study 1 and 11th interview

for Study 3, which concluded that additional interviews did not seem to be significantly adding to the development of a model.

3.14 Research Design

In qualitative research, there are a number of data collection techniques that can be used, for example, observations, focus groups, case study and interviews.

For the purposes of the qualitative studies (1 & 3b), interviews were deemed the most appropriate. Interviews have commonly been used to explore a wide range of illnesses in health research (Arksey & Knight, 1999). The focus is on the participant, which can enable the exploration of topics depth.

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 survey design, whereby the interview format follows a specified set of questions, in a specific order to generate comparable answers from participants. In-depth interviews are less structured, covering one or two issues in-depth at most. Semi-structured interviews are widely used to uncover and explore the meanings that underpin people's lives, behaviours, routines and feelings in relation to health. One-to-one researcher-participant interviews can be personal and informative, and the process can be flexible to meet the needs of the researcher and the participant. In this PhD studies, semi-structured interviews were chosen to obtain data. Semi-structured interviews are more informal and allow for a topic guide with key questions and probes to guide the interview. Furthermore, semi-structured interviews also help to uncover the 'insiders' perspective and enable the interviewees to define social phenomena from their own perspective and experiences.

3.15 Data Analysis: Grounded Theory

GT methodology and analysis (Strauss & Corbin, 1990) was applied throughout studies 1 & 3. The GT process adopted simultaneous data collection and analysis, leading to theoretical saturation (Strauss & Corbin, 1998).

The data analysis for GT comprised of three stages of coding 1) Open coding, 2) Axial coding and 3) Selective coding, whilst the coding process occurred, concepts were derived whereby similar themes were grouped and then these concepts were regrouped to find categories, which led to the development of theory. This research adopted Strauss and Corbin's (1990) approach, as follows:

1. **Open Coding:** Is the part of the data analysis concerned with identifying, naming, categorising and describing the phenomena (Leedy & Ormod, 2001). The goal is to thoroughly examine the categories and select those that are most saturated within the information to create the core category (Creswell, 2014). Primarily, for each interview studies 1 & 3b, the researcher read each line, sentence, and paragraphs of participants transcript to construct abstract and concrete categories that build towards the development of a theory. The transcripts were re-read to make comparisons and similarities between the text. After each interview, the researcher had discussions with the DoS and reflected on each interview (see appendix 3.22).
2. **Axial Coding:** This was conducted to learn more about the core category. The researcher examined the data to look at events or variable that led to the occurrence of the core category. The goal is to relate categories and their properties to one another to deepen the understanding of the central phenomenon. Thus, the researcher was situated between open coding and axial coding to redefine categories to create generic relationships among them that best described the central phenomenon.

3. **Selective Coding:** Entails systematically relating the core category to other categories and their interrelationships to create an explanatory framework of the phenomenon under investigation. The researcher “moved back and forth” among transcripts, open coding and axial coding to refine categories and interrelationships that depict central variables. The basic idea is to develop a theory around which everything else is arranged.

The researcher using Microsoft Word completed all transcription of individual interviews and coding. The researcher used coding techniques, and highlighted text to aid in moving raw data through successive levels of abstraction. Furthermore, after each interview, the researcher wrote a case-based memo and discussed with the supervisory team. In these memos, the researcher reflected on what he had learnt from the interview, feelings, thoughts and any other useful information. Once the data analysis was complete, each study produced a GT framework (Chapters 4 & 6).

3.16 Research reflexivity; Reliability and Validity

To assess the reliability and validity of qualitative research is challenging. However, qualitative researchers such as Lincoln & Guba (1985) have described ways to achieve ‘trustworthiness’ by adopting four methods: Credibility, Transferability, Dependability and Conformability (See Table 3.6). The aforementioned components were considered throughout to ensure research quality.

Table 3.6: Reliability and Validity of Qualitative research

Credibility	The interviews were audio-recorded and were transcribed verbatim. Triangulation (method to increase the credibility of research findings) occurred between researcher and research team by discussing interviews and the creation of codes throughout the interviews.
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	<p>The research team were of mixed ethnicity and gender. The triangulation of views and expertise has enhanced the methodological and analytical credibility of this research:</p> <p>As lead researcher, a SA male in addition to conducting this PhD was employed to work on the NDPP training health professionals and engaging with community members identified as at risk for T2D</p> <p>A supervisory team consisting of Director of Studies (DoS), a White female, registered Health Psychologist with expertise in qualitative methodology and research interest in diabetes; Second Supervisor, a black male, Charted Psychologist and; Third supervisor, a White female, Reader in Dietetics, both with interest in diabetes. A female SA colleague, a PhD student (Tasneem Patel) with specific expertise in GT methodology and T2D, also supported the analytical procedures.</p> <p>It is noteworthy that none of the research team was diagnosed with T2D themselves, although all were aware of their T2D risk. Some of the research team had family members with T1D or T2D, or experience with gestational diabetes.</p> <p>A process of reflexivity and audited discussions occurred throughout the process to ensure rigour in the quality of analysis conducted.</p>
Conformability	<p>Analysis of each transcript was done as soon as possible, and case-based memos were written after each interview. The lead researcher documented the procedures for checking and rechecking the data throughout the study. This was addressed by adopting an iterative process to data collection analysis, peer debriefing, and identifying</p>

	deviant cases. Regular discussion occurred with the supervisory team to evaluate interviewing techniques and maintain reflexivity.
Transferability	To generate a theory, constant comparison methods were used, and the later interviews aided theoretical sampling.
Dependability	Interviews transcripts and analysis of the data obtained from the sets of interviews were stored on a password encrypted computer to allow emergent findings to be organised and for an audit trail to be followed. Interview guides, sets of open, axial and selective coded data also informed audit trails (for example see appendices).

To ensure reliability and validity was implemented throughout the research, the specified GT processes were followed across all the studies. Some of the processes have already been discussed in the earlier section; what is remaining is the way in which the researcher, his background and assumptions may have influenced the studies. This is important, because of the researcher's SA ethnicity, his experience of working with people with T2D or at high risk and pre-existing knowledge of the SA culture. However, precautions were taken to ensure any bias was mitigated throughout. Having a multi-ethnic supervisory team helped to maintain a rounded perspective of the research and created a discussion about the interpretation of data. Throughout this PhD, regular meetings occurred with the DoS and with other supervisors. Peer support was provided by the DoS, who has expertise in qualitative research and diabetes. This supervision challenged the researcher to reflect during both data collection and analytical processes.

3.17 Recruitment

3.17.1 Study Setting

Due to the nature of the studies, a variety of participants were required to part-take in the research from a different ethnic background, e.g. individuals from differing SA backgrounds. Interviews were carried out: For studies 1 & 3, typically in community/religious settings and participant's homes. Study 1 was conducted with SA lay individuals; recruitment initiation was conducted through telephone conversations, emails, attending community groups and snowball sampling. Study 3 recruited participants from the individuals who participated in study 1, who were asked to nominate other members in the community. In a mixed-method (sequential embedded) design, it is common for the same participants to take part in both phases of the study (Creswell, 2003).

3.18 Chapter Summary

In Summary, chapter 3 provided an overview of qualitative research with a focus on the grounded theory approach. This chapter also included sampling methods used to recruit study participants. In addition, procedures for data collection and data analysis, ways of establishing credibility, rigour and the role of the researcher were all included.

4 Chapter 4: Prevention of Type 2 Diabetes in South Asians: A Qualitative Study Exploring Risk Perceptions, Health Beliefs, Values and Community Perspectives.

4.1 Study 1 - Chapter Overview

Type 2 Diabetes (T2D) prevention programmes should target high-risk groups. Given the elevated risk of T2D in those of SA descent, there was a need to understand perceptions, risks and beliefs about T2D.

Twenty SA participants (Mean age= 38 years) without a diagnosis of T2D were recruited from various community and religious settings across the North West of England. In line with Grounded Theory (Strauss & Corbin, 1990), data collection and analysis coincided.

Prevention was the core category, which was informed by three sub-categories: (1) Religious Influences & Destiny, (2) Environmental Influences and (3) Diabetes Knowledge. Religious Influences & Destiny, Environmental influences and Diabetes knowledge are the prominent features of RP for the SA community which has an impact on individuals' preventative behaviours

Overall, SA people did not consider T2D to be an immediate personal health risk. T2D was an 'expected and accepted' health condition, considered inevitable. Such perceptions may account for a limited engagement in diabetes prevention interventions and recommendations to improve engagement are offered.

4.2 Introduction

Epidemiological trends indicate that the world prevalence of diabetes (all types) has increased steadily over the last few decades (World Health Organisation, WHO, 2016). In the United Kingdom (UK), diabetes costs the National Health Service (NHS) nearly £10 billion a year, and such costs are set to increase significantly year on year (NHS England, 2016). By 2035, the rate of diabetes in England alone is estimated to grow to nearly 5 million people (n= 4,936,101), a prevalence of 9.7% of the total population (Public Health England, PHE, 2016). In England and Wales, around 6.7% of the population (n= 3,192,745) have been diagnosed with diabetes, of which the majority (92.4%) have been diagnosed with T2D (T2D) (NHS England, 2016). Although, it is noteworthy that there are around 1,000,000 people in the UK who are predicted to have diabetes, but have not been diagnosed (Diabetes UK, 2018).

People of South Asian (SA) descent are particularly vulnerable to T2D (Gujral et al., 2013). More specifically, UK SAs are more likely to develop T2D, to be diagnosed at younger ages, and to experience more T2D complications than the general UK population (Wilmot & Idris, 2014). Epidemiology of T2D differs across SA sub-ethnicities (e.g. Indians, Pakistani's, Bangladeshi's and Sri Lankan's), although the prevalence in all SAs is higher than is seen in White Europeans (Garduño-Diaz & Khokhar, 2012; Lucas et al., 2013). Approximately 15-20% of SAs will develop T2D compared to 2-5% of White Europeans. This increased prevalence is evident in both SAs who have migrated to the western world and those living in either rural or urban Asia (Fan, Lee, Billimek, Choi & Wang, 2017). The SA population has increased in the UK over several decades, and now represent a significant proportion of the UK population (Willis et al., 2016), which is expected to increase further. Therefore, it is also predicted that the prevalence of T2D in the UK will simultaneously increase (Gujral et al., 2013; Rowley, Bezold, Arikán, Brynw & Krohe, 2017).

Research on prevention has shown that the risk of developing T2D can be significantly decreased with lifestyle improvements (e.g. weight loss, healthy eating and regular PA) (Wu et al., 2014). To address the rising prevalence of T2D in the UK, there has been an increase in healthcare investment. For example, The National Diabetes Prevention Programme (NDPP, NHS Digital, 2018) has been rolled out across the UK to reduce the risk of people being diagnosed with T2D. NDPP is an intensive behavioural intervention promoting weight loss and improvements towards diet and PA. However, research has found that previous attempts for lifestyle interventions targeted towards SAs have had limited success (Bhopal et al., 2014). In particular, programmes have reported low levels of recruitment and retention (Douglas et al., 2011; Quay, Frimer, Janssen & Lamers, 2017). In addition, previous research suggests that amongst SA groups, there is a low level of conceptual understanding of diabetes risk (Grace et al., 2008).

RP is a term used to describe the subjective judgements individuals make about the risk of developing a health condition. People, who underestimate their risk, may be less likely to adopt recommended behaviours from healthcare professionals (Rouyard et al., 2017). A recent meta-narrative review found that people with prediabetes acknowledged prediabetes as a risk factor for T2D. However, a personal diagnosis of prediabetes did not motivate individuals to engage in lifestyle changes, and they tend to underestimate their actual risk of developing T2D (Barry, Greenhalgh & Fahy, 2018). There has been research on RP with individuals from non-specific SA population (Kowall et al., 2017; Shreck et al., 2014). However, to date, the majority of research on SA RP of T2D has focused on individuals who already have a diagnosis of T2D, whereby RP has concentrated on T2D management and the consequences of T2D complications (Macaden & Clarke, 2006; 2010; Seehusen et al., 2019). A few studies have explored RP in SA women developing gestational diabetes (Anand et al., 2017; Sletner et al., 2017). Some studies have examined general health and ill-health RP in SA lay populations,

(e.g. focusing on heart disease risk) in the UK and worldwide (Joshi & Lalvani, 2010; Rana, de Souza, Kandasamy, Lear & Anand, 2014). There has been limited research exploring health-related perceptions and behaviours among UK SA individuals. Of the few studies (Macaden & Clarke, 2006; Patel et al., 2015), research has suggested SA RPs are influenced by factors such as knowledge of the disease and cultural practices related to diet (Lawton et al., 2008; Lucas et al., 2013). However, none of these aforementioned studies has used a theoretical framework to explain the interactions and complexities of RP. Furthermore, little is known about the characteristics of those, who after the provision of risk information perceived their T2D risk accurately. Identifying such characteristics will improve understanding of the potential impact of risk communication and will inform the development of more effective interventions and health promotion campaigns targeted at changing perceived T2D risk within the SA community. More specifically, the findings of this study may improve the potential impact or marketing of the NDPP for the SA community.

The goal of this Grounded Theory (GT) study was to explore RPs in the lay SAs. By understanding and explicitly recognising the complexity of RP, the SA community and the healthcare system can accommodate multiple risk perspectives in strategies to reduce diabetes prevalence in the SA community.

4.3 Methods

4.3.1 Design

This inductive GT (Strauss & Corbin, 1994) qualitative study explored T2D RP health beliefs and health behaviours within the SA community. Specifically, this explored individuals understanding of T2D, the immediacy of their risk, visibility of the proposed risk and beliefs (see chapter 3 for detailed information on GT process and analysis).

4.3.2 Recruitment & Data collection

Following approval from Liverpool John Moores Ethics Committee (16/NSP/005), twenty male (50%) and female participants without a diagnosis of T2D, aged between 25 to 62 years (mean= 38 years) took part. The sample was considered broadly representative of the SA population living in the Northwest of England (Office for National Statistics, 2012).

The recruitment procedures included ‘networking’, a form of snowball sampling (Waters, 2014), the lead researcher contacted various SA communities and religious settings to advertise and promote the study across the North West of England. Interested participants were offered appointments to discuss the study at a time and location convenient for them. Following a discussion, explaining the aims and purpose of the study, and seeking informed consent, face to face interviews commenced. All participants were of SA descent (Indian, Pakistani and Bangladeshi) and proficient in the English language.

Interviews ranged from 15 to 60 minutes in duration (mean = 50 minutes). The interviews were informed by a topic guide (Table 4.1) (see appendix 4.1) which covered: familiarity with diabetes; exercise and PA; diet; and social obligations, these topics guided the interview and allowed the researcher to explore the participant’s knowledge and perception of T2D. As the study progressed, a constant comparative analysis was applied through simultaneous data collection and analysis. Multiple iterations, including theoretical sampling and amendments to the interview questions, were made as part of this GT process (Strauss &

Corbin, 1990). Participants were reminded that they had the right to withdraw from the interview or not to answer any questions. Throughout the interviewer remained neutral, empathic, and adopted a non-judgemental approach using active listening techniques (Cryer & Atkinson, 2015), allowing participants to express themselves in their own words. At the end of the interview, participants were allowed to add any further comments and thanked for their contribution. By way of debriefing, time was taken to address any questions and discussed before the interview concluded. Furthermore, the researcher provided a debrief sheet containing further information regarding links about diabetes risk (such as redirecting to Diabetes UK).

Table 4.1: Initial Interview Topic Guide

SA Interview Topic Guide
<p>Can you tell me how you perceive health?</p> <p>Do you think you are currently at risk of developing T2D?</p> <p>Is there anyone in your family who has T2D?</p> <p>What do you think the causes of T2D are?</p> <p>What do you think of as PA and exercise?</p> <p>What do you think people in the community think about PA?</p> <p>What do you think the main things are that make it difficult for your community group/population to be more active?</p>

4.3.3 Research Team and Methodological Rigour

Strategies were used to ensure the ‘trustworthiness’ of analysis in this study (Cooney, 2011). Meticulous record-keeping promoted a clear decision trail and interpretations of data were consistent and transparent (Noble & Smith, 2015). Researcher triangulation (Heale & Forbes, 2013) occurred via a diverse supervision team, which promoted objectivity between the researcher’s position and the analysis. The lead researcher (PhD student) was a male of SA origin and researcher with specific interests in diabetes RP. The lead researcher conducted all the interviews and led the analysis. The Director of studies was a White female, a Registered Health Psychologist with expertise in qualitative methodology and research interests within diabetes. The PhD supervisors consisted of a black, male Chartered Psychologist and the third supervisor, a White female, Reader in Dietetics, both with research interests in diabetes. A fellow PhD student, a SA female with expertise in GT research and T2D, also aided in the analytical process of this study.

A process of reflexivity and audited discussions occurred throughout the process to ensure rigour in the quality of qualitative analysis conducted (Reynolds et al., 2011). Finally, the documented data transcription and content analysis processes relating to coding and categorisation, established conformability for the research, demonstrating that the findings developed from the data and not the researchers owe predispositions (Richards & Schwartz, 2002). Moreover, detailed verbatim descriptions of participant’s accounts are used within the findings to be transparent in context (Noble & Smith, 2015).

4.3.4 Data Analysis

The following section explains the process of GT that was applied to this study and follows the process set out by Strauss and Corbin (1990).

The interviews were digitally recorded and transcribed verbatim (using the participants chosen pseudonyms). Transcription occurred shortly following each interview to allow for

simultaneous data collection and analysis, according to GT methodology (Strauss & Corbin, 1990). This process also shaped the development of the questions for subsequent semi-structured interviews (discussed during on-going reflexivity and discussions between first and last authors).

The data analysis included three rounds of open coding. The purpose of the first round was to develop a code list from the interview data obtained from all participants. To create a code list, the researcher began with line-by-line coding of interviews. Groups of words or lines of text were highlighted until the content shifted to a different topic. At this point, a decision was made to determine if the text belonged to an existing code or a new code. If two or more codes seemed to define the same phenomenon, they were combined. By the end of the first round of open coding, the code list had changed significantly, between coding of interview 1 and interview 20. Therefore, the researcher engaged in two subsequent rounds of open coding that applied the same set of codes to all transcripts. This way, it ensured that the same phenomenon was labelled with a consistent code. After completing the first round, the researcher had developed over 300 highly specific codes that reflected the variation in perceptions and experiences of participants. The subsequent axial coding process involved arranging and rearranging the codes into groups based on the commonality of meaning. Following this, the process of mapping out and selectively coding commenced. Selective coding integrated the axial codes into a coherent written form. For this study, selective coding related to the reconstruction of the themes from the memos obtained from the axial coded data (Strauss and Corbin, 1998). It was then possible to examine the links between categories and the development of a theoretical framework, where a central phenomenon and the axial coding paradigm were linked.

4.4 Findings

This GT analysis was shaped by three sub-categories: Destiny and Diminished Responsibility; Education and Understanding; and Engagement in Healthy Lifestyle Behaviours which together informed the core category: Tailored Prevention Interventions (See Figure 4.1). Direct quotes from a range of participants act as evidence to support commentary (Charmaz, 1990), annotations following quotes represent the participant identifier (e.g. P7F = Participant number 7, Female).

4.4.1 GT Framework

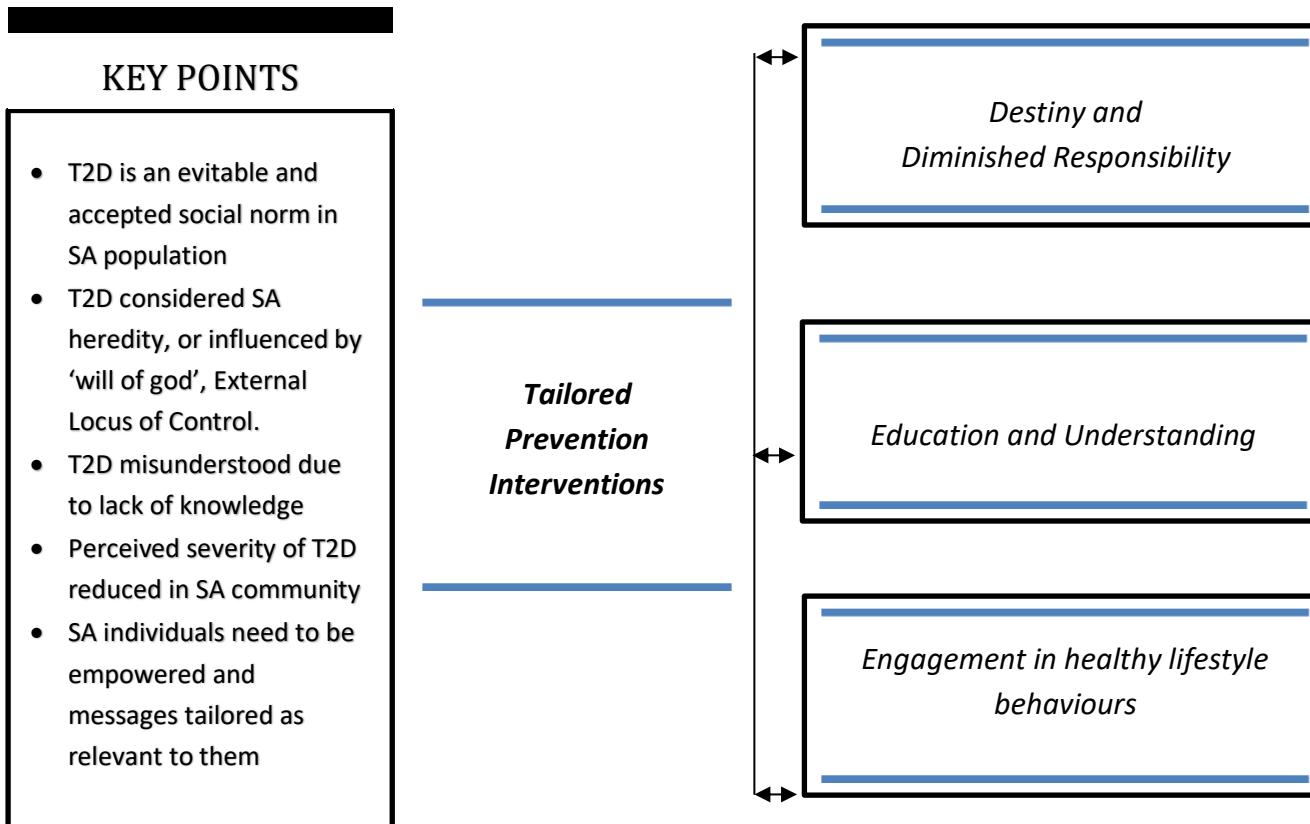


Figure 4.1: Grounded Theory Framework for RP within the SA Population.

Figure 4.1 shows that Destiny and Diminished Responsibility, Education and Understanding and Engagement in Healthy Lifestyle Behaviours are the prominent features of RP for the SA community, which had an impact on individuals' preventative behaviours. The categories presented are not set apart, rather these categories entwine and inform one another, and hence a comprehensive intervention on prevention of T2D in SA community, in order to be effective, should take account of, and consider the influencing factors within each of these categories.

Tailored Prevention Interventions

This study found that individuals made decisions about diabetes risk based on their cultural beliefs, past experiences and external influences rather than depend on a complete understanding of risks. It is evident from the findings of this study that SA individuals had a different understanding of diabetes risk. Indeed, previous research on RP indicates that it is a diverse and complex topic (Shreck et al., 2014).

Participants believed that the fear of the overwhelming consequences of diabetes would motivate preventative action across the SA community. Other individuals claimed prevention as part of a healthy lifestyle that all SA people should follow.

Many participants believed there was not enough information promoted about T2D risk and preventative behaviours. It was suggested that communication would be most influential if delivered through significant others, such as community or religious leaders.

"I don't think there is much information out there in terms of prevention; everything is about management of diabetes. I want to know more about how I don't get it and what I should be doing" (P15, F).

Moreover, participants recognised the value of preventative interventions, although reported minimal or non-existent knowledge of any relevant health campaigns.

“I think there needs to be a focus on social media. Everyone is on social media, why not target that for advertisement, Interactive with the public through videos and clips on Instagram” (P19, M).

The use of social media or mobile phone (e.g. mobile applications) was considered an acceptable vehicle to reach SA individuals. However, there was a recognition that any intervention would need to be tailored towards the SA community, to ensure the health messages were relevant and in context to individuals’ social situations. For example, participants were keen to highlight how dietary advice needs to be tailored and include examples of SA traditional foods and ingredients, and not merely make sweeping assumptions about SA cooking or eating practices.

“We already have apps such as Myfitness pal etc. However, these apps are very generic, as the Asian food is very rich and oily, an app which helps people choose substitutes for healthier options to make curries would be a good idea’. This app could have videos and voice notes in many languages to help people understand” (P9, M).

Destiny and Diminished Responsibility

Locus of Control (LoC), reflects individuals beliefs regarding the extent to which they are able to control or influence outcomes (Mallers, Claver & Lares, 2013). Therefore, an individuals ability (self-efficacy) to be in control of their lifestyle seemed to guide risk behaviour, i.e. ‘will what I do work?’ e.g. will losing weight actually reduce my risk of diabetes?

Participants typically were unaware of, or indeed ignored the concept of T2D risk, and failed to actively engage in preventative behaviours. Participants prioritised their religious values and beliefs before consideration of health needs or lifestyle advice from health professionals. Participants believed that God, was in control of their lives/health and therefore, their actions and behaviours would be judged by him. Hence it was imperative to abide by their religious beliefs. participants viewed fate, luck and God as being responsible for the consequences despite their actions. These participants viewed T2D as an inevitable disease, having a diminished sense of responsibility due to religious beliefs.

The majority of participants considered their lives as preordained, ultimately God was in control, promoting a belief that T2D may be a person's destiny (as a form of punishment or other), and hence created a sense of diminished responsibility for behaviour and helplessness.

"They would not believe in this T2D, they would just if I have diabetes; it's because God has punished me; I need to pray harder" (P6, F).

"They do say it they start saying oh I'm going to die anyway and even if I have it, it 's written in my kismet (destiny), there is nothing I can do about it, if I am going to get it then I will get it" (P7, F).

RPs were influenced significantly by socio-cultural and religious beliefs and were driven by emotional reactions as opposed to educated evaluations. T2D was considered a part of life, and accepted within the community, creating social acceptance and social norm. Participants viewed fate, luck and their creator (God) as being responsible for the consequences despite their actions.

"What I'm saying is it's all a master plan, it's what you're written with. It's what you come within your kismet [destiny]. It's going to happen; you can't just say

I'm doing the right thing, and I'm not going to get this, and I'm not going to get that because I'm controlling myself, I am eating healthy. If you going to get it, you're going to get it, that's my belief" (P13, F).

Participants frequently referred to family and close friends as sources of information for health and wellbeing. One participant reported that religious leaders were the most influential people within the SA community, more so than any health professional. Consequently, participants would seek (health) advice from an imam/priest rather than their doctor.

"I think more so than a doctor who would rather listen to a priest because there is the fear of God, do you know what I mean, they believe in karma so believing in listening to the priests and what God wants you to do" (P3, M).

Education and Understanding

Participants had some basic knowledge of T2D. The majority had a family or friend diagnosed with T2D and acknowledged that it was a common health condition. Family history and genetic hereditary were cited as determinants for the onset of T2D. Moreover, participants considered T2D as a common and accepted disease amongst SA communities.

"My family, my girlfriend's family and the community I am from there's at least five or six people I know" (P1, M).

T2D was not considered a serious health condition, rather a common health condition; people 'live with', in this essence, T2D has become a social norm within the SA population. People from the SA community witness family and friends who are 'coping with diabetes' hence such observations reduced perceived severity of T2D and reduced the value of assessing T2D risk, given it's considered an 'inevitable' condition.

Despite the SA community being at high risk of developing T2D; the participants wanted to maintain a sense of feeling normal and did not accept the seriousness of the condition. Therefore, T2D appeared to be a normalised, everyday experience for participants.

“They see their grandparents with it they still alright, not knowing actually what’s going on inside them. They may be struggling. They think you’re old, so you going be ill, you’re old, so your joints are going to hurt. But this is not the case. My community need to understand that diabetes is a massive health issue, and something needs to be done about it” (P18, M).

However, the majority of the participants reported a poor understanding of T2D, not recognising the symptoms or causes of the condition.

Cultural diversity (Indian, Pakistani, and Bangladeshi) exposed additional nuances of understanding T2D, within the SA participants. This influenced their T2D behaviour (e.g. dietary practices, religious beliefs, and health beliefs), which varied between individuals.

“We always have big portion sizes compared to the Indian community and the majority of our typical curry’s and foods has to include Ghee in it. That’s how we were brought up” (P18, M).

Individuals cultural beliefs and behaviours adopted as a result of specific religious and cultural obligations had an impact on their self-care and risk prevention behaviours. For example, Indian participants were open-minded towards health, acknowledged health messages and reflected on cutting down on traditional SA foods and adopting a more westernised diet. However, with all of the Pakistani participants, the traditional beliefs were deep-rooted within their community, and this formed a sense of their identity. If they were to change their behaviours, i.e. eating a different diet, then a loss of identity would be felt within

the participants, suggesting that conflating ethnicity and culture can create conflict in decisions for T2D preventative behaviours.

“We have started to acknowledge that we can't keep cooking the same way as we used to and our children who are more educated have started to help us with this. They are always looking at packet labels and telling us whether its good for us or not”
(P13, F)

When participants acknowledged health issues, many reported denial or avoidance behaviours, with little importance or considerations given towards preventative behaviours, this was mainly observed with the Pakistani participants. Personal disease risk and cause were often instead attributed to a range of external influences such as T2D being heredity.

“So many Asian people oh yeah my mum's got diabetes it's normal oh yeah my mum's got diabetes as well we started treating it as normal actually it's a lifelong condition when my mum first got it it was a shock she was one of two where's on my dad's side everybody has it so is a shock that my dad doesn't have it we don't look at the implications we take it so normal” (P1, M).

Participants reported a very simplistic understanding of T2D, referencing it as a ‘sugar’ condition. Knowledge of the causes, consequences, and preventative nature of T2D was insufficient. These beliefs were mainly informed by community values and layperson perspectives. Therefore, a lack of knowledge, perhaps misconceptions about T2D could lead them not understanding how these factors could impact on adopting preventative behaviours.

“Members of my family don't know what diabetes is, although it runs in my family, there are certain members that are totally naïve to what diabetes is” (P8, F),

“I think a lot of Asian people I speak to like family members don’t have knowledge of what diabetes is, apart from oh I suffer from diabetes, it’s all about the sugar, they are not aware of all things to do with diabetes” (P16, F).

Engagement in Healthy Lifestyle Behaviours

The idea of preventing disease by engaging with a healthy lifestyle was not accepted for many participants as they exhibited low behavioural control regarding their dietary choices and engagement in PA. PA was recognised as routine behaviour, for example, walking, but rarely acknowledged as a planned activity for health and fitness. Cultural and social expectations, such as cooking, and time constraints were represented as barriers to engaging in PA. As one participant alluded to, there is a powerful notion within the SA community that ‘family needs come first’. Therefore people prioritise their family obligations over the pursuit of their interests and activities (e.g. choosing personal lifestyle behaviour such as diet and activity levels are not prioritised). As a result, some participants (60%) suggested, taking time out for them to go out exercising could be culturally unacceptable, this is line with previous literature (Lucas et al., 2013; Vahabi, Beanlands, Sidani & Fredericks, 2012). However, Vahabi et al., (2012), found that despite the SA community diversity, a ‘women-only’ dance class, led by community female dance instructor, combined with childcare services, would be acceptable in the SA community.

“I don’t really go to the gym, I don’t get my blood pressure higher than 90, I don’t do that, and I know that it’s just commitment and responsibilities lifestyle etc. I can’t find enough hours in the day to do it” (P16, F).

For male participants, the culture of a strong work ethic meant they felt indebted to dedicate their time to provide for their family working very long or anti-social hours (often in family businesses such as shops and restaurants). Participants in this study spoke about some

of the common attributes amongst SA men, which they considered to be barriers towards changing their health and lifestyle behaviours. These were stereotypical descriptions about the dismissive attitudes towards health. For example, men in SA communities were described as governed by their masculine identity, which was considered to be the reason for unhealthy lifestyle behaviours. Men were ascribed to masculine norms, such as pride and work. Masculinity played a vital part in reluctance to engage with health professionals. As one participant described:

“He makes sure the family has been taken care of and work and work and work, and he doesn’t think about himself” (P6, F).

For female participants, once a woman got married, she was expected to attend to domestic chores and responsibilities. Female participants felt they were, engaging appropriately in PA via caregiving, house-keeping, and routine daily activities, so extra time for dedicated PA was not arranged. In a SA household, women typically hold the primary responsibility for cooking. Women are expected to ensure traditional food practices are maintained (Ludwig, Cox and Ellahi, 2011). This is reinforced by a study that found young Pakistani and Bangladeshi women continue to value traditional cooking practices and to cook from scratch, describing it as ‘natural’ (Lawrence et al., 2007). This is an issue also recognised in previous research (Bhopal et al., 2014; Lawton et al., 2008; Lucas et al., 2013). Men cooking a meal was considered a ‘treat’ or ‘break’ from the tradition (Ludwig et al., 2011). Our interpretation suggests low priority in having control over personal health and social freedom in the women groups.

“The mother is always cooking; I’m talking about the Asian women, forget the men they always sitting down, women who are actually always running around feeding the kids and husband” (P7, F).

An intention is influenced by subjective norms, including the perceived expectations of important others (e.g. family or work) with regards to a person's behaviour. There was an identification of priorities and ranking of risk within the SA community. For example, when faced with making choices between risks involving looking after one's health and causing a social offence, the risk preference was to comply with hospitality gestures, i.e. food at social occasions. Food was central to maintaining cultural connections within the community and also building relationships within the family and wider community. Participants highlighted that communal eating of traditional Asian food was central to their social and cultural lives. However, the majority of participants expressed that their diet was one of the main reasons for the SA people receiving a diagnosis of T2D.

“A ‘traditional’ SA diet presented particular problems for health, as participants claimed the amount of oil used in cooking, fried foods, and high sugar content were attributed as reasons for the high rates of diabetes” (P17, F).

“Rich food and with Ramadan coming up there's a risk of fried food on a daily basis living with elders Who can't seem to grasp not having fried food every day can't be good for them and you naturally being in that environment” (P17, F).

Although participants mentioned appetite and taste, their eating behaviours were influenced by social events such as wedding and functions. Food played a significant role in maintaining relationships with others, and there were considerable social pressures to eat, especially during social events and functions. Participants accepted risks that were not visible, or non-imminent (health risk) and were averse to those that were visible and imminent (social risk).

'Yes, definitely you see it at weddings in how they indulge in sugary foods like Jalebi and Methai like there is no tomorrow despite the fact they are already impacted by common health issues' (P1, M).

Furthermore, participants discussed dietary considerations and the difficulties of making dietary changes as embedded within their household. Participants spoke of commonly complying with older relatives' preferences.

'I would say the same just think it just makes it easier like you said it's the elders that tend to stick to the Indian food, so we just eat it because it's convenient for us' (P1, M).

Participants reported there had been an increase in consumption of takeaway foods in the SA households. As one participant described, these foods were seen as part of a weekly family diet. 'I get takeaway once a week' (P9, M).

"When they younger you can manage that, but you can't when they adults, I'm certain he's always out and about, they don't care really they and they don't" (P16, F).

The majority of participants referred to an influx of takeaways, dessert and shisha places opening locally. One participant claimed a typical night out would include traditional food such as curry and then visit dessert and shisha places to fix their 'cravings'.

"I was just about to say that the younger generation will probably look at the Elders and probably want to make adjustments by going to the gym but over there past five years there are dessert places everywhere find shisha houses that offer desserts can you see a lot of young people attending these places" (P4, M).

Food is central to maintaining cultural connections with the homeland and also building relationships within the family and wider community; There is a rapid rise in smoking shisha and attending dessert places central to maintaining cultural connections but also a way of

bringing people together socially – acting as a ‘social lubricant’. Food choice was influenced by cultural norms, such as social acceptance, family expectations and recipes. In addition, food choice in the SA community was also influenced by the physical environments such as social engagement using food, local restaurants and social media reinforces physical environment. Due to this, there has been a high level of exposure to fast food places. Individuals are learning by observing the actions of others visiting food and shisha places, and the results of those actions are positively reinforced.

“It's fun to sit in a place where there's music going on you can get fancy new drinks some people enjoy the smoking side and some people who don't smoke, but we'll go out and sit with their friend's whether we're at home, or we are out it's become this is the norm. I remember few years ago people didn't smoke has openly has now he has become more and more acceptable and more easy to get now you can have one in your own home you can get them ordered has become easier we have got everything at our Fingertips it doesn't cost you that much” (P1, M).

This study’s findings highlight moral conflicts between individualist and collectivist goals in the SA community. For example, the individual goal of eating healthy compared with the shame of the family of not providing guests with special traditional food. The normative belief within this community is to focus on social behaviours rather than health behaviour, such as following traditional norms.

This study has shown that within the SA community, there seems to be an unfavourable attitude towards T2D, along with the demand of adhering to social and community pressure and obligations and low perceived behavioural control. All of the aforementioned elements are strongly embedded within the SA community, thus reduces the focus on T2D as important prevention behaviour.

4.5 Discussion

This study aimed to explore the understanding of RP amongst SA in the general population (e.g. individuals with no diagnosis of T2D). A new GT highlighted the complexities that are embedded in the SA community and how these complexities impact RP of developing T2D. The GT has found a collation of elements which inform their views on T2D and these may be relevant to the whole population. However, there is a need to investigate if these concepts are more specific to SAs or other populations as well.

RP has been explained to be a social process. People's action are largely determined by social aspects and cultural adherence, to what is expected, what has been experienced and what is considered normal (customary or traditional) and approved in the community (Lin, Lin & Hsin, 2018). The HBM (Becker, 1974) has been used in the context of health promotion and disease prevention programmes. The HBM model entails four constructs; perceived severity, perceived susceptibility, perceived benefits and perceived barriers. The findings of this study support the HBM, for understanding risk perception of T2D in SA. For example, this study highlights the notion that participants are more likely to engage in healthier behaviours; if they perceive their risk of T2D to be severe and if the action was considered beneficial. However, as this study suggests, currently, the SA groups are not considering their risk to be severe, and the potential actions are not considered beneficial. Therefore, SA participants perceive the risk of developing T2D as low. Our findings suggest that religion and culture influences shape perceptions of susceptibility to illness and of the benefits of biomedical health practices such as screening for T2D, thus pointing out that the concept of culture should be considered within the HBM and other psychological models. This is important as all cultures have systems of health beliefs to explain what causes illness (Lucas et al., 2013), how to understand, manage, cope with the illness and this is pertinent to the SA community.

This could be explained further with Social Norm Theory (Perkins and Berkowitz, 1986), which emphasizes the influence of others and the role it plays in decision-making. With reference to this theory, a person's perceived norm (what we believe to be normal; rather, the actual normal) are not aligned. In this instance, the misperception that SA participants have about the seriousness of T2D is not representative of the actual condition. Moreover, the RP about the seriousness and consequences of T2D are underestimated. This can be further explained by Social Comparison Theory (SCT) (Festinger, 1954), suggested that people have an innate drive to evaluate themselves, often in comparison to others to assess their own skills, beliefs and attitudes. This is reinforced in this study, as SA participants made social comparisons to compare their risk with those already diagnosed with T2D who are deemed as managing their condition effectively, this can have some resemblance around the seriousness of the risk of developing T2D. Moreover, research has shown to have lower levels of PA in the SA community. Therefore, this can be applied within SCT as people are making constant comparisons with others. If people are not seen to be engaging in healthy behaviours, there is less chance of that individual changing their behaviour. On the other hand, the diets of nearly half of SAs are unhealthy (Medical Xpress, 2019), which includes regularly eating in fast food chains has been positively compared, therefore more people are likely to reinforce this behaviour.

Equally important is the concept of diminished responsibility. This is referred to when someone is not considered to be responsible for their actions (Zeegers, 1981). In the SA community, participants have the concept of diminished responsibility as they do not want to share responsibility. There is a belief around fatalism and religion, whereby, SA participants believe there are not responsible for their own health. The concept of destiny and God is responsible, and if certain illness was given to them, then this was based on their 'luck and 'fate'. Equally, this relates to the concept of LoC. SA participants are more likely to hold an

external LoC on health and illness which means regardless of their own behaviour and action; their fate rests in the hands of chance or other more powerful bodies (Rotter, 1966). This is in line with previous research which has found that SA individuals are more likely to have higher levels of external LoC (Macaden & Clarke, 2010)

Together the GT framework developed in this study brings several theoretical approaches together, which to date have not been previously considered in the research literature or indeed considered within an applied context such as current prevention interventions across the UK to fully understand RPs in the SA population.

4.5.1 Implication for practice

SA community groups are often considered ‘hard to reach’ in terms of their engagement with health screening programmes (e.g. NHS health checks and health promotion interventions, Attwood, Morton & Sutton, 2016). The results of this study are, therefore, relevant to the key aims of the NDPP (PHE, 2016) in the UK and similar worldwide prevention initiatives. In order to motivate and engage SAs to take preventative action, there is a need to improve risk perception within this community, in line with previous research, which suggests health-related risk perception plays an important role in motivating health (Ferrer & Klein, 2015). Health professionals and Public Health can use the findings to provide avenues to improve risk perception at the first instance before advising participants to make changes in their lifestyle and also find ways to accommodate the participants needs while respecting their cultural values and beliefs in line with NICE (2012) and Public Health guidelines (Seeleman, Suurmond & Stronks, 2009).

The findings from this study can be used to develop effective culturally tailored education and prevention programs, which may offer significant help in improving the health of minority communities. Health professionals should consider addressing key issues noted in

this study as part of education and intervention programmes to improve knowledge and self-care behaviours. These include ensuring all individuals have a requisite level of knowledge about T2D and its complications, confirming that individuals understand the importance of implementing self-care behaviours, developing creative solutions for individuals to meet cultural, religious and social obligations while maintaining healthy lifestyles.

4.5.2 Strengths and limitations

The comprehensive approach to ensuring quality and integrity within the methodology and analysis conducted for this research is noteworthy (Meyrick, 2006). To be transparent and demonstrate rigour, this research has been conducted, and the article written with consideration of the Reporting Standards for Qualitative Research (Levitt et al., 2018). Methodological integrity and trustworthiness of the study included the use of interview schedules; focusing the interview towards the research questions; and the researcher remaining open and not bias thus assuring credibility (Jacob & Furgerson, 2012).

Conformability is the qualitative counterpart to objectivity and was achieved through on-going researcher reflexivity, completed throughout by the diverse experiences and expertise of the research team (Stewart, Gapp & Harwood, 2017). While it is important to acknowledge that transferability of findings to a broader context is more challenging to demonstrate in qualitative methods, the GT presented in this study offers a foundation for future interventions and this study represents the first step toward understanding risk perception of T2D in the SA population. This study is part of a bigger research program and contributes explicitly to a need's assessment phase of a Medical Research Council (MRC) (Craig et al., 2008) intervention development framework of understanding a specific group of individuals (SAs) behaviours (risk assessment and prevention of T2D) to be used as part of an intervention design for future research (Penn et al., 2018).

Whilst previous research has highlighted various challenges associated with recruiting to and completing research with ethnic minority and faith groups (Quay, Frimer, Janssen & Lamers 2017), it is noteworthy that the initial recruitment to this study was slow, and participants reported some uncertainty about participating. The process of seeking support to promote the study from community leaders was considered an important step in the recruitment process and, in addition, the first author as a SA himself, provided time and effort to discuss such concerns with participants. Overall the participant sample included men and women across a range of age groups, from a diverse SA descent and thus the researcher deemed this sample to be representative of the local SA population (aiding theoretical sampling). However, it is important to acknowledge the limits in the scope of transferability to other SA communities, which may represent a more diverse SA make-up.

The use of intensive interviewing allowed the flexible pursuit of the topics that arose in the interview and potentially a deeper exploration of the participants' experiences. A limitation of this approach in data gathering is that the participants' voices were consequently not pure and were bound to a specific context and place in time (Mills, Bonner and Francis, 2006). The limitation and potential strength of using grounded theory methodology within this study was that of working towards theoretical sampling and saturation (Strauss & Corbin, 1998), which meant that the focus of the interview data was grounded within the participants experiences and sense of meaning and importance to them (Sutton & Austin, 2015), and not driven by any prerequisites or notions of influence via the researcher (or for example the initial interview schedule). During the process of grounded theory iterations were made to the interview schedule to reflect the ongoing and simultaneous data collection and analysis, in line with the theoretical sampling and theoretical saturation approach (Saunders et al., 2018).

4.5.3 Conclusion

This study provided insight into RPs of developing T2D within the SA community. Categories: Destiny and Diminished Responsibility, Education and Understanding and Engagement in Healthy Lifestyle Behaviours all had significant influences on how the SA people perceive they risk and radically change their views on prevention. The analysis indicated the importance of using a GT framework to explain the complicated relationship of personal, environmental and behavioural factors that influence SA perceptions of risk for T2D. This study contributes to one of the specific PhD objectives, which is to explore SA people's understanding and assessment of T2D risk (Chapter 2). Furthermore, this study offers a unique contribution to new knowledge of RP in the SA population by informing a GT framework using several key health psychology theories to understand the overall SA populations risk of developing T2D.

4.5.4 Key points and unique contribution from this study

- This study used a GT methodology which brought together various health psychology theories such as the HBM and LoC to give a much deeper understanding of behaviours in this population. This study is the first of its kind to do this in the UK SA population.
- There are various constructs that influence a SA individual RP. This study highlighted that: concepts such as destiny (believing it is written for you), lack of education and understanding and lack of engagement in healthy lifestyle behaviours all that a significant impact on the participants RP. This can provide an explanation of the low uptake of health services in this target population.
- Based on this research, it has provided a rationale to explore the SA population in further depth and compare it with other UK population groups.

5 Chapter 5: Measuring Comparative Risk Perception of Developing Type 2 Diabetes Amongst South Asian and White British Populations.

5.1 Study 2 - Chapter Overview

While Study 1 (Chapter 4) provided valuable insight into RP of developing T2D within the overall SA population, there is a need to explore RP further, to understand which specific constructs of RP impact SAs and whether there are any differences between RP and AR in two ethnicity groups. The present study aimed at the gap in the literature by exploring the RP and AR within the SA and White population in the UK.

This study comprised of 210 SA (n=115) and White participants (n=95), focusing on people with no current diagnosis of T2D, completing a RP questionnaire (RPS-DD) and an AR assessment questionnaire across the North-West of England and Merseyside (Bolton, Blackburn, Preston, Manchester, Liverpool). This study employed a 2 x 3 between-groups factorial design with six outcome variables.

SA individuals did not perceive themselves to be susceptible to developing T2D when compared to White participants. Clinically, SA individuals that were at high AR of developing T2D had lower RP compared to the White participants. Furthermore, there were differences in RP constructs, whereby White participants had higher levels of personal control, personal disease risk compared to the SA participants.

Health services are introducing various diabetes risk assessments (NHS & DUK). However, there is limited information on how people from a SA background understand their own risk. Building on from Study 1, this study has filled a critical gap in health research to understand various RP constructs and which crucial RPs need to be targeted for future risk awareness and diabetes prevention intervention for the SA population.

5.2 Introduction

Most of the world's diabetes cases are Type 2 Diabetes (T2D) and is an accelerating public health challenge with a rapid increase over the last 35 years (Rosengren, 2018). Due to the rise of diabetes prevalence, this has huge effects on global health (Rosengren, 2018). Some risk factors for T2D – such as genetics, ethnicity and age – are not modifiable. Others, such as being overweight or obese, unhealthy diet, insufficient PA and smoking are modifiable through behavioural and environmental changes (Hills, Byrne, Lindstrom & Hill, 2013). Several effective policy options are available to facilitate these behavioural changes and create supportive environments for healthy lifestyles (Bowen, Barrington & Beresford, 2015). At the individual level, intensive interventions to improve diet and PA can prevent or delay the onset of T2D in people at high risk, e.g. National Diabetes Prevention Programme (NDPP) (Penn et al., 2018).

There are strong indications – if not yet direct evidence – that population-based programmes aimed at modifiable risk factors can reduce the incidence of diabetes while also lowering blood pressure and other cardiovascular risk factors (Wildgust & Beary, 2010). Population-based data from Cuba show a fall in T2D during a period of economic crisis when the population experienced a reduction in calorie intake and a simultaneous increase in PA (Franco et al., 2013), suggesting wide population changes in diet and PA do affect T2D prevalence.

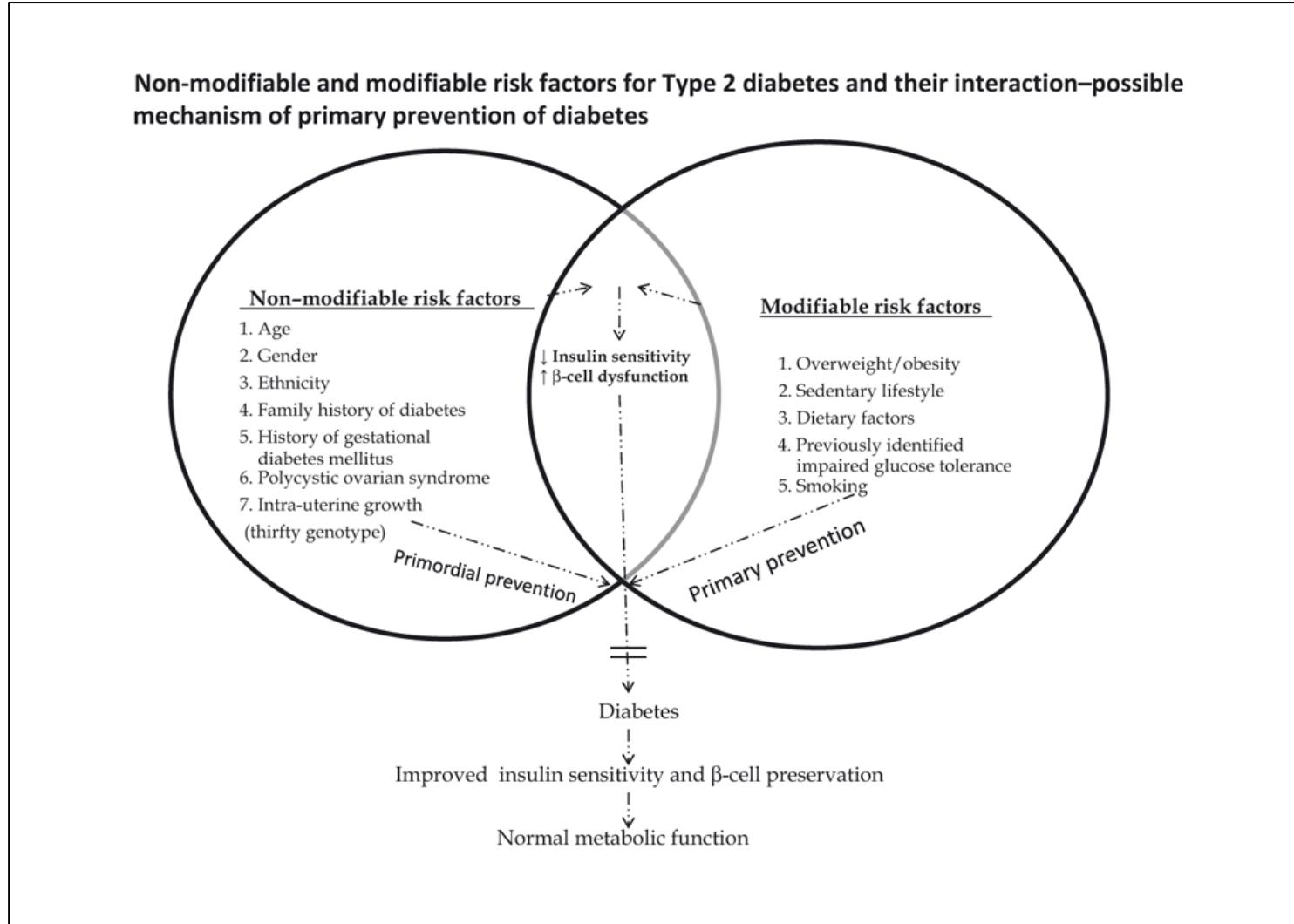


Figure 5.1: Modifiable and Non-Modifiable Risk Factors of T2D (Ambady, Snehalatha, Shetty & Nanditha, 2013)

T2D is more prevalent in individuals from BAME groups (Majeed-Ariss, Jackson, Knapp & Cheater, 2015; Wilkinson et al., 2016). Specifically, T2D is up to six times more common in people from SA descent and up to three times higher in people among African and African-Caribbean origin (Gujral et al., 2013; Oldroyd, Banerjee, Heald & Cruickshank, 2005) than White Europeans. T2D is almost four times as prevalent in Bangladeshi men, and three times as prevalent in Pakistani and Indian men compared to men from the White population (Jayawardena et al., 2012). Among women, T2D is five times as likely among Pakistani women, and at least three times as likely among Bangladeshi women (Jayawardena et al., 2012).

Prevention interventions focus on promoting changes in modifiable risk factors (Salinas & Schwamm, 2017). However, research has demonstrated that SA people are often hesitant to engage in preventative screening behaviour, for example, studies in the US (Bharmal & Chaudhry, 2012) and Canada (Sohal, 2008) suggest fear, lack of social support, lack of motivation, and misunderstandings. Health literacy, cultural practices and misconceptions regarding diabetes have also been reported in other SA population (Murugesan, Snehalatha, Shobhana, Roglic, & Ramachandran, 2007).

5.2.1 NICE Guidance (2016)

Early intervention to prevent T2D is considered as part of an integrated package of measures to promote health and prevent a range of non-communicable diseases. For example, in the UK, NICE (2016) guidance recommended national action to address the adverse environmental factors driving the increasing prevalence of T2D.

NICE (2016) also recommends culturally appropriate interventions, which take account of the community's cultural or religious beliefs, language and literacy skills (Ali et al., 2017). This can be done by using community resources to improve awareness of and increase access

to interventions. E.g., they involve community leaders or organisations early in the development stage. In addition to this, consider how closely aligned people are to their ethnic group or religion and whether they are exposed to influences from both mainstream and their community in relation to diet and PA.

Disease risk is often characterised as unidimensional with a specific range of probability; risk is a complex term with multiple dimensions (Kruk & Czerniak, 2013). Risk can be presented as a probability of, or vulnerability to disease, and a consequence or seriousness of a disease (Mrazek & Haggerty, 1994). In this context, Risk can be calculated (deemed Actual Risk, AR). AR is the fundamental underlying risk, based on the Diabetes UK (2016) risk assessment of developing T2D.

Conversely, risk can also be presented as a psychological measure; something dreaded, such as lack of control or fatality or unknown (effect delayed) (Bodemer, Ruggeri & Galesic, 2013). Personal Risk Perceptions (RP) differs among both individuals and groups. For example, wide gaps exist between health professional's opinion of risk and a lay individual's perception of the same disease (Walker et al., 2003). When people are not aware or lack acknowledgements of their personal risk, it may prevent them from taking necessary actions to alleviate the problem or prevent it from getting worse (Bond & Nolan, 2011). NICE (2018) introduced UK guidelines to identify individuals at 'high-risk' of developing T2D. These guidelines advocated the use of validated risk assessment tools to identify individuals AR of developing T2D. However, it has been acknowledged that risk assessment scores have not been routinely used to recognise people at high risk of developing T2D (Penn et al., 2018).

Ethnic differences in diabetes care contribute to the most adverse outcomes for those from BAME groups. SAs are reluctant to make use of health service interventions, due to language barriers, lack of cultural information available and cultural beliefs (Sohal, Sohal,

King-Shier & Khan, 2015). Recently, interventions targeting diet and PA have been implemented to reduce the risk of T2D among SA populations. However, trials evaluating lifestyle interventions in these groups only show moderate effects (Brown et al., 2017). This indicates that strategies investigated in intervention trials among SA to date are not entirely appropriate for this population. As Study 1 found, within the SA population, there were significant variations in understanding the risk of T2D, and the barriers to implementing change. Prevention of T2D for SAs on a national scale is an uphill task because of the multitude of barriers. Therefore, interventions require a multifaceted approach by evolving cheap and far-reaching strategies to educate, train and motivate the SA public regarding diabetes (Ambady et al., 2013).

It is unclear if individuals at increased risk for T2D perceive themselves to be high risk (Godino, Van Sluis, Sutton & Griffin, 2014). If high-risk individuals do not recognise that they are more susceptible, they may not be responsive to efforts aimed at promoting risk-reducing behaviours (e.g. attending a National Diabetes Intervention or engaging in healthy lifestyle behaviours). RP plays a significant part in the clinical care and self-management of SAs (Macaden & Clarke, 2006). Those who are identified as high AR are encouraged by health professionals to monitor their behaviour, engage in self-care and manage their own risks. However, the successful self-management of T2D is dependent on how it is perceived as a risk (RP) to health, which can influence health behaviours (linked to HBM).

Studies that have assessed RP of T2D have focused on differences according to family history and report that individuals deemed to be at high risk due to family history, are not aware of their increased AR (Godino et al., 2014; Heidermann et al., 2019). In an epidemiological study with 4345 adults, those adults with a family history of T2D were more likely to report making a change in general lifestyle behaviours to prevent diabetes. Although family history is a significant AR factor, it is only one of the numerous influences of risk. According to the

population-based German Cooperative Health Research with 2186 adults, (including 94 with undiagnosed diabetes (4.3%) and 773 with prediabetes (35.4%), most of the sample, with either undiagnosed diabetes or prediabetes, estimated their probability of having diabetes as negligible, low or very low; hence their RP was low. This was further reinforced by numerous studies (Barnett et al., 2006; Kanaya et al., 2010; Pitts-Tucker, 2012). Kowall et al. (2017) found that three out of four individuals believed that the probability of having undetected diabetes was low or very low. More than 70% of people with prediabetes believed that they were not at risk of developing T2D in the next few years (Shah & Kanaya, 2014).

The previous qualitative study (Chapter 4) found that SA people do not consider diabetes to be an immediate personal health risk (Pujilestari, Ng, Hakimi & Eriksson, 2014). They believe the threat to be ubiquitous and inevitable. This raises the possibility that SAs underestimate diabetes RP compared to White populations and research is needed to understand how RP influences adult's engagement and maintenance in risk reduction activities.

Previous research investigating the risk of diabetes and participant demographics such as ethnicity has not been well documented. There are minimal studies that have examined RP vs AR, in more than one ethnic group and explored how ethnicity may influence diabetes self-management behaviours and public health preventative initiatives (Yang & Yang, 2019). Whilst SAs might be more statistically vulnerable to developing T2D; there is a need to understand why they may not engage with preventative interventions to modify their lifestyle behaviours. Hence, it is proposed there is a social-psychological barrier in beliefs towards developing T2D, and this is manifested as a gap between their calculated Actual Risk (AR, which is what NDPP referral and other health professionals focus on), and the individuals RP towards T2D. If it could be understood, such a gap exists and is more prominent in SA compared to White populations; then this can help inform public health strategies on how to target those at higher risk and justify why there is a need to focus on specific population groups.

Aim

This study examined the relationship between RP and AR among SA and White populations in T2D prevention.

Hypothesis

H1: There will be a main effect of AR on RP, such that people at high AR will not have high RP of developing T2D.

This prediction is based on previous research showing that people at high risk (those with prediabetes or categorised high risk on risk assessment tool) underestimate their risk (Kowall et al., 2017; Shah & Kanaya, 2014). Although previous research has based AR status on a clinical measure (e.g. blood analysis), not a calculated diabetes risk score, nevertheless, these findings provide some support for the hypothesis.

H2: There will be a main effect of ethnicity on RP: such that SAs will perceive less risk of developing T2D than White participants.

This prediction is based on previous research, which seems to indicate that SA communities underestimate their risk of developing T2D greater than White's, but the evidence is inconclusive (Barnett et al., 2006; Kanaya et al., 2010; Pitts-Tucker, 2012).

H3: There will be an AR x Ethnicity interaction such as SA participants will have a significantly lower RP score compared to the White group, but only amongst individuals at high AR.

5.3 Methods

5.3.1 Design

This study used a 2 (Ethnicity: SA Vs White) x 3 (T2D Actual Risk: Low/Med/High) between-groups factorial design with six outcome variables. The Dependent Variables (DV) were RP (total score); assessed by subscale scores of 1) Personal Control (LoC: reflecting individuals' beliefs regarding the extent to which they are able to control or influence outcomes); 2) Worry (concern/anxiety about developing diabetes); 3) Comparative Disease Risk (measure of perceived risk across 15 diseases and conditions); and 4) Environmental Risk (influences of the environment on the risk of developing diabetes) and 5) Optimistic Bias (less likely to develop T2D) (Walker et al., 2003). A quasi-experimental design was used in this study because the Independent Variable (IV) was ex post facto, and people were not randomly assigned (Cohen, Manion & Morrison, 2000). Ethical approval for this study was granted from the Liverpool John Moores Ethics Committee (17/NSP/022).

5.3.2 Participants

The research team recruited a purposive sample of SA and White participants. Eligibility criteria included over the age of 18; residing in the United Kingdom (UK); no current diagnosis of T2D; and self-identified as SA or White /White British. For the purposes of this study, ethnic groups were informed by the UK Census. According to the most recent census, 81.9% of the UK population were defined as White/ White British. Overall South Asian/South Asian British accounted for 5.3% of the UK population (identified as Indian, Pakistani, Bangladeshi sub-groups (ONS, 2011).

5.3.3 Materials

Participants completed a batch of validated questionnaires as follows:

- 1) The Personal-Information questionnaire collected participant demographic data, which included: SA ethnicity, age, gender, religion, family history and education level.
- 2) RP was assessed using the validated Risk Perception Survey of Developing Diabetes (RPS-DD) questionnaire (Walker et al., 2003) (Full details in the Methodology Chapter 3).
- 3) AR of developing T2D was measured using the Diabetes UK (DUK) risk assessment tool “Know your Risk Assessment Tool” (NICE, 2019) (Full details in the Methodology Chapter 3).

5.3.4 Data Collection

Non-probability sampling techniques were adopted for recruitment of participants. Targeted snowball sampling (Johnson, 2014) invited SA and White individuals to participate in the online survey. Invitations to participate were sent out via email, online, and text messaging services to potential participant groups and individuals known to the research team. In addition, the researchers targeted community venues (e.g. cultural organisations in SA residential areas in North-West England) in an effort to recruit a convenient sample. In these settings, paper copies of the study information and subsequent questionnaires were available and given out to random members of the public.

Interested participants were presented with a plain language description of the study (PIS) and consent information. Subject to the participant indicating informed consent, eligibility screening commenced. Eligibility assessed individuals as self- identified as SA or White ethnicity and were over the age of 18 with no diagnosis of diabetes (any type). Ineligible participants were screened out and presented with a message thanking them for their interest.

Eligible participants were then presented with the questionnaires to complete. Upon completion, participants were provided with debriefing information.

Online participant data was downloaded for analysis in SPSS v.25 (IBM Corp, 2017).

Hard copy questionnaire responses were entered manually into SPSS and checked by another member of the research team for accuracy.

5.4 Results

5.4.1 Participants

The study sample consisted of n=209 adults from SA (n= 114) and White (n= 95) ethnicity. The sample was a near equal split of males and female, 105 males and 104 females, between the ages of 18 and 75 ($M= 37$ years old, $SD = 12.81$). Of the SA sample (n=114), n42 were SA Indians, n37 Pakistani and n35 Bangladeshi. The White sample (n=95) consisted of n79 White British and n16 White Irish.

Table 5.1: Demographic Information for All Participants.

		Total	South Asian	White
Ethnicity		n=209	55	45
SA	Indian		20	
	Pakistani		18	
	Bangladeshi		17	
White	British			37.5
	Irish			7.5
Age (Years)				
	18-25	21	12	31
	26-32	18.8	27	12
	33-40	23.5	32	17
	41-47	16.2	23	11
	48-54	9.4	9	12
	55-62	6.7	8	6
	65-75	4.4	3	6

Gender				
	Male	50.5	58	47
	Female	49.5	56	48
Family History				
	Yes	45.7	73	22
	No	54.3	41	73
Religion				
	Christianity	36.2	0	76
	Islam	47.6	100	0
	Hinduism	7.2	14	0
	Atheism	7.6	0	16
	Prefer Not to Say	1.4	0	3
Education				
	High School	14	10	3
	College/Sixth Form	53	26	27
	Degree	75	37	38
	Masters	26	14	12
	PhD	5	2	3
	Other	4	3	1
	No Education	28	21	7
	Did not disclose	5	1	4
BMI				
	< 18.5	9	3	5
	18.5 - 24.9	113	55	58
	25 - 29.9	66	38	28
	30 - 39.9	19	16	3
	> 40	3	2	1

5.4.2 Descriptive Statistics

The descriptive statistics, displayed in Table 5.2, provide the Means and Standard Deviations for each of the IVs and the DV used in this study.

There were significant differences in demographic characteristics between ethnic groups. For example, more SA reported a family history of T2D compared to White participants, and more SA participants were likely to have stated that they did not have any form of education compared to White participants (See Table 5.2 for statistics). Between - groups, there were no significant differences between the SA and White population on age, gender, education, or BMI ($p > .05$). There were significant differences between groups on religion and family history of T2D ($p < .05$). The majority of the SA sample were Muslims whilst the White sample were Christians. A higher proportion of the SA sample reported that they had a family history of T2D compared to the White sample.

Participants were assigned to either a low/increased or moderated to high risk category based on the point system scoring guide from the Diabetes UK risk assessment tool (see figure 1.5 for scoring guide for risk category). As there was no participants that scored on moderate risk, the researcher decided to combine the moderate and high-risk category together (anyone scored between 16-47 on the risk assessment was assigned to this category). Based on the means and standard deviations, the SA moderate to high-risk participants ($M = 22.09$, $SD = 5.65$) had a higher AR score compared to the White participants ($M = 18.5$, $SD = 1.19$). In addition to this, the moderate to high-risk participants had a higher RP score. However, this was more prominent in White's ($M = 64.87$, $SD = 11.45$) compared to the SA ($M = 57.72$, $SD = 9.08$) participants. In addition to this, the White group scored higher on all RP variables, except Worry in the moderate to high-risk group, compared to the SA participants. In the Personal Control group, the SA moderate to high-risk participants had lower control over their risk ($M = 10.36$, $SD = 2.27$) compared to the White participants ($M = 13.62$, $SD = 1.40$).

However, despite the differences, the SA moderate to high-risk group, scored higher on Worry ($M = 4.66$, $SD = 1.16$) compared to the White individuals ($M = 4.00$, $SD = 0.92$), indicating the SA group were more concerned about the risk of developing T2D compared to the White group (See Table 5.2).

Table 5.2: Descriptive Table for All Variables (*M & SD*)

	All Participants				South Asian				White British			
	Total sample	Low risk	Increase d risk	Moderate /high risk	SA total sample	Low risk	Increase d risk	Moderat e /high risk	White total sample	Low risk	Increase d risk	Moderat e / high risk
	n=209	n=57	n=72	n=80	n=114	n=8	n=34	n=72	n=95	n=49	n=38	n=8
Actual Risk	13.15 (8.44)	3.15 (2.36)	11.52 (2.24)	21.73 (5.47)	18.07 (7.17)	6 (0)	12.4 (2.01)	22.09 (5.65)	7.24 (5.56)	2.69 (2.22)	11 (3.01)	18.5 (1.19)
Risk Perception Total Score	54.75 (9.37)	49.92 (8.19)	54.48 (8.36)	58.43 (9.51)	56.65 (8.99)	53.50 (6.02)	55.14 (9.21)	57.72 (9.08)	52.48 (9.36)	49.34 (8.40)	53.89 (7.61)	64.87 (11.45)
<i>Risk Perception Subscales</i>												
Personal Control	11.29 (2.29)	12.17 (1.77)	11.27 (2.33)	10.68 (2.41)	10.61 (2.47)	12.25 (2.43)	10.76 (2.77)	10.36 (2.27)	12.11 (1.75)	12.16 (1.67)	11.73 (1.78)	13.62 (1.40)
Worry	4.33 (1.18)	4.08 (1.12)	4.22 (1.23)	4.60 (1.15)	4.57 (1.12)	4.62 (0.74)	4.35 (1.12)	4.66 (1.16)	4.04 (1.20)	4.00 (1.15)	4.10 (1.33)	4.00 (0.92)
Optimistic Bias	5.36 (1.24)	5.98 (1.00)	5.31 (1.28)	4.96 (1.19)	4.94 (1.18)	5.62 (0.74)	5.05 (1.30)	4.81 (1.15)	5.86 (1.12)	6.04 (1.04)	5.55 (1.24)	6.25 (0.70)
Personal Disease Risk	22.2 (6.64)	19.31 (5.47)	22.27 (6.07)	24.28 (7.17)	22.59 (6.28)	21.12 (5.91)	21.64 (6.63)	23.20 (6.15)	21.81 (7.06)	19.02 (5.41)	22.84 (5.54)	34.00 (8.78)
Comparative Environmental Risk	14.84 (3.10)	14.68 (2.64)	14.58 (2.89)	15.20 (3.57)	15.05 (3.43)	15.62 (1.99)	14.97 (3.26)	15.02 (3.65)	14.60 (2.66)	14.53 (2.71)	14.23 (2.51)	16.75 (2.31)

* For significant relationship, please refer directly to statistical analysis below

* (=) SD's

The correlation statistics presented in Table 5.3 provides the correlations and significance levels for each of the IVs. Correlations were examined as a check for possible collinearity between IVs. It is noted that Personal Disease Risk and Comparative Environmental Risk correlated highly with each other.

Table 5.3: Correlations Statistics for All Variables on total sample.

Variables	(1)	(2)	(3)	(4)	(5)	Mean	SD
1) Personal Control	-					11.30	2.29
2) Worry	-.094	-				4.32	1.19
3) Optimistic Bias	.008	-.237 ^a	-			5.35	1.24
4) Personal Disease Risk	.145	.356 ^a	-.312 ^a	-		22.26	6.63
5) Comparative Environmental Risk	.188 ^a	.169	-.049	.465 ^a	-	14.84	3.10

Note. ^a $p < .05$, total sample size is 209.

5.4.3 Assumptions

Before conducting a One-Way ANOVA and MANOVA, there were assumptions to be tested. The Kolmogorov-Smirnov (KS) normality test was used to compare the cumulative distributions of two data sets. Within this study's data set, the KS indicated all the variables for the SA, ($D (115) = .115, P = .001$), and White ($D (95) = .189, P = .001$) data significantly deviate from a normal distribution. Further testing was conducted to explore this issue further through boxplots, histogram, outliers, kurtosis and skewness. There were outliers present in the Worry, Personal Disease Risk and Comparative Environmental Risk subscales, and the histograms graphs showed the data was skewed and indicated that there wasn't a normal distribution. Ideally, variable distribution should resemble a bell-shaped curve to reflect a normal distribution of residuals (Field, 2005), and this wasn't evident for the independent variables in this study. Furthermore, the normal probability plots indicated that the IVs didn't have a normal distribution. Preferably, the points of normal probability plots form a straight line that represents a normal distribution (Field, 2005). Based on these assumption results, the data set in this study had violated the assumption of normality. Furthermore, as a means of checking multicollinearity, the correlations should be low or moderate. If correlations were .60 or above, this would be resolved by either making a composite variable or eliminating one of the dependent variables. Within this study, all the correlations were low or moderate and were not above .60, and hence Personal Control, Worry, Optimistic Bias, Personal Disease Risk, Comparative Environmental Risk and Total Risk Score (DV's) were not eliminated.

Furthermore, The Box's Test of Equality of Covariance Matrices checks the assumption of homogeneity of covariance across the groups using $p < .001$ as a criterion. This assumption was violated in this study as Box's M (134.0) was significant, $p (.003)$

< a (.001). The explanation for this is that the Box's test is sensitive to departure from normality. If the sample comes from a non-normal distribution, then Box's test may simply be testing for non-normality.

Based on the violations of assumptions, a bootstrapping technique was used to analyse the data without any removals of outliers.

5.4.4 Bootstrapping

As the sample size was relatively small compared to the number of groups used in the study, this could be an explanation why the data violated the assumption of normality; therefore, the more stringent Bootstrapping technique was adopted (Konietzschke, Bathke, Harrar & Pauly, 2015) to run a MANOVA. Bootstrapping is, by far the most prevalent method of validating statistical findings. Random samples (1000's of them) of the dataset is taken, statistical analyses are run on each random sample, and a 95% bootstrap confidence interval for the primary finding is generated. If the bootstrap confidence intervals are relatively narrow, then the researcher can assume the results are valid. With this in mind, the bootstrapping technique was the ideal solution to be used due to the relative sample size.

5.5 Main Analysis

5.5.1 Multivariate tests

Here Wilks Lambda is used to test whether there were differences between the means of identified groups of subjects on the combined (composite) DVs (Allen, 2017). Therefore, after the preliminary assumption tests, the multivariate test performed in the MANOVA showed that there was a statistical difference between all people in different AR group on all of the DVs (RP constructs), ($F(10, 398) = 5.20, p < .001$; Wilks' Lambda = 0.78; partial $\eta^2 = 0.11$). Supporting hypothesis 1.

In addition to this, the multivariate test pointed out that there was also a statistically significant difference between ethnicity and the combined DVs, ($F(5, 199) = 11.82, p < .001$; Wilks' Lambda = 0.77; partial $\eta^2 = 0.22$), supporting hypothesis 2.

Finally, the multivariate test demonstrated that there was also a statistically significant difference between the AR group and ethnicity on the combined DVs, ($F(10, 398) = 4.21, p < .001$; Wilks' Lambda = 0.81; partial $\eta^2 = 0.09$). Supporting hypothesis 3 (see appendix 5.1).

5.5.2 Test of between-subject's effects

After the significant results of the multivariate have been confirmed, further investigation in relation to each of the DVs follows. This information is given in the test of between-subject effects.

Hypothesis 1: There will be a significant main effect of AR on RP, such that people at high AR will not have high RP of developing T2D. Hypothesis 1 partially accepted.

The main effect for T2D AR group had a statistically significant difference in total RP $F(2, 203) = 9.85, p < .001$. Considering the specific concepts of RP on AR group had a statistically significant difference in Personal Disease risk subscale $F(2, 203) = 15.96, p < .001$. However, on all the other subscales, there was not a statistically significant difference. Participants categorised as Moderate or High AR had greater RP score compared to people from Low and Increased AR.

Hypothesis 2: There will be a significant main effect of ethnicity on RP, such that SAs will perceive less risk of developing T2D than White participants. Hypothesis partially accepted.

The main effect for ethnicity did not have a statistically significant difference on total RP $F(1, 203) = 8.98, p > .05$. However, when considering the specific constructs of RP: there was a statistically significant difference on ethnicity for RP, indicating that White participants had significantly higher levels of: Personal Control $F(1, 203) = 11.05, p < .001$ ($M = 12.11, SD = 1.75$) compared to SA ($M = 10.61, SD = 2.47$); Optimistic Bias $F(1, 203) = 12.23, p < .001$ ($M = 5.86, SD = 1.12$) compared to SA ($M = 4.94, SD = 1.18$). However, white participants had significantly lower levels of Personal Disease Risk $F(1, 203) = 7.80, p < .001$, ($M = 21.81, SD = 7.06$) compared to SA ($M = 22.59, SD = 6.28$) and had significantly lower levels of Worry $F(1, 203) = 5.10, p < .05$, ($M = 4.66, SD = 1.16$), compared to SA ($M = 4.66, SD = 1.16$).

There was not, however, a statistically significant difference in ethnicity on Environmental risk subscale $F(1, 203) = 0.03, p > .05$ White participants ($M = 16.75, SD = 2.31$) compared to SA ($M = 15.02, SD = 3.65$).

Hypothesis 3: There will be a significant AR x Ethnicity interaction such SA participants will have a significantly lower RP score compared to the White group, but only amongst individuals at high AR. Hypothesis accepted

The main effect indicates there was a statistically significant difference of ethnicity and diabetes AR interaction on total RP $F(2, 203) = 3.40, p < .05$. Investigation of the mean scores indicates that the SA group had lower levels of risk perception scores when they were in the high-risk group ($M = 57.72, SD = 9.08$) compared to the White British group ($M = 64.87, SD = 11.45$). In addition, with reference to the specific constructs of RP, significant interactions between ethnicity and AR were found for: Personal Control $F(2, 203) = 4.67, p < .05$; Personal Disease Risk $F(2, 203) = 9.11, p < .001$. However, no other subscales were significant ($p > 0.05$).

5.6 Discussion

This study is unique in its examination of associations between RP vs AR of T2D among SAs and White population. This study fills important gaps in the literature in the field of RP of T2D. At a time when many health systems are introducing diabetes risk assessments (DUK/NHS), and knowledge about the risk of developing disease is a key element of public health campaigns, it is surprising that there is limited information on how people understand their risk of T2D, and why ethnic groups such as SAs don't participate in lifestyle interventions. Public health prevention programmes and campaigns assume that one approach fits all, starting from how the risk scores are calculated through to how they are communicated and understood by the individuals being assessed. While there are studies focusing on RP (Adriaanse et al., 2003; Harwell et al., 2001), studies particularly focusing on RP and actual risk in SA and White are rare. Based on these findings, it suggests that individuals who were categorised as moderate to high AR of T2D scored greater on their RP scores. However, when this was investigated further, this was more apparent in the Whites compared to the SA individuals. White participants were more aware of their risk compared to the SA participants, especially if they were from the moderate/high AR group, that is SA had lower RP than White's.

The results regarding T2D RP indicated that, on average, SA individuals did not perceive themselves to be susceptible to developing T2D when compared to White participants. Clinically, SA individuals were at the highest AR of developing T2D. However, still did not perceive their own personal risk as high, and they believed that they were not at risk of developing T2D. Understanding how individuals perceive their T2D risk is vital, according to the HBM (Becker, 1974), individuals who perceive more risk tend to take actions for screening and other preventive measures. Therefore, it is

imperative to understand how an individual's perception of diabetes risk differs by ethnic groups to be able to implement early preventive intervention strategies.

When investigating the RPS-DD subscales, White individual's had higher scores on personal control and optimistic bias. Underestimating one's diabetes risk indicates an optimistic bias concerning negative health outcomes. Weinstein (1980) suggested potential explanations for optimistic bias about susceptibility to health problems. Unrealistic optimism is more likely when people lack previous experience with a disease and when they perceive their disease risk as controllable as found in the subscales whereby SAs and White's differed. Weinstein (1980) found having a strong perception of controllability of an event increases optimism bias. That is, the greater the belief in influencing the outcome of an event, the greater the tendency to believe in higher chances of experiencing positive outcomes. This is reinforced by the findings in this study, as the White individuals had higher optimistic bias scores than SAs. These results are consistent with past studies that have indicated it is more likely for individuals to stereotype others as being more prone to acquiring a chronic disease like diabetes than do themselves (Klein & Helweglarsen, 2002; Mongielo, Freudenberg, Jones & Spark, 2016). In addition to this, White's scored higher on personal control compared to the SAs. This shows that these individuals had a strong perception of controllability of an event compared to the SA community, which indicates that the risk of developing diabetes may be perceived outside their control (Kowall et al., 2017). Optimism, sense of personal control and the ability to find meaning in one's life experiences are valuable psychological resources believed to be associated with mental health (Seligman, 1998). These psychological resources become more important when people are faced with challenging or threatening events (Taylor, 1983). They may act as reserves, enabling people to cope more effectively with such events. Whilst Whites were found to have positive protective traits such as

personal control and optimism to influence their RP, SAs have higher levels of worry within the risk of developing T2D. Worry is a characteristic of anxiety (Borkovec, Robinson, Pruzinsky & DePree, 1983) and such psychological states such as anxiety and depression have a variety of physiological concomitants and have been related to altered immune processes (Herbert & Cohen, 1993) and to the development and course of T2D. Strine et al. (2008) reported that smoking, PA, and obesity are significantly associated with a lifetime diagnosis of anxiety; these behaviours are known to increase diabetes AR. This can be relevant to the SA population, as high levels of anxiety/ worry can have an impact on RP. However, the majority of studies investigating anxiety and risk of T2D have been inconclusive (Edwards & Mezuk, 2012; Sun et al., 2016). Therefore, there is a need for future research investigating the role of anxiety on RP of developing T2D, especially focusing on the SA population.

There is independent evidence that positive emotional states are linked to positive physiological changes (Fredrickson, 2001). Positive beliefs are tied to physiological changes by positive affect (Chiew & Braver, 2011). Furthermore, positive beliefs are also connected to physical disease by promoting better health behaviours (Ownby, Acevedo, Jacobs, Cabellero & Waldrop-Valverde, 2014). People who believe in their own control and optimism about the future may be more likely to practice conscientious health habits and use services appropriately. Therefore, we can assume that these positive psychological resources are more pertinent in the White group, which had a positive impact on RP.

Furthermore, the subscale personal disease risk (knowledge), indicated there was a higher mean score for the moderate/high-risk group for the White individuals compared to the SA individuals. This subscale is the overall measure of the respondent's knowledge of the risk of developing diabetes. This shows that the White individuals were more

knowledgeable about their risk of developing diabetes compared to the SA individuals. Knowledge of risk factors of diabetes seems to be generally lacking within the SA participants; therefore, their RP of developing diabetes was lower than the White participants. This is in line with previous studies, for example in a large population-based study focused at understanding the risk of diabetes amongst Singaporean's and related health preventive behaviours, the researchers were able to conclude that better understanding of the disease was associated with favourable behaviours (Wong & Toh, 2009). Researchers noted that though the participants in the study understood the importance of knowledge of risk factors of diabetes and healthy behaviours, this knowledge never translated to healthier lifestyle behaviours. Ethnic minorities including SAs have always reported lower levels of PA, poorer diets when compared to the general population (Leung & Stanner, 2011; Mathieu et al., 2012; Muilwijk et al., 2018).

Hivert, Warner, Shrader, Grant & Meigs (2009), indicate that higher perceived diabetes risk does not often accord with greater intentions of behaviour changes, this shows that people may not have an accurate knowledge which lifestyle are appropriate to reduce their risk (i.e., low response efficacy), or they do not believe in their ability to execute the recommended behaviour changes. Due to the heightened level of prevalence of diabetes today, studies have emerged that try to determine or measure the level of understanding of their respective population of this disease (Nazar, Bojerenu & Marwat, 2016; Well et al., 2016). This understanding is very important because people must be fully involved in the prevention of the disease. This implies a general understanding and awareness is considered a first and most important step in actions aimed at reducing the threat of diabetes (Allen, Purcell, Szanton & Dennison, 2010). The above analyses indicate the need for interventions tailored at empowering the SA community to be involved in the prevention of this disease. Therefore, it is imperative for the NHS and

health professionals to understand how individuals' perceptions of diabetes risk differ by racial/ethnic group to implement early tailored preventative interventions to reduce disparities.

5.6.1 Strengths and limitations

This study contributes to new evidence to our knowledge, and to my knowledge, this is the first UK study to investigate the differences that exist between an individual's AR (clinical) compared to their RP. In 2013, the ADA called "for research to focus on how social determinants, including ethnicity influence behaviours for the prevention and management of diabetes with ethnic minorities". As such a large-scale American Study was conducted (Yang, Baniak, Imes, Choi & Chasens, 2018), which examined associations between RP and AR of T2D by race and/or ethnicity and found 'Asians' were least likely to perceive lifestyles behaviours as risk factors for T2D. Yang et al. (2018) concluded that ethnic/race differences are significantly different within populations, as demonstrated between RP and AR. If individuals do not recognise their AR and their perceptions are skewed, then they are unlikely to attempt to change modifiable lifestyle behaviours, to reduce AR of T2D. However, Yang et al. (2018) study did not specify their 'Asian' classification. Based on this, it was unclear which groups belonged in this ethnic classification, and in the total sample, only 5% were represented as Asians. In addition to this, RP was measured by two questions and didn't use a validated RP tool. RP is a complex topic and requires more in-depth investigation (Ferrer & Klein, 2015). In contrast to Yang & Colleagues (2018), this study used the validated RPS-DD to investigate the different constructs of RP and also a majority of the participants in this study were SA and representative to the local population. Therefore, to my knowledge, this is the first study to investigate RP and AR of T2D in SA and White participants in the UK and Worldwide.

5.6.2 Conclusion

This study was designed to measure RP and AR in the SA and White populations. This study showed that when RP was compared to AR, associations differed statistically by ethnicity. Data collected for this study revealed a lack of knowledge of the risk factors of T2D in the SA population. The lack of knowledge of risk factors of diabetes within this population was found to be consistent with previous studies. Furthermore, the data collected for this study reveals on all RP variables except worry, the White individuals scored higher compared to the SA population, based on this understanding, the SA individuals that are clinically at high AR of developing T2D underestimate their risk. Those delivering the diabetes prevention programme (DPP) should consider how information about risk is provided in order to optimise efforts to reduce disease incidence in the SA population. Therefore, there is a need for a targeted intervention exploring delivery messages about RP on the SA population in order to alter their RP of T2D.

5.6.3 Key points & unique contribution from this study

- To my knowledge, this was the first study to investigate RP and AR of T2D in SA and White population in the UK and worldwide.
- Individuals who were categorised as moderate to high AR of T2D scored greater on their RP scores. However, when this was investigated further, this trend was more apparent in the White compared to the SA individuals.
- Furthermore, certain psychological constructs such as personal control were higher in White's compared to SA. However, SAs had higher levels of anxiety/worry.
- Based on these findings, future research was warranted to investigate the concept of personal control and anxiety and stress in the SA population.

6 Chapter 6: A Mixed-Method Study: Investigating the Dimensions of Locus of Control and Current Psychological State in South Asian Populations

6.1 Study 3 – Chapter Overview

As highlighted in earlier chapters (Chapters 4 & 5) within the SA population, there is variance in RP of developing T2D and is the impact of socio-cultural barriers within the community. Based on Study 2 findings, SA participants had higher levels of worry/anxiety and lower levels of personal control, and it was pertinent to further explore these dimensions. Therefore, this study purely focuses on SA participants as a target population to investigate Locus of Control (LoC) and current psychological state (DASS) and investigate their relationships with RPs.

A mixed-method approach was used, consisting of 99 SA adults from the North West of England and Merseyside (Bolton, Blackburn, Preston, Manchester and Liverpool). Participants were given three questionnaires, RPS-DD, Multidimensional Health Locus of Control and DASS. In the qualitative phase, 11 SA participants without a diagnosis of T2D were recruited from various community and religious settings across the North West of England. In line with Grounded Theory (Strauss & Corbin, 1990), data collection and analysis coincided.

Chance, Other People and Powerful Others had a significant impact on SA participants RP. SA participants had an external LoC over their lifestyle behaviours. In addition to this, anxiety had a significant impact on RP, compared to depression and stress within the SA participants. For the qualitative findings, the core category Disengagement with health behaviours was informed by the interaction of the following three categories: Patronage of the family; Insufficient culturally care and Power of the externals

The findings suggest that Health LoC (HLoC) and DASS made a significant contribution to the variance in RP within the SA participants. Therefore, future interventions need to consider how key messages are portrayed in public health campaigns targeted at SA populations and intervention design should focus on LoC and the role of the SA community.

6.2 Introduction

As found in Study 2 (Chapter 5), there is an interaction between ethnicity, AR and RP whereby SA that were at a high actual risk of developing T2D had lower levels of RP compared to the White population. This was further explained by the different RP constructs, whereby White's had higher levels of Personal Control, Optimism, Personal Disease Risk compared to the SAs who had higher levels of Worry/Anxiety. As a result of these findings, it was pertinent to explore further the dimensions that influence SA populations more specifically. This study focusses purely on SA participants as a target population as found previously; they are the most at AR for developing T2D. Factors such as LoC and current psychological state (DASS) are to be examined further to understand the complex dimensions that influence RP.

Previous research on diabetes risk, RP and diabetes prevention tends to focus on attempting to change modifiable behavioural lifestyle factors (Yang et al., 2018). For example, the application of research to the National Diabetes Prevention Programme (NDPP) (Penn et al., 2018) focusses on encouraging individuals to change their health behaviours to subsequently improve their health markers such as BMI, smoking status, PA levels and weight status. However, despite interventions focusing on encouraging individuals to improve their lifestyle behaviours, few studies achieve sustainable behaviour change (Davis, Campbell, Hildon, Hobbs & Michie, 2015; Laverack, 2017). Of the interventions available they do not typically focus on supporting individuals to change their psychological wellbeing, aspects of HLOC, psychological states such as anxiety, stress and depression anxiety are known to be both predictors of diabetes risk (clinical AR) and can be a consequence of not engaging in behaviours or may indeed impact on the success of lifestyle behaviour changes, yet limited research has explored

how psychological emotions may influence intervention design and outcomes (Wang et al., 2017).

The concept of LoC originated as a fundamental element of the SLT of personality (Rotter, 1966). LoC refers to the extent to which a person believes that reinforcement is dependent upon his or her own behaviour or personal qualities. People with high internal LoC believe that they will receive reinforcement based upon their own behaviour and actions. In contrast, people with high external LoC believe that regardless of their own behaviour and actions, their fate rests in the hands of chance, or other more powerful bodies (Rotter, 1966). In other words, internal LoC refers to the perception of positive or negative events as being the consequence of one's own actions, whereas external LoC refers to the perception of positive or negative events as being unrelated to one's own behaviour beyond personal control. Norman, Barnett, Smith & Murphy (1998) performed a large-scale analysis of Multidimensional Health Locus of Control (HLoC), health value and likelihood to participate in health behaviours in 11,632 individuals from the UK. Individuals scoring high on the internality scale were more likely to participate in several health behaviours. Those who believed that chance and fate played a role in their health status were less likely to engage in preventative health behaviours. Furthermore, a strong belief in powerful others was found to be linked to the performance of fewer health behaviours. Collectively, HLoC studies have shown that individuals who tend to internalise in their health beliefs are more likely to participate in preventative health behaviours than those individuals who are external in health beliefs (Davis et al., 2015). More specifically, there are studies that support significant relationships between internal LoC and metabolic control of diabetes (Morowatisharifabad et al., 2010; O'Hea et al., 2005). In these studies, a positive relationship was found between internal LoC and adaptation to diabetes management. However, these studies are specific to the

management of T2D and not investigating prevention and influence on RP. In addition to this, these studies are not considering the role of ethnicity in HLoC. Therefore, to our knowledge, there are no studies which investigate the role of HLoC and current psychological state within the UK SA population and how these traits impact RP.

SA individuals tend to perceive that somebody else will take control of illnesses and in their minds transfer the responsibility to their health professional rather than recognise it as their own (Hjelm et al., 1998). Similarly, SA individuals often expect doctors to know all the answers and make all the decisions (Ha & Longnecker, 2010). SA individuals often assume a passive role, preferring to be told what to do, rather than actively participating in their healthcare decisions (Kannayiram & Chopra, 2006).

The belief that individuals can have special control over their health automatically has a positive psychological and behavioural effect on them. On the contrary, disbelief leads to an individual's loneliness and helplessness (Stenstrom & Andersson, 2000). People with external LoC have more mental disorders compared to individuals that hold an internal LoC (Franca, De Martino, Aniceto & Silva, 2012). Therefore, it can be said that LoC is a diagnostic variable showing an individual's perception of the environment and position, and the role, rate and influence of a person in successful events or failures (Asgari & Vakili, 2012).

In relation to Study 2, it was found that personal control was more pertinent with the White group and less so for the SA participants. Within personal control, there is an element of HLoC. Therefore, it was vital to investigate HLoC in this context to understand which specific constructs influence personal control and RP of T2D.

Previous studies are inconsistent in their findings, and some studies do not find any association or little explanatory power between LoC and health behaviour (Bennett,

Norman, Murphy, Moore & Tudor-Smith, 1998; Berglund, Lytsy & Westerling, 2014).

Most of the studies, on HLOC in SAs (Greenhalgh et al., 2015; Macaden & Clarke, 2010) have been inpatient populations in individuals who have already been diagnosed with a health condition, such as T2D.

Overall, research on T2D prevention has predominately focussed on obesity and PA, and these are well-established risk factors, but less is known about the psychosocial effects on diabetes risk. Some evidence has suggested that general emotional stress (Rod, Gronbaek, Schnohr, Prescott & Kristensen, 2009; Zhang et al., 2006) and anxiety or depression (Engum, 2007; Mezuk, Eaton, Albrecht & Golden, 2008) are associated with a higher AR of developing T2D. Psychosocial stress may also contribute to unhealthy lifestyle behaviours that are known risk factors for T2D, such as poor dietary habits, physical inactivity, smoking and alcohol abuse (Bonnet et al., 2005).

Furthermore, depression is the most commonly researched factor in studies of diabetes. Results from two meta-analyses indicate that depression is associated with up to 60% increased risk of developing T2D (Knol et al., 2006; Mezuk et al., 2008). Although levels of depression within the general and T2D populations have been well researched (Ali, Stone, Peters, Davies & Khunti, 2006), the generalizability of the findings to minority populations is less well understood. It has been well established that SA individuals are at elevated risk of developing T2D and cardiovascular disease (Gholap, Davies, Patel, Sattar & Khunti, 2011). As a result, SA individuals may be at increased risk of depression because of the bidirectional relationship between diabetes and depression (Golden et al., 2008). There is some evidence suggesting SA populations have worse mental health than White's (Williams et al., 2015). Much of the previous literature has considered psychological traits (such as depression) as health outcomes.

However, there is limited research that considers the role that psychological states play as influencing factors towards actual health behaviours/outcomes.

Overall, it's known that psychological states such as anxiety, depression and stress can increase T2D AR and that SA individuals are more susceptible to mental health disorders, e.g. higher rates of depression compared to White's. However, there has been no research that has investigated whether these factors influence T2D RP in the SA population.

Therefore, it was decided that a mixed-methods design should be used in this study because by mixing both quantitative and qualitative research and data, the researcher gains a breadth and depth of understanding and corroboration while offsetting the weaknesses inherent to using each approach by itself (Almalki, 2016)

Quantitative Aim

The aim of this study was to investigate HLoC and DASS to see whether these traits predict RP in the SA population.

Hypothesis

H1: Overall, there will be a significantly positive relationship between the HLoC and DASS on RP. HLoC and DASS will predict RP.

H2: Individuals that score higher on External HLoC will have a significantly negative impact on their RP. More specifically, Powerful Others, Chance and Other People.

H3: Individuals that score higher on Depression, Stress and Anxiety will have a significantly negative impact on their RP of developing T2D. More Specifically, Anxiety will be the biggest contributor to RP.

Qualitative Aim

The aim of this study was to develop a GT framework to investigate HLoC and DASS further based on the Quantitative findings.

6.3 Methods

6.3.1 Design

This was a mixed-method study. The quantitative study preceded the qualitative analysis, which was undertaken in order to generate explanations for the quantitative findings and explore SA participants experiences in more depth: this constitutes an explanatory mixed methods design (Creswell & Plano Clark, 2017).

This study tested the outcome variable of RP. The first predictor variable was Health Locus of Control (HLoC), split into the five dimensions, which were: 1) Internal HLoC (I-HLoC); 2) Doctor (D-HLoC); 3) Powerful Others (P-HLoC); 4) Chance (C-HLoC); and 5) and Other People (OP-HLoC). The second predictor variable was DASS, split into the symptoms of Depression, Anxiety and Stress in relation to developing T2D.

This inductive GT (Strauss & Corbin, 1990) qualitative study explored T2D RP, HLoC and DASS within the SA community. Specifically, this study explored the key constructs of HLoC such as the five dimensions mentioned above and the key DASS constructs (see chapter 3 for detailed information on grounded theory process and analysis).

6.3.2 Recruitment and Procedure

The research team recruited a purposive sample of SA living in the UK. Specific eligibility criteria included over the age of 18 years; residing in the UK; no current diagnosis of T2D; no current diagnosis of mental health illness; and from a SA background. The research team collaborated with SA faith-based and cultural organisations in the UK (e.g. Bolton Council of Mosques, BCOM) for recruitment and data collection. BCOM held male and female events and specific groups on set days, and the researcher was invited to attend and collect data directly from these groups. Furthermore, a snowballing sampling technique (Johnson, 2014) was used with these

participants, requesting their engagement in recruitment so to pass the study information to their family and friends.

In addition, a convenient sample of potential participants was recruited through the researchers SA family and friends' network via email and text messages, inviting them to participate in this study. These invitations were forwarded through the family, and friends' social network (snowball sampling) and interested participants could access further information and subsequently complete the online survey in English by clicking on the web link provided in the invitation. Once the participants visited the web link, they were presented with a plain language description of the study (PIS) and an online consent information. Those who agreed they were fully informed of the study, and thus consented to participate, were directed through to the eligibility screening.

Furthermore, the researcher used social media advertising to recruit SA participants. Due to health disparities, it is vital to use different tactics to involve SA participation in health research (Mukkherjea, Ivey, Shariff-Marco, Kapoor & Allen, 2018). Therefore, Twitter, Facebook and Instagram were used to direct potential participants to the Qualtrics link, thus encouraging them to participate in this study.

Eligibility for this study were individuals from SA and over the age of 18 with no diagnosis of diabetes (any type), or of mental illness. Ineligible participants were screened out automatically and presented a message thanking them for their interest. At the end of the survey, participants were invited to provide their email address to receive notifications about future research opportunities; and to address any questions. Provision of an email address was voluntary. As participants progressed through the survey, their data was saved automatically. All online survey responses were logged by the survey platform and downloaded at survey close into data files for analysis in SPSS (IBM Corp,

2017). In addition to online recruitment, participants may have requested to complete the questionnaire in a hard copy format. Hard copy questionnaire responses were entered manually by the researcher into a SPSS data file and checked by the research team for accuracy.

In line with ethical approval, participant consent was obtained prior to questionnaire completion.

Followed by this, the qualitative recruitment procedures included ‘networking’, a form of snowball sampling (Waters, 2014), the lead researcher contacted various SA communities and religious settings to advertise and promote the study across the North West of England. Interested participants were offered appointments to discuss the study at a time and location convenient for them. Following a discussion, explaining the aims and purpose of the study, and seeking informed consent, face to face interviews commenced. Furthermore, participants that took part in the quantitative phase were also invited to take part in the qualitative phase.

6.3.3 Measures

Participants completed a batch of validated questionnaires as follows:

- 1) The Personal-Information questionnaire collected participant demographic data, which included: SA ethnicity, age, gender, religion, family history and education level.
- 2) The Multidimensional Health Locus of Control Scale (MHLC), developed by Wallston, Wallston and Devellis in 1978, was applied to represent beliefs about control of one’s general health outcomes (Full details in the Methodology Chapter 3).

3) Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995) was administered to measure psychological wellbeing and mental health (Full details in the Methodology Chapter 3).

Interviews ranged from 15 to 60 minutes in duration (Mean = 45 minutes). The interviews were informed by a topic guide (Table 6.1) which covered: HLoC, specific dimensions such as Internal, External, Powerful Others; discussions around DASS (mental health); current healthcare experiences and general stigma in the SA community. These topics guided the interview and allowed the researcher to explore the participant's knowledge and perception of T2D. As the study progressed, a constant comparative analysis was applied through simultaneous data collection and analysis. Multiple iterations, including theoretical sampling and amendments to the interview questions, were made as part of this GT process (Strauss & Corbin, 1990).

Table 6.1: Qualitative Interview Guide

SA Interview Topic Guide
Can you tell me how you perceive health?
Do you think you are currently at risk of developing T2D?
Is there anyone in your family who has T2D?
What do you think the causes of T2D are?
Do you think you have control over your health?
If you were to be diagnosed with an illness, who is responsible?
Do you think this is common in the SA community?
Would you go see a doctor if you have an issue with your health?
Do you think there is a disconnect between SAs and health care services?
Can you tell me a bit of depression, stress and anxiety in the SA community?
What do you know about the risk of these conditions in the community?
Why do you think there's such a stigma in the SA community?

6.3.4 Participants

The sample consisted of n=99 adults from SA ethnic background. Of these participants, there were n=60 SA Indians, n=28 Pakistani and n=11 Bangladeshi. This split is representative of the UK populations, as the SA Indians are the highest proportion of SA in the UK, followed by Pakistani and then Bangladeshi (Census, 2011). The participants were 65 males and 34 females, between the ages of 18 and 65 ($M = 36$ years old, $SD = 12.55$). There were differences in religious beliefs within the sample; there were 81 Islam beliefs and 18 Hinduism. Two-thirds of the participants reported a family history of diabetes and just over a third (35.4%) had an education level of degree or

higher, with 19.2% reporting no formal education. For a complete summary of all demographic's information for the quantitative phase please see Table (6.2).

Table 6.2: Participant Characteristics for Quantitative Phase

		Total	SA Indian	SA Pakistani	SA Bangladeshi
Ethnicity					
	Number	99	60	18	11
	Percentage of eligible		60.6	28.3	11.1
Age (years)					
	18-25	19.2	13	7	1
	26-32	33.4	20	11	2
	33-40	16.2	10	2	2
	41-47	6	3	3	0
	48-54	15.2	10	2	3
	55-62	7	3	2	2
	63-75	3	1	1	1
Gender					
	Male	65.7	40	18	7
	Female	34.3	20	10	4
Family History					
	Yes	66.7	36	19	11
	No	33.3	24	9	0
Religion					

	Christianity	0	0	0	0
	Islam	81.8	42	28	11
	Hinduism	18.2	18	0	0
	Atheism	0	0	0	0
	Prefer Not to Say	0	0	0	0
Education					
	High School	13.1	7	4	2
	College/Sixth Form	29.3	15	11	3
	Degree	29.3	19	10	0
	Masters	6.1	5	0	1
	Other	3	2	1	0
	No Education	19.2	12	2	5

For the qualitative phase, eleven male (50%) and female participants without a diagnosis of T2D, aged between 30 to 60 years ($M = 45$ years, $SD = 8.65$) took part in the qualitative interviews. The sample was considered broadly representative of the SA population living in the Northwest of England (Office for National Statistics, 2012). All participants were of SA descent (Indian, Pakistani and Bangladeshi) and proficient in the English language.

6.4 Analytical Procedure

Linear multiple regression analysis was used to measure the relationship of the predictor variables (HLoC & DASS) to the outcome variable (RP Score). According to Field (2005), “Regression Analysis enables us to predict future outcomes based on the

predictor variables” (p. 198). Linear regression attempts to model the relationship between two variables by fitting a linear equation to observed data. Before attempting to fit a linear model to observed data, a modeller should first determine whether there is a relationship between the variables of interest. In a standard multiple regression, all predictor variables are entered all at one in the regression equation, and every predictor is assessed on its unique predictability of the DV (Tabachnick & Fidell, 1996). In order to carry out this analysis, certain assumptions have to be met. In the next few paragraphs, each assumption of the multiple regression analysis is described and evaluated for the data.

6.4.1 Sample Size

In order to preserve the generalisability of the results, the sample size should be a certain size (Pallant, 2005). Fields (2005) suggests for a precise estimate, to use a power analysis. Cohen (1992) provides a clear table from which the precise sample size can be derived. For the power analysis, the level of power, the effect size, the significance criterion and the number of IVs should be known. Cohen used a power level of 0.80 and a significance criterion of 0.05, which are both used generally used values in power analysis, and a medium effect level is chosen, as it is the average size of observed effects in many areas of research (Cohen, 1992). According to Cohen (1992), the required sample size for multiple regression, corresponding to 8 IVs is 97. With a sample size of 99 respondents, the requirement for generalisability is achieved.

6.4.2 Multicollinearity and Singularity

Multicollinearity results from two IVs that are highly correlated (Pallant, 2005). When multicollinearity is present, the regression coefficient might become insignificant because of the large size of standard errors (Tabachnick & Fidell, 1996). Singularity is caused when an IV is a combination of other IVs (Pallant, 2005). Statistical problems

created by singularity and multicollinearity occur at much higher correlations (0.9 and higher) (Tabachnick & Fidell, 1996, p.86). According to Franke (2010), one should hesitate to include two IVs with correlations of 0.8 or more. As all the intercorrelations are below 0.8, all the IVs were retained.

Another measure for multicollinearity is Squared Multiple Correlation of a variable (SMC). The squared measure of multiple correlations serves as DV, with the other variables as IVs. A high SMC means a high correlation between the IVs and therefore results in multicollinearity. Often, the SMC is computed to tolerance for multicollinearity (Tabachnick & Fidell, 1996). The Variance Inflation Factor (VIF) is the inverse of the tolerance value and therefore, also a measure of multicollinearity. If either the tolerance value falls below 0.10 or the VIF exceeds 10, there can be a concern of multicollinearity (Pallant, 2005). In this study, the IVs had SMCs and VIFs within an acceptable range, and thus it can be concluded that there was no multicollinearity or singularity present in this dataset.

6.4.3 Outliers

Multiple regression is very sensitive to outliers, which are either very high or very low scores (Pallant, 2005, p. 143). Outliers are known to distort statistics. In order to find the presence of outliers, any cases with standardised residuals that exceeds -3.3 or 3.3 are defined as outliers (Tabachnick & Fidell, 1996). For the current data, no case was found to exceed either -3.3 or 3.3. Additionally, the Mahalanobis distance was computed to find potential outliers, following Tabachnick and Fidells' alpha level of 0.001. Having 8 IVs, the critical value was 26.12. As no cases with a Mahalanobis distance exceeded the critical value, no extreme values were found. Therefore, it can be concluded that no outliers were present within this data.

6.4.4 Normality, Linearity and Homoscedasticity

Other assumptions for the multiple regression analysis include that the variables were normally distributed, that the relationship between two variables was a straight linear relationship, that the variability of score of one variable was roughly the same for all the other predicted variables, and that the residuals of variables were independent (Tabachnick & Fidell, 1996). Homoscedasticity is related to the assumption of normality. In order to check normality, two components of normality were evaluated, namely skewness and kurtosis. Skewness concerns the symmetry of the distribution, whereas kurtosis refers to the peakedness of a distribution (Tabachnick & Fidell, 1996). If a variable's value for skewness or kurtosis falls within the range of ± 1.96 (Kim, 2013) than the variable is highly skewed. As all values fell within these ranges, it can be concluded that all variables were normally distributed.

Furthermore, as the scatterplot had a roughly rectangular shape, and most scores were concentrated around the centre, it can be concluded that the data was not non-linear or heteroscedastic. As all variables were found to be normally distributed, homoscedasticity could be assumed.

Finally, the independence of residuals is associated with the order of cases and occurs when there is a systematic change over time in the respondents or the research procedure (Cohen, Cohen, West & Aiken, 2003). As this is not the case in this research, it is not probable that the residuals are dependent. This is checked by assessing the Durbin-Watson statistic, which search for serial correlation between errors. The possible values can range between 0 and 4, with the value of two indicating that the residuals are uncorrelated (Field, 2005). For the current data, the Durbin-Watson statistic was 1.62, which indicates that the residuals were independent.

In conclusion, it can be said that the assumptions of normality, linearity, homoscedasticity and the independence of residuals were not violated.

For the Qualitative phase, the interviews were digitally recorded and transcribed verbatim (using the participants chosen pseudonyms). Transcription occurred shortly following each interview to allow for simultaneous data collection and analysis, according to GT methodology (Strauss & Corbin, 1990). This process also shaped the development of the questions for subsequent semi-structured interviews (discussed during on-going reflexivity and discussions between first and last authors).

The data analysis included three rounds of open coding. The purpose of the first round was to develop a code list from the interview data obtained from all participants. To create a code list, the researcher began with line-by-line coding of interviews. Groups of words or lines of text were highlighted until the content shifted to a different topic. At this point, a decision was made to determine if the text belonged to an existing code or a new code. If two or more codes seemed to define the same phenomenon, they were combined. By the end of the first round of open coding, the code list had changed significantly, between coding of interview 1 and interview 11. Therefore, the researcher engaged in two subsequent rounds of open coding that applied the same set of codes to all transcripts. This way, it ensured that the same phenomenon was labelled with a consistent code. After completing the first round, the researcher had developed over 150 highly specific codes that reflected the variation in perceptions and experiences of participants. The subsequent axial coding process involved arranging and rearranging the codes into groups based on the commonality of meaning. Following this, the process of mapping out and selectively coding commenced. Selective coding integrated the axial codes into a coherent written form. For this study, selective coding related to the reconstruction of the themes from the memos obtained from the axial coded data (Strauss

and Corbin, 1998). It was then possible to examine the links between categories and the development of a theoretical framework, where a central phenomenon and the axial coding paradigm were linked.

6.5 Results

6.5.1 Descriptive Statistics

The descriptive statistics provide the Means and Standard Deviations for each of the IVs and the DV used in this study. Overall for the SA sample, there were higher levels of stress ($M = 5.47$, $SD = 3.75$) compared to Anxiety ($M = 4.00$, $SD = 3.34$) and Depression ($M = 3.59$, $SD = 3.54$).

In terms of HLoC, SA participants scored higher on the external LoC subscales of Chance ($M = 31.17$, $SD = 3.19$) and Powerful Others ($M = 32.91$, $SD = 1.56$) compared to Internal LoC ($M = 25.81$, $SD = 3.67$). In addition to this, there were higher scores for Other People ($M = 17.19$, $SD = 0.82$) compared to Doctors ($M = 16.65$, $SD = 1.17$).

The correlation statistics presented in Table 6.3 provides the correlations for each of the variables. Correlations were examined as a check for possible collinearity between IVs.

Table 6.3: Correlations Statistics for All Variables.

Variables	1	2	3	4	5	6	7	8	Mean	SD
1) Risk Perception	-								56.49	8.77
2) Stress	.046	-							5.47	3.75
3) Anxiety	.146	.712 ^a	-						4.00	3.34
4) Depression	.075	.693 ^a	.758 ^a	-					3.59	3.54
5) Internal	-.143	-.294 ^a	-.310 ^a	-.379 ^a	-				25.81	3.67
6) Powerful	-.047	.153	.137	.224 ^a	-.063	-			32.91	1.56
7) Other People	-.139	.147	.180 ^a	.339 ^a	-.206 ^a	.737 ^a	-		17.19	0.82
8) Doctor	.034	.194 ^a	.209 ^a	.308 ^a	-.297 ^a	.633 ^a	.506 ^a	-	16.65	1.17
9) Chance	-.285 ^a	-.001	.002	-.199 ^a	.108	.146	-.113	.010	31.17	3.19

Note. ^a $p < .05$, Sample size is 99.

6.5.2 Evaluating the model

When evaluating whether the model, in which all constructs were added is successful in predicting RP, the model summary has been assessed. The R Square is an important measure which indicates how much variance in the DV is accounted for by the different predictors in the model. The adjusted R Square indicates how well the model can be generalised in a population (Fields, 2005).

The R Square in the data analysis was 0.469, which means that 46.9% of the variance in RP was explained by the combination of IVs. According to Pallant (2005), a value of around 0.45 for the *R* square is a respectable result.

The adjusted R square is quite lower than the squared *R* with a value of 0.22. It can be concluded that the model has considerable predictive capabilities in predicting RP ($F(8, 90) = 3.16, p < .05$). Hypothesis 1 is supported: HLoC and DASS predicted RP (see appendix 6.1).

Table 6.4: Summary of Multiple Regression (DV)

Construct (DV)	B	SE B	β	t	p
Stress	-.26	.33	-.11	-.79	.42
Anxiety	.88	.41	.33	2.12	.03
Depression	-.41	.42	-.16	-.97	.33
Internal	-.39	.25	-.16	-1.53	.12
Powerful	1.97	.95	.35	2.06	.04
Other People	-4.97	1.61	-.46	-3.08	.00
Doctor	.06	.95	.00	.06	.95
Chance	-1.11	.28	-.40	-3.88	.00

Hypothesis 2 – Individuals that score higher on External HLoC will have a negative impact on their RP. More specifically, Powerful Others, Chance and Other People.

Chance was found to correlate significantly with RP, demonstrating a negative relationship ($\beta = -.40$, $t(98) = -3.88$, $p < .001$). This indicates that individuals who scored higher on C-HLoC had lower levels of RP. Furthermore, OP-HLoC was found to be statistically significant with RP, presenting a negative relationship ($\beta = -.46$, $t(98) = -3.08$, $p < .05$). Suggesting that individuals who scored higher on OP-HLoC had lower levels of RP. Hypothesis 2 was partially supported.

Finally, P-HLoC was found to be statistically significant with RP, presenting a positive relationship ($\beta = .35$, $t(98) = 2.06$, $p < .05$), indicating that individuals who scored higher on P-HLoC had higher RPs, that were influenced by powerful others. However, D-HLoC and I-HLoC were not found to be statistically significant predictors of RP ($p > .05$).

Hypothesis 3: Individuals that score higher on Depression, Stress and Anxiety will have a significantly lower RP of developing T2D. More Specifically, Anxiety will be the biggest contributor to RP.

Anxiety was found to be a statistically significant predictor of RP, demonstrating a positive relationship ($\beta = .33$, $t(98) = 2.12$, $p < .05$). This finding indicates that individuals with higher scores on Anxiety had higher levels of RP. However, there was not a statistically significant relationship between Depression or Stress on RP ($p > .05$). Hypothesis 3 was partially supported.

This section presents the analysis of interview data from the SA participants relating to HLoC and DASS of T2D. The core category Disengagement with health behaviours was informed by the interaction of the following three categories: Patronage of the family; Insufficient culturally care and Power of the externals (Figure 6.1). Direct quotes from a range of participants act as evidence to support commentary (Charmaz, 1990).

6.6 GT Framework

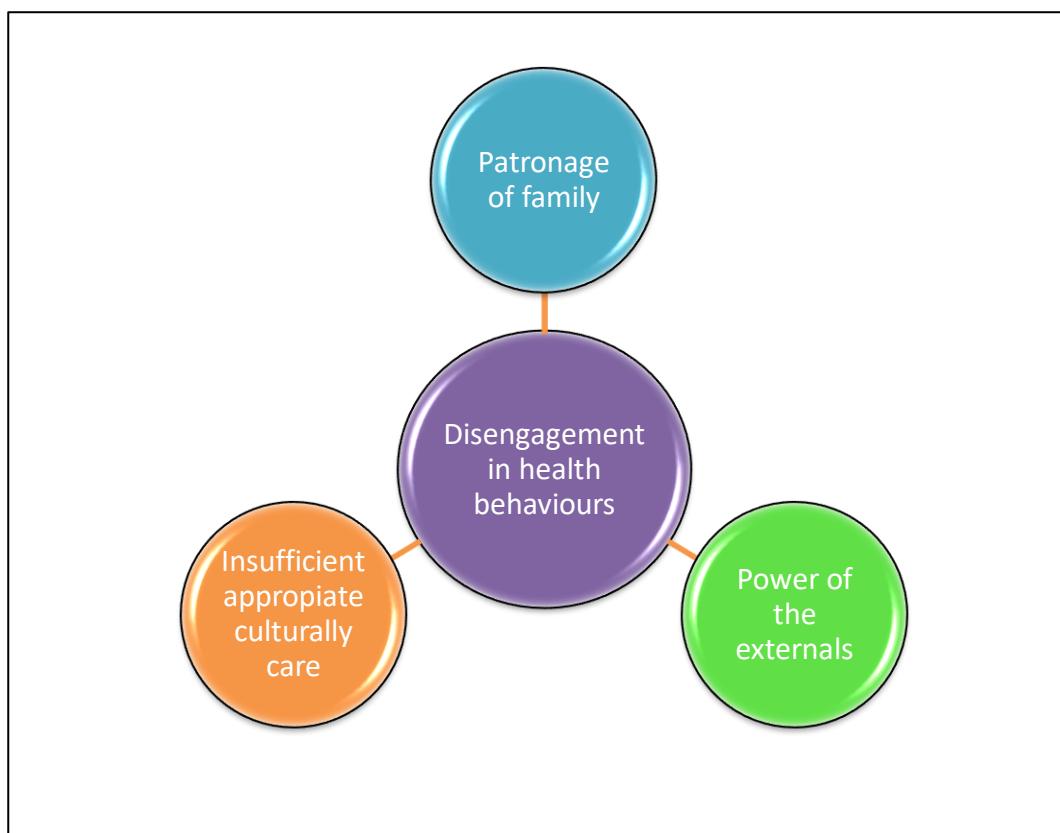


Figure 6.1: GT framework: LOC within the SA population

Disengagement in health behaviours

There were contextual influences within the SA communities investigated in this study. Investigation of these offers insight into factors that may be mediators of motivation to change behaviour influenced by cultural identity, control and beliefs. SA

participants made decisions about their health-related activities that were influenced and validated by the complex cultural and moral environment in which they lived.

'We adhere to the social norms of going out on weekends and social occasions, and we have little control over our behaviours during these times' (P1, F)

Patronage of the family

Support from family members was common within the SA community. Most of the participants were surrounded by either their immediate family, relatives or extended relatives. Spouses, children, daughters and sons-in-law, friends were judged important sources of support and information.

'We are so lucky within our community because we have so much support. If I ever need anything, I can always rely on my people' (P2, F)

This category was constructed upon the following emergent initial concepts such as support, encouragement, with assistance, guide influence, motivating and me all the way. SA participants expressed the need for the family when in crisis and that they can take a break from making decisions. This emphasises that within the SA communities, it is common practice for people to decide collectively with a family unit and not made by the individual.

'If we ever need to make a decision about our health or anything, we always consult our families and other people in the community' (P3, M).

Readiness to make lifestyle changes was often prompted by family. For participants, most importantly, this 'support' also influenced how they manage dietary changes, PA and other changes in their behaviour. The family is the primary source of assistance for elders in difficulty or in need. The support from their family included

transportation, translation and information support. However, the family sometimes also hindered help-seeking.

'I haven't mentioned a certain health problem to the doctor. My son told me if there are no symptoms, the doctor won't check it' (P4, F).

All participants reported receiving excellent family support following diagnosis on any condition. Family reactions included worrying about the patients' health, supporting modifications and in some cases providing financial support. Some participants said their families were stressed after learning about any health condition. Some participants reported family stress regarding health conditions because family members did not understand the cause and consequences.

'When my family came to know about my health, they became stressed because they didn't know how to manage my condition' (P5, M).

SA participants seemed to rely on family members or friends to provide them with information about any condition. Therefore, the majority of the information is external to a SA participant.

'If I have any issues with my health, my sons tells me what to do. However, if my family do not know what to do, I speak to my friends about this. For example, my friend has diabetes, I ask him' (P10, F).

While educated SA participants utilised the internet for health-related information, the family and friends of the less educated were their sources of such information. Some participants did not understand and had limited English language skills. Thus, their access to information was limited because most of the information is most often only presented in English in GP surgeries/hospitals.

'I don't even know if there are any information's leaflets available or how to get advice about health issues apart from asking my friends' (P9, M).

One Pakistani woman acknowledged the availability of some health-related information in SA language but raised serious concerns about the quality and comprehensibility of the content.

'The information provided was very difficult to understand, even to me. The content was not substantial and did not resemble our culture/languages' (P11, F).

Insufficient cultural care

Culturally competent care is crucial for an effective relationship between healthcare professionals and patients (Brooks, Manias & Bloomer, 2018). It is the means by which both patients and healthcare professionals expect to engage with each other and enable beneficial change in patient's health outcomes. It builds mutual trust and satisfaction. The SA participants reported that doctors and nurses lacked an understanding of their religious and cultural values, beliefs and behaviours. They raised concerns about the practitioner's limited awareness and sensitivity of SAs. This inadequate cultural competence has resulted in misunderstanding, stereotyping, and negative attitudes of healthcare providers. One Indian participant expected effective interpersonal communication and felt dissatisfied at the lack of such communication.

'In India, the first thing a doctor does is the patient's pulse, and as soon as the doctor does this, the patient feels a connection and confident the doctor understands the problem' (P9, M).

Although many SAs do not regularly go to their doctors, some of the participants who had visited their doctor felt they had not received any valuable advice and few consultations had actually tackled the underlying issues.

'Whenever I go to the doctors, they always say, don't worry about it it's just because 'you're getting older' (P11, F).

The ancient Indian medicinal system, Ayurveda (Pandey, Rastogi & Rawat, 2013) has become so culturally ingrained in the SA culture that patients still feel connected with doctors. However, in this study in the UK, participants were dissatisfied with their unmet expectations of receiving advice from healthcare providers. This led to a lack of trust of providers and resulted in an unwillingness to seek care from the healthcare system.

'Doctors gave me some medicine when I had issues with my digestions, but no advice was given to me about food. In Pakistan, if you have issues with digestion or anything, they will tell you what to eat and exercise. Here, I think doctors do not know anything about our practices' (P5, M).

One participant felt strongly about not going to the doctors.

'What's the point going to the doctors, it's a waste of time, you can get information from anywhere nowadays' (P11, F).

The stigma attached to certain diseases and mental health problems was evident. Participant's fear of disclosure affected their ability to seek appropriate care.

'I know people suffering from depression, but they scared of telling everything to their doctors or health care professionals because they don't know if the information might get leaked' (P3, M).

Participants discussed the impact and invisible barrier of stigma when interacting with family and friends. Some described their relatives as reluctant to allow them to disclose their health/mental health problems to anyone, including their GPs. Family members themselves were reported to experience shame, self-blame and fear of public reactions.

'I think she was worried, because of reactions of the people towards me being open about it' (P2, F).

Due to this attitude around mental health problems, participants were less likely to visit GP practices for any health issues. This led to participants finding other external sources for information but also more anxious around their future.

Power of the externals

SA participants that visit their GP tend to have an external view that it is a health professional's responsibility to look after your health.

*'I go to my doctors when I am not well, they give me medication, and I take it'.
Without the medication, I might not get better' (P5, M).*

Their view is external to them and has a frustrating attitude towards health care professionals about finding a cure for any health condition.

'Doctors are not doing enough; they have studied for many years and still don't found a cure for anything' (P4, F).

People assume the power lies with the GP's and health professionals and tend to listen to them in and this is very similar to the concept of religion and fate.

It is apparent that religious scholars are a preferred method for advice as exhibited by one participant.

'People will go to scholars, imams, for advice' (P3, M).

This related to Padela et al. (2012) findings in terms of religion being the central resource for healing; as most of the participants explained that these religious preachers are sought after, as Islam promotes peace and mental illness is seen as 'disturbing the peace or is an imbalance'. As one participant alludes to pre-existing negative views, it is likely that the scholars are going to result in prayers as a treatment.

'Just pray and read some religious paragraph from the holy book, and you should be fine' (P3, M).

People will follow the religious scholar's advice, even though these scholars have a lack of knowledge and expertise within this area (Ciftci, 2012).

Religious scholars can have a positive impact on the community in changing people's negative perception and raising awareness as one participant alludes to.

'He discussed stuff with the imam on stuff that he never used to do' (P10, F).

The religious preacher is seen as an authority figure as an Indian participant states.

'my father respects the imam, wouldn't question the imam' (P10, F).

This is due to the 'authoritative power the imam has' with the SA community. These examples highlight the authoritative power the imam possess; through counselling and promoting mental health, the religious scholars can play a beneficial role in changing perceptions and could challenge the stigma within the SA community (Abu-Ras et al.,

2008). However, there should be a balance between using powerful others as a coping strategy as well as receiving medical advice from doctors.

6.7 Discussion

This study explored the different dimensions of HLoC and current psychological state (Depression, Anxiety and Stress) and the role, if any, these play on RP of developing T2D. In this study, a multiple linear regression was conducted in order to determine the relationship between HLoC and DASS in predicting RP of T2D within the SA population. This examination of HLOC and DASS was warranted by Study 1 and 2, as SA individuals did not recognise their AR of developing T2D and that their RP was largely influenced by external factors. By means of the multiple regression, it was assessed whether these constructs could predict RP, and explored which constructs were the most important predictors in the model. In addition to this, a grounded theory framework was developed explaining differences in the SA community in relation to HLoC and the current psychological state.

From the results of the multiple regression, it can be concluded that HLoC and DASS made a significant contribution to the variance in RP. The implication of this conclusion is that HLoC and DASS constructs can have an impact on an individual's T2D RP. More specifically, it was found that Powerful Others, Chance and Other People were the HLoC dimensions which directly influenced RP. In this context, individuals that scored high on Chance and Other People had low levels of RP. and were most influenced by external factors, such as believing that other people and fate influenced their risk of developing T2D. However, individuals that scored high on Powerful Others had high levels of RP. In this instance, powerful others, such as religious leaders, were deemed influential for these participants in their acknowledgement of T2D risk.

In line with the concept of Health Locus of Control and T2D risk of complications (in those diagnosed (Macaden & Clarke, 2010) and in line with RP studies in other conditions such as Cancer (Peretti-Watel, Fressard, Bocquier & Verger, 2016). This was further reinforced by the qualitative findings; the family was an essential source of support for SA in terms of providing emotional support as well as day to day decisions such as food practice at home. Strong family networks are an essential feature of SA communities (Grace et al., 2008). Within the SA culture, family members and close friends are expected to participate and help with providing care and attention to individuals. It is perceived as a valuable opportunity and a social obligation to provide support to the individual and 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 the interdependence and connectedness within the family (Markus & Kitayama, 1991). However, 'family' may not always be supportive on all occasions and may cause conflict and sometimes be obstructive. For example, families may impose their sociocultural beliefs onto the person's risk and mental health state to avoid the social stigma surrounding different conditions in the SA community, thereby making self-care for people even more complex.

In one UK study, the social stigma associated with mental health disorders was the underlying reason that a group of SAs caring for adult relatives did not consult a professional for their relative's care (Ahmedani, 2011). Furthermore, accessing mental health services among Pakistani Muslim women found that family and personal reputation were important reasons for not seeking professional help (Memon et al., 2016). strong family ties have been found to play a vital role in shaping the attitudes and experience of people in this group. Close family networks have been found be an

important source of information, sharing knowledge and language support (Fleming & Gillibrand, 2009; Stone et al., 2005). Bottroff et al. (1998) found that practices are strongly influenced by family and community responsibilities and whether SA engaged in self-care activities depend on family and social expectation. Therefore, the social networks of the SAs may not always have a positive effect on self-care behaviours since family and friends may have their own beliefs and experiences about the healthcare system which may influence or pressure the individual to engage in these behaviours. In other words, for people in the SA community, their risk is probably best understood within the context of their family/significant others, and if healthcare recommendations are not consistent with the belief system of significant others, it is likely that those recommendations will not be followed. This is further reinforced by the quantitative findings as Powerful Others and Other People were significant predictors of RP and also provided significance within the community.

National guidelines suggest that there are different layers of prevention of T2D, from national strategy and policy to local action (NICE, 2018). These include healthier lifestyle messages to the population, strategy for diseases linked to PA, diet and obesity, encouraging people to be more active and group-individual level intervention for individuals at high risk. Although these are all meaningful implications, these strategies and policies may need to be refined for the SA community. As previously discussed, SAs have low uptake of PA (Chapter 1), low uptake of health screening (Chapter 1), and present challenging health beliefs around diet (Chapters 1 & 4). Within the SA community, these health behaviours are largely influenced by external HLoC which influences an individual's RP of developing T2D. Therefore, future strategies/interventions could target specific constructs of HLoC to increase RP in the SA community.

When considering the psychological-emotional traits, anxiety was a significant predictor of T2D RP. This means individuals that were more anxious with their risk of developing T2D perceived themselves to be at higher risk of developing T2D. These individuals may well be more likely to seek out a formal risk assessment or engage in preventative T2D lifestyle behaviours or in contrast, given the cultural taboos and stigma related to health conditions in the SA communities not seeking formal help (Stangl et al., 2019). For example, modesty and honour are highly valued in these cultures to maintain the family's reputation (Mantovani, Pizzolati & Edge, 2017). Therefore, it is not considered appropriate to openly talk about illness, which can compromise the family's status. Not openly talking about conditions may contribute to increased levels of anxiety. Which can also explain why SA individuals are less likely to seek or receive support. This was further reinforced by the qualitative findings as there was a lack of understanding among healthcare providers regarding the sensitivity of participants cultural norms deterred participants from seeking healthcare, thereby influencing their ability to seek and engage with health care. The lack of cultural competency among healthcare providers, especially nurses, tend to demonstrate negative and ethnocentric behaviour toward culturally diverse participants (Sutherland, 2002). Cultural competency at an organisational level must meet the needs of culturally diverse participants by providing appropriate culturally and linguistic health information and culturally diverse healthcare providers.

Efforts should be made by health professionals to decrease burden and anxiety without compromising accurate risk awareness. This has been reinforced by large-scale community studies (Fazil & Cochrane, 2003; Sonuga-Barke & Mistry, 2000) seemingly point to SA individuals as being vulnerable to anxiety. For example, Creed and his associates found that Muslim women obtained the highest scores on the Self-Rating

Questionnaire used (anxiety) and this was supported by Sonunga-Barke and Mistry (2000) who found that levels of anxiety were more pronounced among Muslim women. Malik (2000) argues that understanding experiences of anxiety in the SA communities requires a broader understanding of cultural ideologies. Malik (2000), used a social constructionist approach and found that the causes of anxiety were linked to external factors such as situations and relationships, rather than personally internalised. Affective, somatic and socio-behavioural symptoms of anxiety were described and expressed in relation to 'others' and social roles.

Depression is a highly prevalent disease associated with substantial morbidity and mortality and is recognised as an important comorbidity for several chronic conditions such as diabetes (Anderson, Clouse, Freedland & Lustman, 2001). Results from meta-analyses of longitudinal studies indicate that depression is associated with 37–60 % increased risk of developing diabetes (Knol et al., 2006). Prospective evidence suggests that elevated depressive symptoms, as well as clinical depression, are related to the subsequent incidence of diabetes (Pan et al., 2010). The associations reported in these studies remained significant after controlling for diabetes risk factors such as BMI, family history of diabetes, smoking, PA, diet, and alcohol consumption. However, despite these associations, the findings in this study indicate depression itself was not a direct predictor of T2D RP. An explanation of this is that aspect of depression influence people differently; not everyone who is depressed experiences every symptom and the severity and frequency can vary. With the link of depression and Learned Helplessness (LH), the model predicts, if certain obstacles are believed not be in an individual's control, it may lead to deficits in cognitive decision-making, deficits that could certainly influence their RP (Pittiglio, 2017). Therefore, in this case, there is a possibility due to LH; the SA individuals emphasise less importance on RP.

Prospective studies have tested the hypothesis that stress is associated with an increased risk for the development of T2D (Kato et al., 2009; Rod et al., 2009). Interestingly, participants who had reported high levels of stress were less likely to quit smoking, more likely to be physically inactive and less likely to stop drinking, all these factors are known to be associated with an increased risk for T2D and could mediate the link between stress and onset of diabetes. Contrary to these associations, the findings in this study indicate stress sub-scale itself was not a direct predictor of T2D RP. An explanation of this could be that culture conflict has been identified as a major source of stress for SA (Inman, 2006; Samuel, 2009). SA individuals reported acculturative stress due to inter-generational conflict at home, which was correlated with the ability to cope (Samuel, 2009). Differences in key values and ways of life make the cultural transition process challenging for SAs. Furthermore, numerous studies have demonstrated that the ethnic identity formation process can be particularly problematic for SAs due to the wider enforcement of traditional values and behaviours (McPherson, 2017; Talbani & Hasanali, 2000; Iwamoto & Liu, 2010). SAs facing these identity conflicts have been reported alienation from family members, increase levels of stress and depression (Shams, 2001).

Efforts must be made to empower individuals to take charge of their behaviour. One possible explanation for individuals who score high on powerful others is poor communication with their health professionals. An individual's communication behaviour can influence the communication of the doctor (Ha & Longnecker, 2010). RCT's have shown that coaching individuals in verbal behaviour techniques to increase their participation during surgery visits can increase communication behaviour and improve health outcomes (Pinto et al., 2012). Plescia & Groblewski (2004) used the findings of a strong, powerful other HLoC in BAME groups to educate lay health advisors, who then went on to use these findings by involving ministers and forming

partnerships with local religious settings in order to promote health behaviour change. Furthermore, the Witness Project (1999) used African breast cancer survivors to provide information and insight into the early detection and breast self-exams. Breast cancer survivors shared their stories and taught self-breast exams to women within religious and community settings (Wells, Gulbas, Sanders-Thompson, Shon & Kreuter, 2014). Educating individuals within the community to relay information about T2D AR and to use a more targeted family approach could be a multi-level outreach plan designed to educate both the community and the individual.

Therefore, future interventions should consider the mismatch between RP and AR. As shown in this study, there appears to be a need to focus on efforts in intervention design towards External LOC and the role of the SA community, such as Powerful Others.

The sequential design in study 3 was very beneficial in order to get an in-depth knowledge of the SA community. In order to do this, the qualitative data explored further the quantitative data, and this provides a strength of this study. This design allowed to go deeper than just using one method and aimed to get a more meaningful understanding of the SA population. Therefore, the sequential design was used in study 3.

6.7.1 Study limitations

Within this sample, the researcher has deemed it representative based on the 2011 Census. However, we have to be mindful that this heterogenous SA sample, may have also changed over time. As the SA ethnic make-up in the UK may have changed since the last census data. Therefore, future research may include a more up to date sample of SA to be representative of the full UK SAs (Lomax, Wohland, Rees & Norman, 2019).

Furthermore, other previous research using multiple regression on SA population consider Socio-economic status, family history of diabetes and other CVD illnesses to understand if there are any covariate influences. This is an important point as there was a 0.22 variance on the adjusted R squared, indicating the regressor is contributing little to the explanation of the response variable. Other influences may account for more of the variance. However, this study didn't consider other influences such as socio-economic status, other CVD illnesses, therefore it is difficult to confidently interpret these results in its entirety. Future research may account for these covariates in the analysis to understand what factors influences RP in the SA community.

Finally, within this study, the psychological traits that have been investigated are depression, anxiety and stress. However, it is noteworthy to highlight that the DASS scores for this participant sample were broadly considered within normal population range. The stress and depression scores were 'normal', and the anxiety score was considered 'mild'. Hence, despite previous research suggests levels of anxiety, depression and stress are higher in SA populations (Islam, Khanlou & Tamim, 2014; Lord et al., 2013). This was not reflected upon the sample recruited for this RP study. Levels of anxiety were significant in this study associated with increased RP. However, it is important to highlight that when comparing the mean score of anxiety based on the DASS scoring criteria, the overall rates of anxiety were classed as 'mild' and therefore didn't represent a highly anxious cohort. This could have implications for wider application to the south Asian community as a whole, and future research may need to recruit a broader SA sample explicitly seek out individuals with particularly high levels of anxiety, depression and stress (Stoet, 2017).

DASS-21 has been validated in a number of populations such as Hispanic adults, American, British and Australian (Crawford et al., 2009, Norton, 2007). The findings

show that the DASS-21 is psychometrically sound with good reliability and validity. It is clear from the literature that the DASS-21 is a well-established instrument for measuring depression, anxiety and stress in the Western world. Nonetheless, the lack of appropriate validation amongst Asian populations continues to pose concerns over the use of the DASS-21 in Asian samples. It is clear that culture can influence the experience and expression of depression and anxiety, including the forms of illness experiences, as symptomatology and symptom interpretation (Kirmayer, Robbins, Dworkind & Yaffe, 1993). If this is the case then the way an individual talk about distress and how it is perceived and defined will be a function of their culture. However, there has been limited research on the appropriateness of DASS in native Asian countries such as India, Pakistan, and other Asian counties such as Hong Kong and China. This questionnaire was administered in the western world with SAs living in the UK. Therefore, it was deemed cultural appropriate to use.

It is noteworthy that in this study, depression and anxiety was as assessed by the DASS-21, but was not used a clinical measure, and scores were calculated independently of participants completing the questionnaires. The nature of the DASS was used for research purposes only to calculate levels of anxiety and depression. In accordance with ethical procedures, individuals were encouraged (via debrief information) to seek medical support if they felt their mental health was an issue and may benefit from assessment of depression or anxiety interventions from their GP.

Over the past decade, the use of online and mobile research methods like online surveys (Qualtrics) has increased. The benefits of using Qualtrics is that it has the potential to reach the general population (otherwise ‘hard to reach’) and invite them to participate in research at their convenience. Previous research (Buchanan & Scofield, 2018) have used online surveys such as Qualtrics and has been deemed a suitable method

to collect data. However, conducting online research may limit participants to those only familiar and confident to use technology and may not reduce anxiety for those not trusting the research.

6.7.2 Conclusion

This study evaluated the Health Locus of Control and specific psychological constructs (Anxiety, Depression and Stress) within a SA population, to explore if these different constructs predict RP of developing T2D.

This study highlights approaches to improve RP by tailored intervention addressing individuals with the differing locus of control by (1) Maximising the role of powerful others on risk information; (2) Improving communication between health professionals and the SA community; (3) Maximising the role of community members.

The findings provide a strong foundation of factors influencing RP when designing an intervention targeting to improve RP in the SA community. Therefore, this study has important clinical and public health implications.

Overall Study 3 provides a unique contribution to new evidence, as to our knowledge there hasn't been a mixed-method approach investigating HLoC and DASS comprehensively in the UK SA population. Together, these findings provide further insight into future interventions.

6.7.3 Key points and unique contribution from this study

- To our knowledge, this was the first study to adopt a mixed-method approach and investigate key psychological constructs such as HLoC and DASS in the SA population.
- SA participants expressed a higher external LoC which impacted their RP, and anxiety was significantly associated with RP. Key variables such as powerful others, other people and chance were additional significant predictors for RP.
- In addition to this, the qualitative findings provided additional information on key constructs that impacted RP. Factors such as family roles, insufficient cultural care and power of the externals all impacted RP, and these are linked to quantitative findings.
- This study provided valuable information for intervention design to include certain key psychological constructs that are pertinent to the SA community.

7 Chapter 7: Empirical Findings Summary

7.1 Chapter Overview

This chapter brings together the PhD's empirical findings thus far, and summaries the key theories presented within each study.

7.1.1 Summary of Study 1 findings

This study (Chapter 4) was aimed to explore health-related RPs and behaviours in the UK SA population. Although there's limited research that has investigated RP in the SA population, none of the studies has used a theoretical framework to understand RP. As the initial study of the PhD, it was important to use a qualitative methodology to allow SA participants the freedom of expression in discussing RP and to give greater depth of meaning to understand RP in the SA population. Overall, the GT framework highlighted the complexities that are embedded in the SA community and how these complexities impact RP of developing T2D. People's actions are largely determined by social aspects and cultural adherence, which is considered normal and approved by the community. The HBM (Becker, 1974) was used to explain the findings further. For example, this study highlights that participants are more likely to engage in healthier behaviours if they perceive their risk of T2D as severe. However, SA participants are not considering their risk to be severe, and the potential actions are not considered beneficial. This is further reinforced by the concept of LoC. As SA participants have an external view on illness, they emphasised the importance of fatalism and destiny. Due to this belief, it shapes the perception of susceptibility to illness. In addition to this, the Social Norm Theory (Perkins & Berkowitz, 1986) was used to explain the findings further. With reference to this theory, a person's perceived norm is not aligned. In this instance, the misperception that SA participants have about the seriousness of T2D is not representative of the actual condition. SA participants made social comparisons (SCT, Festinger, 1954) to compare their risk with those already diagnosed with T2D, who are deemed as managing their condition effectively. Because of this observation, it impacts the seriousness of developing T2D. Together the GT framework developed brings together various key psychological theories (HBM, LoC, SCT) to fully understand RP in the SA population.

After finding unique evidence in Study 1, it was important to investigate the concept of RP further to understand whether these findings were only relevant to SAs or other ethnic populations as well. Therefore, this provided a basis for Study 2.

7.1.2 Summary of Study 2 findings

This Study (Chapter 4) aimed to assess specific constructs of RP and compare these to AR explicitly to the SA and White population in the UK. Very few studies have examined RP vs AR in more than one ethnic group and explored how ethnicity may influence self-care behaviours and preventative intervention. The findings suggest that individuals that were categorised AR as moderate or high of T2D scored greater on RP scores. However, this trend was more apparent in White's compared to SAs. Overall, the White population had higher RP of developing T2D compared to SAs. This finding can be linked back to the HBM, as a person's belief in a personal threat of an illness or disease together with a person's belief in the effectiveness of the recommended health behaviour or action will predict the likelihood the person will adopt the behaviour. This is observed in this study as White participants had higher RP than SAs. Furthermore, when investigating RP in more detail, White participants had higher levels of personal control, optimism, personal disease risk compared to the SAs. Linking back to the findings of Study 1, the concept of control can be linked with the concept of LoC. As previously discussed in Study 1, SA participants tend to have higher levels of external LoC. However, Study 2 has shown that White participants had higher levels of personal control and this may be because they hold a higher level of internal LoC (Ng-Knight & Schoon, 2017) compared to SAs. Finally, within this study, SAs expressed higher levels of anxiety/worry compared to White participants. This study provided a unique contribution addressing the gap in knowledge around RP and AR within SAs and White population. This study highlighted some key concepts that needed to be taken into consideration such

as the concept of LoC and current psychological states (anxiety/worry) and warranted further investigation.

7.1.3 Summary of Study 3 findings

As there was the consistent theme of LoC from Study 1 and Study 2, it was vital that this was investigated further to understand which aspects of LoC impacts SAs RP (Chapter 6) to support the design of the intervention. In addition to this, previous research on diabetes prevention has tended to focus on changing modifiable behavioural factors (Yang et al., 2018), and such interventions have not focused on changing psychological wellbeing. There is limited research that has explored how psychological state (e.g. anxiety, depression and stress) may influence RP. As it was suggested in Study 2, SAs had higher levels of anxiety/worry, and this was investigated further in Study 3. It was found that powerful others, chance and other people were the HLoC dimensions which directly influenced RP within the SA participants. This finding can be linked back to previous studies, such as in Study 1 participants were more inclined to believe in the matter of fatalism and destiny, and this can be related to the LoC concepts of powerful others and chance. Furthermore, these findings can be discussed further through TPB (Ajzen, 1985) and Perceived Behavioural Control (PBC). This is a person's belief as to how easy or difficult performance of the behaviour is likely to be. PBC reflect perceptions of factors that are both internal (knowledge, skills, will-power, self-efficacy) and external (the cooperation of others and external support) to the participants. Therefore, it is important to increase a SA participant internal LoC such as their knowledge, skills of adopting a behaviour and improve their external to support their intended actions. Furthermore, when investigating current psychological state, depression and stress were non-significant predictors on RP. However, anxiety was a significant predictor indicating individuals were more anxious with their risk of developing T2D.

7.2 Discussion

It is acknowledged that changing behaviours can be an extremely difficult and complex process (Kelly & Barker, 2016). When developing interventions, it is necessary to have a theoretical understanding of how behaviours can be changed (Kwasnicka et al., 2016). The explicit use of theory to develop or plan behaviour change interventions have been recommended by the UK's Medical Research Council (MRC, Craig et al., 2008) and the NICE (2011). The appropriate use of theory has been stated to provide three benefits for the process of intervention design: (i) providing a framework to consider the full range of antecedents (Michie, Van Stralen & West, 2011); (ii) supporting theorising about mechanisms of actions for assessment of appropriate mediators and refinement of interventions (Rothman et al., 2004); (iii) testing the theories used in development to provide evidence of effectiveness of the relevant theories (Michie, Johnston, Francis, Hardeman & Eccles, 2008). In this thesis, Chapters 1 (literature review), 3, 4, & 5 (qualitative and quantitative empirical research) investigated different dimensions of RP, using various methodological designs, within the SA community. Various theoretical discussions are offered, and Table 9.1 offers a summary of the overall findings and theoretical applications presented from the empirical studies. Within phase 1 of this PhD, the primary role was to collect data that was deemed potentially useful to help understand and fully formulate the problem and explore the concept of RP within the SA community. The findings from the literature review (Chapter 1, Section 1.20) and Studies 1, 2 and 3 (Chapters 4, 5, & 6) revealed the complexity and underestimation of RP within the SA community and the influence of LoC which impacts peoples RP in the SAs. Several different data collection methods were used, including the literature review, interviews and questionnaires, which provided a triangulated methodology to promote a rounded understanding of the problem to be addressed within this intervention

Chapter 8:
PhD PHASE 2
Intervention Design and Evaluation

Chapter 9: Intervention Design

Chapter 10: Intervention Evaluation, Study 4a & 4b

Chapter 11: PhD Discussion

9 Chapter 9: Intervention Design

9.1 Chapter Overview

The aim of this PhD was to develop a multi-theory intervention based on the MRC and Person-Centred approach to assessing RP in the SA community.

The aims and objectives of this thesis were to (1) to understand the complexities in the SA community and to explore reasons for lack of engagement in preventative actions influenced by lifestyle behaviours and (2) to develop an intervention for SA general population to assess these complexities based on identified needs and preferences. So far, this thesis has followed the MRC Framework (Craig et al., 2008). MRC guidance for developing and evaluating complex interventions advises that an intervention should include three stages: 1) identify an existing evidence base; 2) identify or develop appropriate theory, and 3) model processes and outcomes (Craig et al., 2008).

In this PhD, Phase One has been dedicated to achieving these three MRC stages: the first stage was addressed via the review of the existing evidence base on T2D, RP and SA health literature exploring issues pertinent to this community and consideration for the existing evidence base on preventative interventions and T2D RP. Subsequently, stage 2 of the MRC framework was achieved first via the conduct of four empirical research studies, utilising mixed methods which investigated RP and health beliefs in the SA community, and explored issues around low uptake of preventative behaviours. The second part of this stage of the MRC framework was addressed through a person-based approach (Yardley et al., 2015), which we considered would enhance the intervention, rather than simply adopting a theoretical only informed intervention design: This person-based approach employed discussions with key stakeholders regarding the empirical research and findings conducted to date (i.e. the new knowledge developed in Chapters 1, 4, 5 & 6 and discussed their application and relevance). Within these meetings, the

researcher conducted presentations explaining the rationale's and aims of the studies and provided a summary of the key findings and theoretical applications. The stakeholders reflected on this information from a 'real-world' applied perspective and provided various recommendations for the intervention design, and what they considered necessary for appeal and relevance within the SA communities. Insight from these sessions was directly applied to the design of the intervention. Subsequently, additional meetings took place with both the key stakeholders and the research team to tweak and finalise the intervention design, key components and agree on the future dissemination and evaluation of the intervention.

Of specific importance to these discussions was the application of the empirical findings and theoretical frameworks presented. Through the discussion of the empirical findings (See Table 9.1), certain key psychological theories were highlighted as consistent through the studies, such as HBM, SLT and TPB. The stakeholders recognised that there was overlap in social-contextual constructs between the theories identified, across the studies, and taking a lead in the design from the key stakeholders, these theoretical components have been merged together into the intervention design. These theories have provided a deeper understanding additional to the empirical findings on the topic of RP in the UK SA population.

In summary, the various theoretical concepts, the empirical evidence (including both qualitative and quantitative findings) and the person-based approach involving key stakeholders, informed the intervention design. A multi-theory approach using different components from theories was the preferred method for the intervention design as highlighted in Chapter 1. None of the theories referred to within this thesis (HBM, TPB and SLT), have been applied comprehensively to the investigation of RP in the UK SA population. Therefore, through empirical investigation, theoretical development and the

person-based approaches the following theories, the HBM, TPB and SLT, were integrated to inform the intervention design (highlighted in Table 9.1).

This chapter presents the intervention designed and then applied to a preliminary evaluation study, to test a proof of concept, acceptability and feasibility, thus addressing stage 3, model processes and outcomes, of the MRC intervention framework.

Within these meetings, the researcher conducted a small presentation explaining the rationales of the studies and the key findings. Once this was completed, the stakeholders provided various recommendations for intervention design and what is necessary within the SA communities. More meetings took place with key stakeholders and research team to discuss the intervention design, key components and dissemination and evaluation of the intervention.

The evidence presented has provided a foundation for the intervention design. The intervention design process has utilised the new knowledge developed in Chapters 1, 4, 5 & 6 and discussed their application and relevance with key stakeholders. Together this information has collectively formed the developed of a new intervention which aimed to improve RP of T2D in the SA population.

Table 9.1: Summary of Key Findings, Informing the Intervention

Chapter	Findings
Chapter 1 – Literature Review	<ul style="list-style-type: none"> * SA culture is a heterogeneous and complex group, requiring further investigation of increased risk of T2D * RP is a multifaceted variable that requires in-depth understanding. There has been previous research on T2D, however, limited research on lay SA population to understand RP using psychological theories * Current prevention programme indicates a low/moderate change in behaviour and SAs low uptake of health programmes in the UK * Therefore, need to understand risk perception further using a theoretical stance and how this can be improved in SAs
Chapter 4 – Study 1 Qualitative	<ul style="list-style-type: none"> * Varied levels of RP within the SA community * Diminished responsibility * Pressure to adhere to social norms (Social norm theory – Linked with Perceived subjective norms, normative and subjective beliefs of the TPB) * Social comparison theory, SA participants compare their behaviour to others in their social groups (optimistic bias, control beliefs vs behaviour control, TPB)

	<ul style="list-style-type: none"> * Developed GT framework which shows the multi-complex psychosocial influences in the SA community that affects RP using different psychological theories.
Chapter 5 – Study 2 Quantitative	<ul style="list-style-type: none"> * Major differences in RP between SA and White community * SA underestimate their risk compared to their counterparts when at high risk of developing T2D * Whites have higher T2D RP, whereas SA have higher levels of worry of developing T2D * Findings linked to the HBM. Perceived severity of the disease, SA lacked personal control and seriousness around T2D (linked to Study 1 theory, social comparison theory & diminished responsibility) compared to their counterparts.
Chapter 6 – Study 3 Mixed- Methods	<ul style="list-style-type: none"> * LoC and anxiety (psychological trait) were the main predictors when investigating RP * SA had an external LoC, and constructs found significant, powerful others (subjective norms), chance and other people. People were influenced by these external variables. * Anxiety was a significant predictor of RP compared to depression and stress. Although levels of anxiety were within the normal population range. * GT framework indicates the complex nature of external factors influences SAs such as disengagement in health behaviours based on external powers, insufficient cultural care and patronage family.

* Theoretical links similar from previous research. social norms theory, social comparison theory, diminished responsibility, HBM, LoC and the TPB specific constructs such as PBC linked to LoC. Subjective norms (social influence), attitudes towards the behaviour. Constructs from the HBM, TPB and SLT were taken forward for the intervention design and evaluation.

9.1.1 Translation of findings into intervention development:

The process used to develop a theory-based, culturally tailored RP intervention to encourage risk awareness in the SA population is shown in Figure 9.1. The MRC framework was the overarching guide.

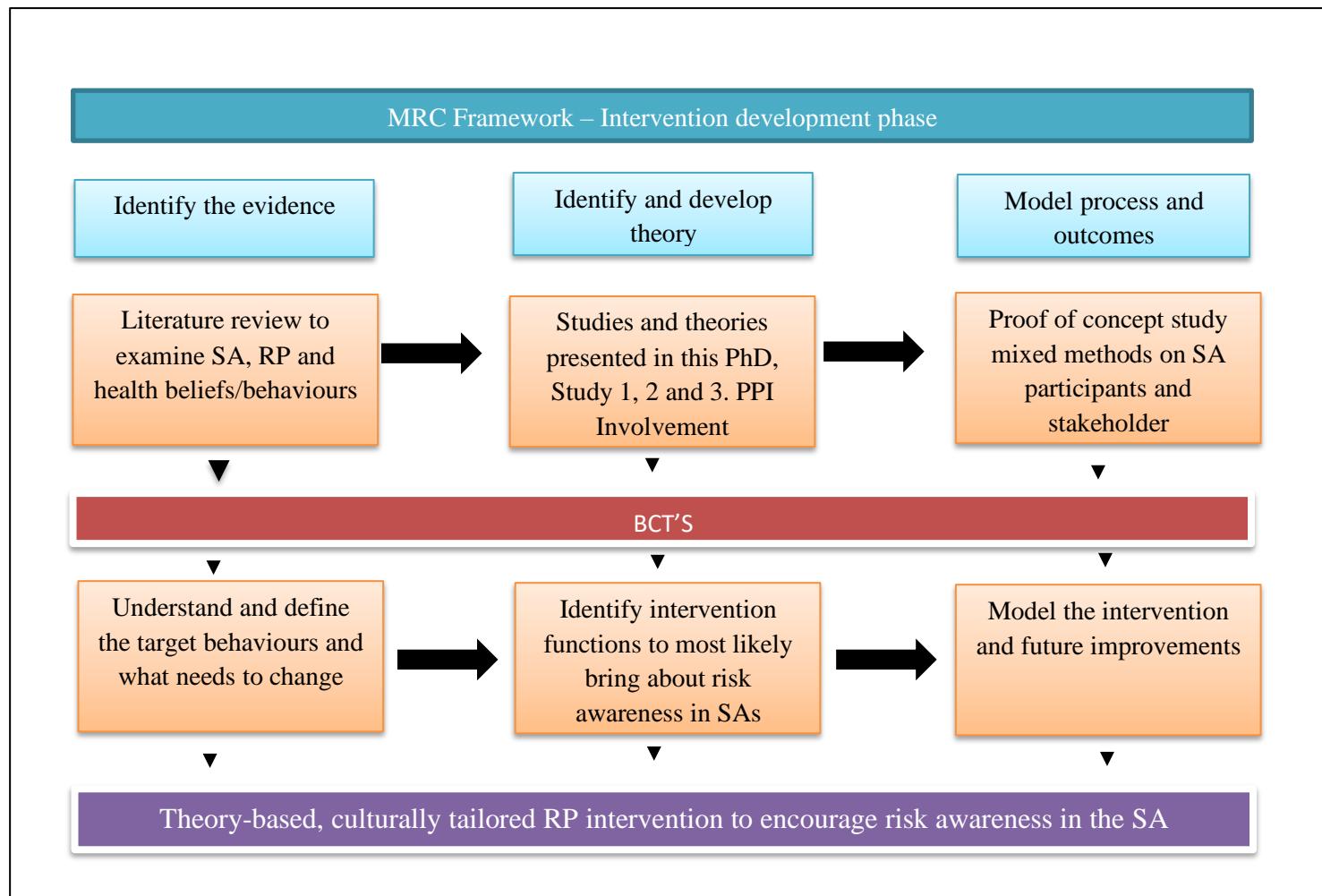


Figure 9.1: MRC Intervention Development Mod

9.1.2 Understanding and selecting target behaviours

Phase one of this PhD has identified important health behaviours and key theories to include in a RP intervention for SA population. HLoC was one of the key behaviours that have been targeted for this intervention, which was informed by LoC Theory, as well as other theories (See key findings in table 9.1, Chapter 9).

For the development of this intervention, the empirical evidence as summarised in Table 9.1 (Chapter 9), has been applied to aspects of the BCT (Michie et al., 2013) to help identify specific techniques to adopt within the design of this new intervention (Table 9.2).

Table 9.2: Overview of BCT'S

Determinant of behaviour	Behaviour	Relevant theory	Relevant behaviour change techniques in this intervention	Study
Outcome expectancies (BCT – Information about the seriousness of health condition)	Risk behaviour of T2D	Social Cognitive Theory & Health Belief Model	Provide information on the seriousness of diabetes	Identified study 1
Self-efficacy (BCT – Goal Setting, Graded Tasks, Action Planning)	Lifestyle behaviours	Social Cognitive Theory Locus of Control Theory	Boost motivation and self-efficacy by the messages and messenger (Powerful Others, i.e. Religious Leaders)	Identified study 1, 2 and 3
Perception of social norms (BCT – Social Comparison)	T2D	Social Cognitive Theory, Health Belief Model	Provide normative information about other behaviours and experiences in the community	Identified study 2

Motivation to change dietary behaviours (BCT – Social Support, Action Planning, Goal Setting)	Diet and T2D	Health Belief Model, Theory of Planned Behaviour & Social Norms	Provides importance of changes by fellow SA	Identified study 1,2 and 3
Increase internal locus of control (BCT – Instruction on how to perform the behaviour)	Risk perception T2D	Health Belief Model, Theory of Planned Behaviour	Motivating statements by key stakeholders in the community	Identified in study 3

9.1.3 Intervention Design with Stakeholders

Stakeholders can be defined as people or organisations who have an interest in the research project, affect or are affected by its outcomes (Chu et al., 2017). For the intervention design stakeholders involved with this development process included (see table 9.3).

Table 9.3: Description of the Stakeholders

Type of Stakeholder	Part Involved	Recruited from
A lay representative of the community	Involved from Study 1	Family and friends' network
A lay representative of the community	Involved from Study 1	Family and friend's network
A lay representative of the community	Involved from Study 1	Family and friend's network
A lay representative of the community	Involved from Study 2	Family and friend's network
A religious leader of the community	Involved from Study 3	Local Mosque
A religious leader of the community	Involved from Study 3	Local Mosque
A community leader of the community	Involved from Intervention Design	Through researcher professional network
A community leader of the community	Involved from Intervention Design	Through professional network

An academic, expertise in diabetes	Involved from Start of the PhD	Professional network of the researcher/part of the supervisory team
A local health and wellbeing organisation	Involved from Study 1	Close relationship with the researcher
A Health professional	Involved from Intervention Design	Family and friend's network

These stakeholders were consulted at various stages of development. It is noteworthy that stakeholders were consulted during the design and conduct of the empirical studies conducted within phase one of this PhD thesis. However, within this phase, various stakeholders, which included members of the SA community had an integral part of the intervention content (as recommended by Yardley et al., 2015, person-based principles to complex intervention design). Discussions with stakeholders occurred on a one-to-one and group basis depending on the availability and circumstances of the stakeholder themselves. The following section outlines each step of the design process and how stakeholders were involved:

Step 1: Discussion with stakeholders regarding key findings and recommended techniques and approaches to consider.

Stakeholders were interested in the empirical findings and broadly agreed with the summaries. Lay SA individuals were concerned with the complexity of language and ensuring that people would be able to understand the messages in the video intervention. Therefore, there were regular meetings with religious leaders and health professionals to ensure the language used was effective to ensure people would understand the messages.

This was then further discussed with the research team to ensure all communication approaches for the intervention were considered. Furthermore, initial discussions focused on the researcher's key findings and previous investigations within the SA community. Stakeholder discussions contemplated what interventions had and had not worked, thus far in the SA community. As a consequence of these discussions, approaches which had previously been promoted around the SA community (e.g. tailored health leaflets and promotional materials, were disregarded from the intervention design.

Following a review of all feedback, and discussions, the aims of the intervention and overall objectives were finalised within the research team:

The intervention would aim to: improve RP of T2D in the SA population, with the objective of encouraging intent to engage in preventative behaviours.

Based on the aim of the intervention, there were discussions with the stakeholders regarding the key outcomes of the intervention. It was agreed during the stakeholder meetings that the primary outcome was to see changes in RP. Over the course of the intervention, does RP of developing T2D change from pre-intervention to post-intervention. In addition to this, secondary outcomes were discussed such as changes in attitudes and intent to change behaviour. Discussions were taken place around how these outcomes were to be measured between the researcher and stakeholders. Therefore, adopting certain key constructs from the TPB model such as attitude, intention, planning and behaviour were deemed suitable for the design and preliminary evaluation of this intervention.

Step 2: Review of possible intervention methods with stakeholders (such as face-to-face intervention; poster/leaflet; mobile app; video messages)

As identified within Study 1, participants expressed a favourable opinion towards audio and visual intervention designs. During the process of development, members of the public and key stakeholders (religious leaders, health professionals) were engaged in discussions about the intervention design and delivery. Video and text have been used to convey content, and all content was tailored for the SA community. A video intervention targeting RP and LoC within the SA community was chosen as the delivery mechanism for this intervention. This was based on stakeholders and lay SA representative preferences. Latif, Ahmed, Amin, Syed & Ahmed (2016) used a health educational video influencing knowledge and attitudes towards a preventable illness amongst Bangladeshi's in the UK. They found that the intervention significantly improved the knowledge of coronary artery disease on selected demographic groups in the UK. Upon viewing the video, all participants agreed that they wanted to implement the advice from the video into their current lifestyle. This is further reinforced by several studies which have demonstrated the effectiveness of health educational video intervention (Bisallah et al., 2018; Salina et al., 2012; Williams, Lindsell, Rue & Blomkalns, 2007). Text-based content was written through Word processing software, which was proof-read by several volunteers from the SA community.

Step 3 Initial message design.

Message concepts and writing the messages: This phase was to determine the aim and content of each message to be included in the intervention. This step aided the writing of targeted messages that would be included in the intervention; this required message concepts to be developed, which involved a list of aims that each part of the intervention should address. Message concepts can be viewed in Table 9.5.

Writing the messages was a matter of combining the message concepts with the tailoring variable. This is where the intervention development group (DoS, supervisors, stakeholders and SA community) was most actively involved. The initial messages were constructed by the researcher and the stakeholder using keywords and phrases for each topic. For example, the researcher would ask the stakeholder to write down all the keywords related to religion and then all the other topics. Once all the keywords and phrases were developed, they would be linked together into sentences. Once the initial sentences were constructed, these were then discussed with the supervisory team to understand if the concepts were understood. The supervisory team provided feedback on these messages, feedback provided such as sentences were too long; certain words used were confusing to understand and sentences did not reflect the topics in its entirety. Therefore, this feedback was taken back to the stakeholders, and more discussions took place, and new sentences were constructed. After the second round of changes, the messages were piloted to the wider SA community for understanding and sense checking, and after some feedback from the SA participants, there was one final meeting with the stakeholders around message change. These final versions of the messages were checked by the stakeholders, SA participants and supervisory team. Once the researcher had satisfaction across these groups, these messages were deemed verified to be included in the video intervention (see 9.5)

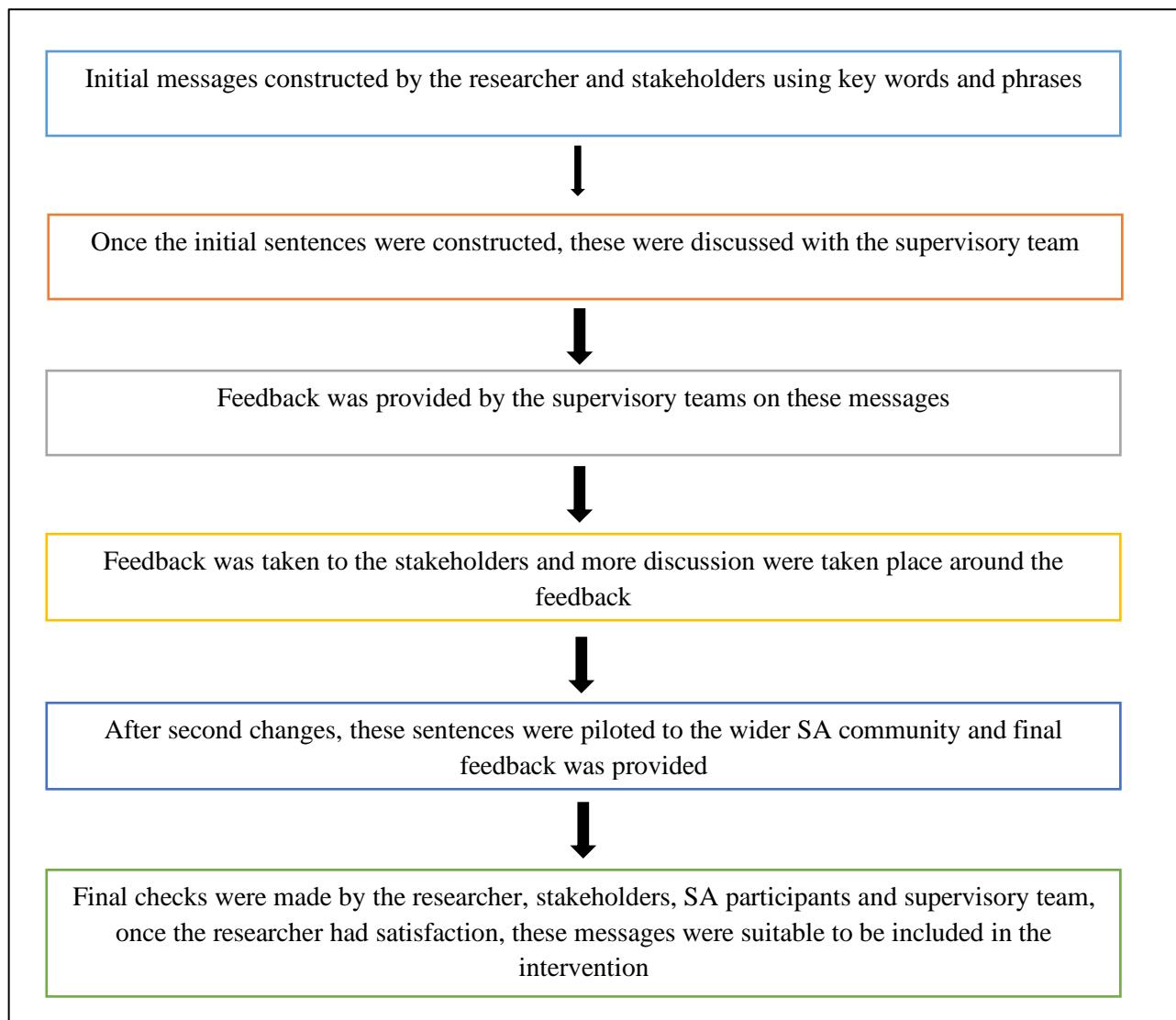


Figure 9.2: Flow Chart of Message Development

Step 4 Reviewed by the research team

Discussions took place between the researcher and the research team on all the information provided by the stakeholders. All of the messages were discussed with the research team, and some minor refinements were made based on input from the research team. Furthermore, intervention design and delivery were discussed on an ongoing and continuous basis within the research team. A review of evidence-based on previous

prevention interventions was discussed to ensure the researcher had covered all aspects of intervention design.

Step 5 Discussion with stakeholders regarding suggested intervention design to date.

Based on the preferences of the stakeholders and lay SA people, a video intervention was deemed suitable for the SA population. Once this was agreed, minor alterations were made on the content based on stakeholder feedback, i.e. choosing the correct terminology to address a specific point, for example, the initial title in the video intervention was food practices. After discussions with the SA community, it was more suitable to change food practices to food culture. Stakeholders felt the word culture was more collective compared to practices. Five short videos were created using stakeholders from the SA community; including a religious leader, health professional and three members of the community. This was designed to address the external locus of control dimensions such as powerful others. As we have seen from previous literature and Studies 1, 2 and 3, SA participants view religious leaders as a powerful source of information.

Step 6 Recording the content of the intervention with stakeholders

A number of stakeholders agreed to be ‘actors’ for the intervention content. For this process, a number of stakeholders consented to be part of the intervention. Within the discussion groups, certain stakeholders were deemed more appropriate to be part of the intervention based on knowledge, popularity within the community and previous work in the SA community. In total, 5 people provided 2 minutes of recordings in total. The video clips were filmed with the speaker talking towards the camera, who had previously learned a brief script of the specific intervention message. The five videos filmed, each lasted between 15-60 seconds. The messages focused on: describing the awareness that T2D is a serious condition in the SA community; addressing the commonality of this

condition and participants need to be more aware of their risk; emphasised the importance of internal locus of control by stakeholders providing examples of their lifestyle and how they have changed their behaviour based on internal responsibility. These messages were designed with the support of psychological theories such as the HBM, LoC, SLT and TPB. Each statement was given to a representative stakeholder for example, the religious leader was given the religious message, and the healthcare professional was given the health message. In this way, the person and the message were both aiming to reduce external locus of control by reinforcing that the understanding of RP and the responsibility to make change lies with the viewer of the intervention.

Once the clips had been recorded, these were edited to shorten the total intervention length to approximately 2 minutes. In 2018, HubSpot revealed the optimal length for a video is around 2 minutes. They found that after one minute, only 5% of viewers stop watching videos. However, 60% stopped watching the videos after two minutes. Hence the design of this intervention aimed to engage as many people in the SA population as possible. Again, during this process, various stakeholders were consulted (including the research team, SA lay members and religious leaders) on where and how to cut and edit the clips (such as ensuring women and men were included).

9.2 Final Intervention

This intervention consisted of five clips combined into one health promotion video discussion different aspect of LoC and RP for the SA community. Within this intervention, there were 5 different speakers; Religious leader, healthcare professional (GP), a mother with two children, two female friends and one male. Each of these speakers delivered a health message targeting a specific behaviour for the SA community based on all of the empirical findings in this PhD, literature review and preferences from the SA community and stakeholders. The total video length was approximately 2 minutes,

with each speaker clip around 15-60 seconds (see below for screenshots of the intervention).



Introduction slide to the intervention.

The title was deemed acceptable from the stakeholder and bold colours used to capture the audience.



First clip of the intervention. This is based on the notion of social media and external influences.

These two stakeholders were lay representatives of the community who were deemed the most suitable to deliver this topic.

Relevant BCT – Social Comparison



Second clip of the intervention. This was based on the notion of food culture. This individual was a lay representative of the community who was deemed the most suitable for this topic.

Relevant BCT – Social Support and Action Planning, Information about the seriousness of the condition



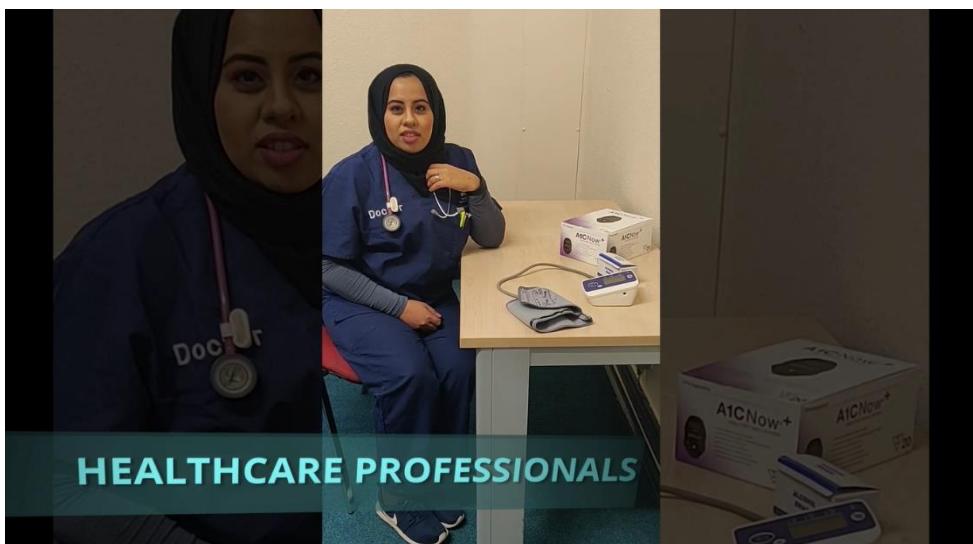
Third clip of the intervention. This was based on the notion of family history and practices. This individual was a lay representative of the community who was deemed the most suitable for this topic alongside the children as a motivation factor.

Relevant BCT – Social Support and Action Planning, Information about the seriousness of the



Fourth clip of the intervention. This is based on the notion of religious beliefs. This individual was a key stakeholder and key religious figure in the community who was deemed the most suitable for this topic.

Relevant BCT – Social Support and Action Planning, Information about the seriousness of the condition.



Fifth clip of the intervention. This is based on the notion of healthcare professional. This individual was a key stakeholder and key professional figure in the community who was deemed the most suitable for this topic.

Relevant BCT – Social Support and Action Planning, Information about the seriousness of the condition.

Figure 9.3: Screenshots of the Final Intervention

Table 9.5: Intervention Script

Intervention Script	
Social Media (First Clip) – 30 seconds	‘Do you not think there is increase use of social media today we constantly uploading pictures of unhealthy food and fatty desserts that just make us want to go out more. Your right, you know, we should look after our health and risk and our community. We should not let social media dictate what we are going to eat that day’.
Food Culture (Second Clip) – 20 seconds	‘Food is a big part of our culture like weddings, festivals, parties and other functions but we must be mindful of putting our health first’!
Family History (Third Clip) – 30 seconds	‘Diabetes is a serious condition in our community’. I was told by my doctor I was at high risk of developing type 2 diabetes. However, with a little exercise and looking after my diet, I am no longer a pre-diabetic. If I can do, you can do it too!
Religious Beliefs (Fourth Clip) – 30 seconds	‘Regardless of our religious and traditional beliefs, we should still ensure we have a healthy lifestyle for ourselves and our families’!
Healthcare Professional (Fifth Clip)- 15 seconds	‘Diabetes is a serious condition in our community, and you can change that by having regular screening check-ups at your GP surgery. Don’t leave it too late, act now and book that appointment’!

10 Chapter 10: Intervention Evaluation

Proof-of-Concept (POC) and Acceptability Testing

10.1 Study 4 - Chapter Overview

The previous chapter described the development of a RP prevention intervention (Chapter 9). The aim of the following chapter is to assess whether the RP intervention had the potential to be applied in a real-world setting and has the potential to change RP in the SA population. A mixed-methods approach was used, whereby both qualitative and quantitative data were collected and analysed (Cresswell & Clark, 2017).

This chapter is presented as two studies, which aimed to 1) test the proof-of-concept of this new intervention, to identify if the intervention was able to change RP in SA people (Quantitative Study 4a), and 2) to assess the acceptability and feasibility of this new intervention with the target audience in the real world, the SA general public (Qualitative Study 4b). Following the results of these studies, a combined discussion is offered, which explores the implications for further research testing (progression to an RCT) and the possibilities for future roll-out in the real-world.

10.2 Study 4a: Proof-of-Concept Study: Quantitative Methods

Aim

To identify the preliminary effectiveness of the intervention, which aimed to improve the RP of T2D in the SA population, with the objective of encouraging intent to engage in preventative behaviours.

Research questions:

1. Was the intervention associated with positive changes in RP?
2. Was the intervention associated with an increased internal LoC to change risk behaviours?
3. Was the intervention associated with positive changes in attitude, perceived behavioural control, intention and behaviour towards RP and diabetes prevention?

10.2.1 Design

This Study adopted a Proof-of-Concept (PoC) approach (Gewandter et al., 2014). PoC is a realisation of a certain method or idea in order to demonstrate its feasibility or a demonstration in principle with the aim of verifying that some concept or theory has practical potential.

A one-way repeated measures MANOVA design was conducted. The DVs were RP, LoC and TPB variables. The IV was the intervention time points (pre and post-test scores).

Ethical approval for this study was granted from Liverpool John Moores Ethics Committee (19/NSP/012)

10.2.2 Participants

The research team recruited a purposive sample of SA participants. Eligibility criteria included over the age of 18; residing in the UK; no current diagnosis of T2D; and self-identified as SA. Non-probability sampling techniques were adopted for recruitment of participants. Targeted snowball sampling (Johnson, 2014) was used to invite SA people to participate in a face-to-face intervention study. In addition, the researchers targeted community venues (e.g. religious settings, community organisations and friends and family) in an effort to recruit a convenient sample.

10.2.3 Materials

A demographic information questionnaire included: age, gender, country of residence, level of education, ethnic background, religion, a family member with diabetes, waist measurement, height and weight measurement and asked if they ever had high blood pressure or medication for it.

The same questionnaires were used as per the previous studies and were administered pre and post-intervention: RPS-DD, MHLC, and one new questionnaire were added: The Diabetes Intention, Attitude and Behaviour Questionnaire (DIAB-Q) (Traina et al., 2016) to measure intention to engage in self-care behaviours (Full details in the Methodology Chapter 3). The post-DIAB-Q was revised to reflect the future adoption and intention of behaviour for example, in the next 7 days, how likely are you to exercise? The post-DIAB-Q questionnaire was used once the participants had completed watching the intervention.

10.2.4 Data Collection and Procedure

Available participants attending a local community centre were presented with a plain language description of the study (PIS) and consent information. Participants were encouraged to ask questions if unsure, and the researcher clarified any issues prior to

taking consent. If participants were happy to take part, they were advised to sign the consent form. Subject to the participant indicating informed consent, eligibility screening commenced. Eligibility assessed individuals identified as SA were over the age of 18 with no diagnosis of diabetes (any type). Ineligible participants thanked with a debrief information sheet. Eligible participants were presented with the pre – questionnaires (RPS-DD, Pre-DIAB-Q and MHLC) to complete before watching the intervention. Once completed, the participants were asked to watch the intervention (a 2-minute video clip). Straight after watching the intervention, the participants were given the post-intervention questionnaires (RPS-DD, Post- DIAB-Q and MHLC) to assess any changes in RP. Upon completion, participants were provided with a debrief information sheet.

10.3 Results

10.3.1 Sample

Overall there were n=120 SA participants ($M = 34$ years old, $SD = 9.72$) who took part in this study; 51% females and 48% males. Within this sample, all were from a Muslim background, and more than half of the participants had a family history of T2D. Finally, within this sample, 38% of participants were educated to a degree level (see table 10.1).

Table 10.1: Participant Characteristics

		Total (%)	SA Indian	SA Pakistani	SA Bangladeshi
Ethnicity					
	Number	120	58	39	23
	Percentage		48.3	32.5	19.2
Age (years)					
	18-25	15.9	8	7	4
	26-32	30.1	23	8	5
	33-40	29.2	17	12	6
	41-47	16.6	7	8	5
	48-54	4.1	0	4	1
	55-66	4.1	3	0	2
Gender					
	Male	48.3	25	17	16
	Female	51.7	33	22	7
Family History					
	Yes	55	30	22	14
	No	45	28	17	9
Religion					
	Christianity	0	0	0	0
	Islam	100	58	39	23
	Hinduism	0	0	0	0
	Atheism	0	0	0	0
	Prefer Not to Say	0	0	0	0
Education					
	High School	7.5	2	3	4
	College/Sixth Form	27.5	16	13	4
	Degree	38.3	28	9	9
	Masters	18.3	9	10	3
	Other	5	1	3	2
	No Education	3.4	2	1	2

10.3.2 Assumptions

In order to conduct a One-Way Repeated Measures MANOVA, there were certain assumptions which were tested. All the assumptions were met in order to carry on with

the analysis. There were no outliers present in the data set, there was no multicollinearity present, and this was examined through correlations. All the DVs were moderately correlated, and none of the correlation was higher than 0.9. Therefore, we can assume no multicollinearity was present.

10.3.3 Descriptive Statistics

The descriptive statistics provide the Means and Standard Deviations for each of the DVs and the IV used in this study. Overall for the SA sample, there was an increase from the pre intervention to the post intervention ($M = 46.6, SD = 0.62$), alongside I-LOC ($M = 31.0, SD = 0.21$). Overall, there was a decrease in all of the external LOC constructs, such as Powerful Others ($M = 15.8, SD = 0.25$), Chance ($M = 12.1, SD = 0.20$), Doctors ($M = 9.46, SD = 0.18$) and Other People ($M = 6.33, SD = 0.18$).

Table 10.2: Descriptive Statistics (M & SD's)

South Asian		
	Pre-Intervention	Post-Intervention
Risk Perception	36.5 (0.60)	46.7 (0.71)
Internal	16.5 (0.37)	30.8 (0.24)
Chance	26.0 (0.39)	11.8 (0.22)
Powerful Others	23.9 (0.38)	15.9 (0.28)
Doctors	11.5 (0.26)	9.41 (0.20)
Other People	12.3 (0.24)	6.49 (0.19)
DIAB-Q Subjective Norm	8.92 (0.29)	13.5 (0.36)
DIAB-Q Attitude	8.74 (0.26)	16.2 (0.24)
DIAB-Q PBC	9.81 (0.26)	17.1 (0.25)
DIAB-Q Intention	8.65 (0.25)	15.9 (0.26)
DIAB-Q Planning	7.12 (0.24)	15.1 (0.25)
DIAB-Q Behaviour	4.31 (0.15)	9.60 (0.19)

10.4 Main Analysis

10.4.1 Multivariate tests

Wilks Lambda is used to test whether there are differences between the Means of identified groups of subjects on the combined (composite) DVs (Allen, 2017). The multivariate test performed in the One Way Repeated Measured MANOVA showed that there was a statistical difference in time (pre & post-intervention), ($F(11, 109) = 328.5$, $p < .001$; Wilks' Lambda = 0.02; partial $\eta^2 = 0.97$).

Further investigation took place to understand which specific constructs were significant pre and post-intervention. RP was statistically significant with time, pre and post-intervention $F(1, 119) = 198.4, p < .001$. When comparing the means of RP, it was found that SA individual's RP increasing from pre ($M = 36.9, SD = 0.53$) to post-intervention ($M = 46.6, SD = 0.62$). This shows that once SA people viewed the intervention, their own RP was increased (see appendix 10.1).

When investigating different constructs of LOC, it was found that there was a statistically significant difference on Internal LOC to time of intervention $F(1,119) = 1279.7, p < .001$. Means indicate that SA individual's had higher scores on internal from pre ($M = 16.0, SD = 0.34$) to post ($M = 31.0, SD = 0.21$) intervention.

Furthermore, there was a statistically significant difference on all External LOC on time of intervention, Chance $F(1,119) = 1276.9, p < .001$, Powerful Others $F(1,119) = 681.5, p < .001$, Doctors $F(1,119) = 116.7, p < .001$ and Other People $F(1,119) = 661.2, p < .001$. All of these External LOC constructs decreased from pre to post-intervention. Overall, indicating SA individual's had higher levels of Internal LOC and lower levels of External LOC post-intervention.

Finally, there was a statistically significant difference on all DIAB-Q constructs on time of intervention, Subjective Norm $F(1,119) = 189.1, p < .001$, Attitude $F(1,119) = 575.3, p < .001$, Perceived Behavioural Control $F(1,119) = 527.5, p < .001$, Intention $F(1,119) = 581.5, p < .001$, Planning $F(1,119) = 660.2, p < .001$ and Behaviour $F(1,119) = 799.4, p < .001$. Based on these constructs, it was found that SA individual's attitudes, behavioural control, intention, planning and behaviour increased post intervention. SAs were more intent to plan and adopt healthy behaviour such as lose weight and engage in PA post- intervention (see table 10.2).

10.4.2 Summary of Findings

Overall this intervention was successful and demonstrated preliminary evidence in the effectiveness of improving RP of T2D in the SA population. The study answered the three research questions confirmed that SA participants scored higher on RP of T2D after engaging in the intervention. Furthermore, SA participants scored higher on internal LoC and decreased scores in their external LoC. This was further supported by participants scoring higher post-intervention on intention, perceived behavioural control and behaviour towards RP and diabetes prevention.

10.5 Qualitative Study 4b: Exploring the Acceptability and Feasibility of the Intervention

The overall aim of this study was to engage key stakeholders in the process of intervention validation, to consider future implications for the intervention, and to offer SA in the community an opportunity to comment on the relevance and acceptance of the intervention in plain English, not using ‘NHS-speak’ or research jargon.

10.5.1 Methods

This study implemented a Patient Public Involvement (PPI) methodology (Gray-Burrows et al., 2018), which occurred in the community with groups of SAs. PPI is defined as “being carried out ‘with’ or ‘by’ members of the public not just ‘to’, ‘about’ or ‘for’ them” (INVOLVE, 2018). The methodological process for this qualitative study adopted the process of Mental Health and Wellbeing Impact Assessment: Stakeholder and key informant – MWIA workshop (Cooke et al., 2011). This methodology created opportunities for enhanced participation, invited participants to have a sense of belonging, and meaning relevant to the topic. This approach encouraged active participation rather than passive consultation. Ethical approval was sought and approved (19/NSP/012).

10.5.2 Sampling

Participants who had completed Study 4a were invited to participate in this follow-on study. Additional participants were recruited through religious community venues such as local mosques and one community centre group in Bolton, North-West England (BCOM). Thirty SA community members participated in one of three PPI workshops (Between March- April 2019). Various additional stakeholders (religious leaders, health professionals, research team, members of the public unable to participate in group sessions) were shown the intervention and provided their feedback regarding the intervention acceptability and feasibility with the lead researcher through 1-1 and group

discussions. These various recruitment strategies have attempted to engage a ‘representative’ sample of participants for this qualitative intervention evaluation.

10.5.3 Procedure

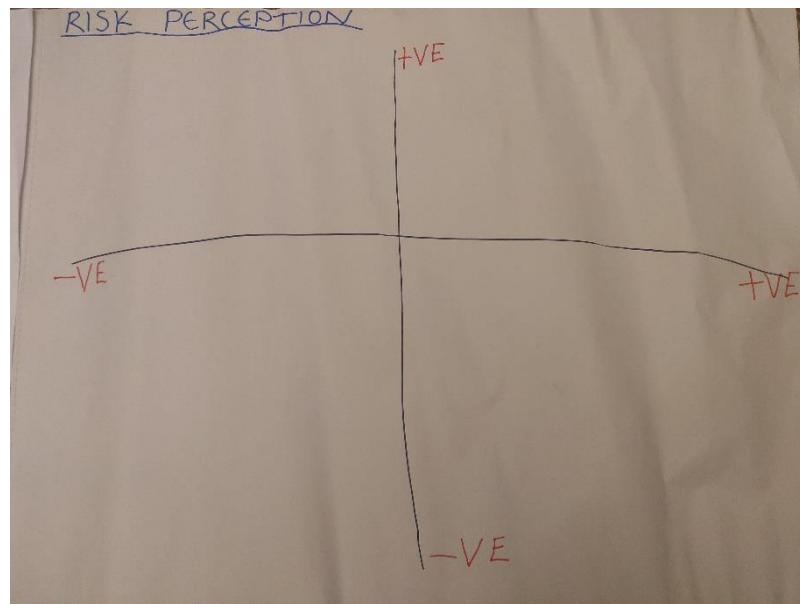
As informed by the Public Health, Mental Health and Wellbeing Impact Assessment Toolkit (MWIA workshop) (Cooke et al., 2011), the community PPI workshops were guided by an agenda to structure the session (Table 10.3) and adopted focus group methodology, aiming to bring together a variety of views at once (Nyumba, Wilson, Derrick & Mukherjee, 2018). Participants completed a demographic sheet and provided informed consent to take part.

Table 10.3: Workshop Agenda

Workshop Agenda
Introduction
Group Intervention
Break
Group Discussion & prioritisation
Take Away Actions
Thank Participants and Close

The lead researcher explained the purpose of the intervention to the participants and gave a brief overview of the development of the intervention, and some initial questions were asked around each participant’s risk of developing T2D. There was a flipchart paper present in the room with a risk and intervention matrix diagram (see figure 10.1), and each participant was given a blank pre-intervention sticky note (yellow) and a post-intervention sticky note (orange). Participants were asked to use the yellow sticky

notes to record their thoughts, and opinion relevant to the initial discussions and then add them onto the matrix. Initial discussions included topics such as participants perceptions of risk of developing T2D, factors that can hinder risk, the importance of understanding risk and how to increase risk perception. Answers to questions such as factors that hinder risk (negative), participants were asked to put the sticky note on the negative axis. The lead researcher was interested to see whether these negative answers changed to positive post-intervention. The discussions were flexible, with a basic structured conversation, everyone had the opportunity to take part in this discussion (Facilitation was aided by the use of sticky notes for all to add to the matrix).



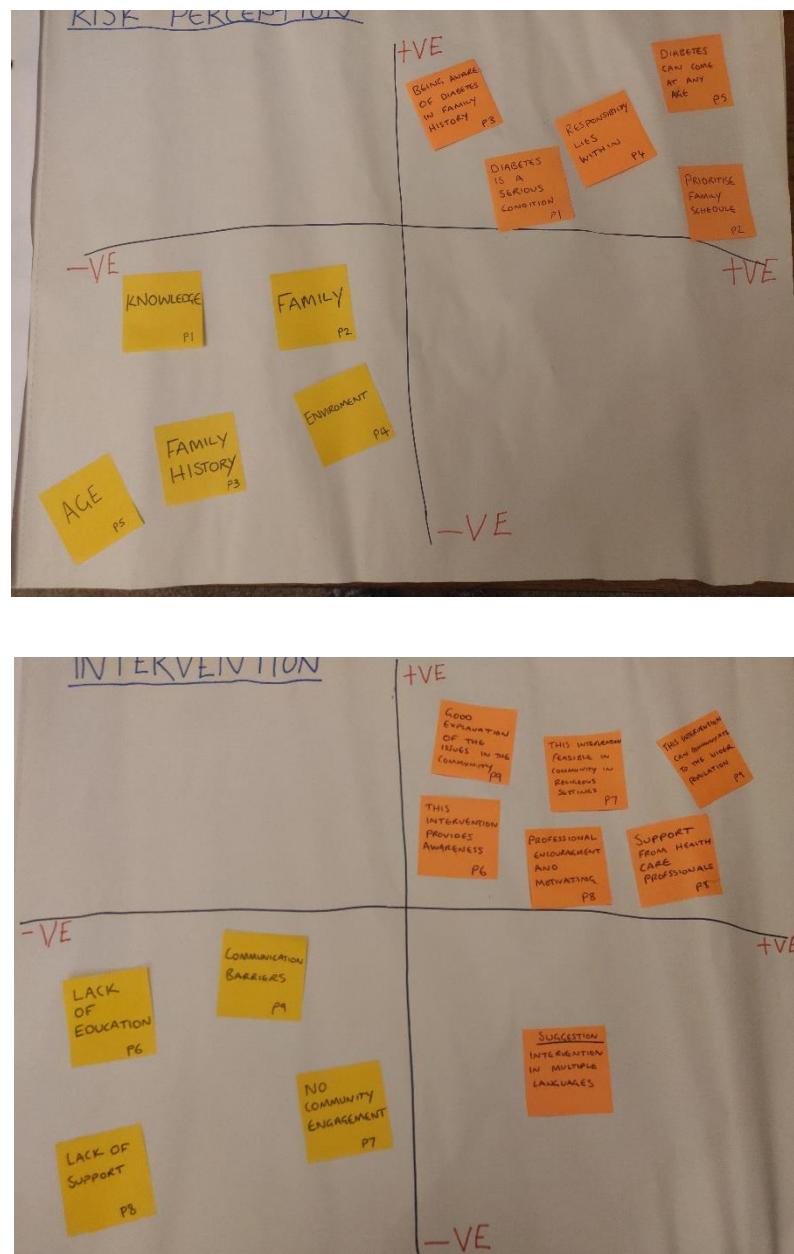


Figure 10.1: Intervention Matrix and Thoughts of Participants

Following the initial discussions, participants were asked to watch the 2-minute intervention, which was played on a projector screen to the whole group. Once the participants finished watching the video, the researcher encouraged the group to engage in a discussion about the intervention, specifically focusing on the appropriateness, suitability and feasibility of the intervention. Questions such as, what are your thoughts on the intervention, what aspects did you like the most/least, is there anything you would

change, has the intervention changed the way you think about risk (Table 10.4), whether their believed risk of developing T2D had changed since watching the video; if this intervention would have a positive or negative impact on the SA community. Participants were asked to reflect on the answers they put down for the initial discussion and whether these have changed to positive. As this point, participants would put orange sticky notes on the positive axis to show the influence of the intervention. The researcher captured the conversations that took place in the workshops by hand-written field notes; the decision to not use a digital recorder was made so that participants could speak freely and openly, as it is often claimed that recording can create unease in the interviewee (McGonagle, Brown & Schoeni, 2015). However, photographs of the matrix were taken at various timepoint to help the researcher capture discussions and messages, and link these to priority points.

The purpose of this process was to spark discussion and to consider if there were any perceived changes in participants attitudes, thoughts and intentions pre and post-intervention. Participants were asked to decide which were the most important and influential aspects of the intervention. The most important aspects of the intervention, deemed by the participants, were discussed in greater depth. This was an iterative process, whereby all participants who contributed to the evidence were encouraged to prioritise as part of the workshops (aided via the yellow-orange sticky note process). Once agreed, the most important points were then discussed further. Whilst the discussion was taking place between the group; the researcher recorded the key points of these discussions via field notes. Once, exhausted, the researcher asked the group for any final points and then thanked everyone for their participation.

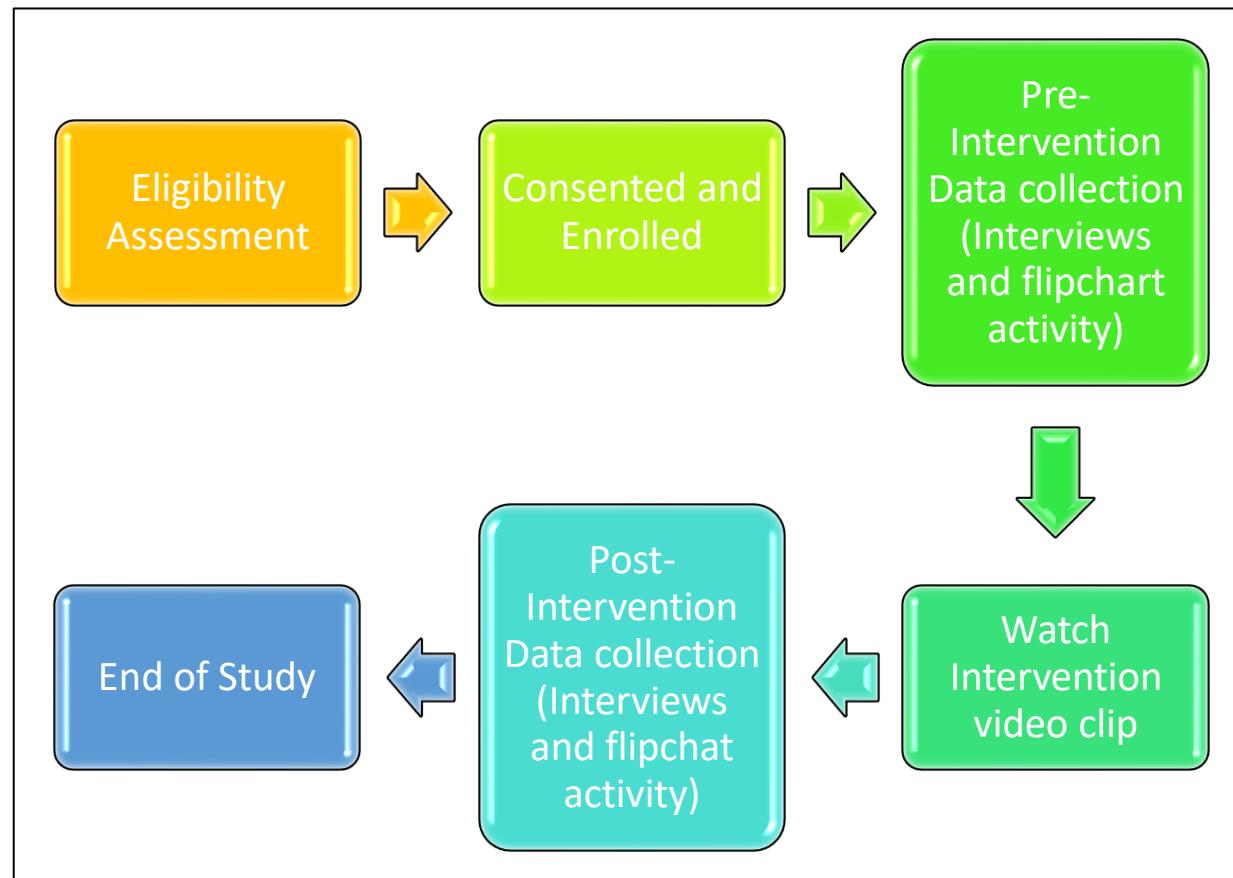


Figure 10.2: Process Chart of Data Collection

Table 10.4: Key questions for Intervention Discussion

Acceptability & Feasibility	Key Questions
Acceptability	Overall, what are your thoughts about this intervention?
Process of Change	If you're at high risk of developing T2D, watching this intervention will help with.....?
Suggestions for Further Improvement	Is there anything you would change with this intervention?
Acceptability	Do you think this intervention represents the SA community?
Implementing Change	Having watched the intervention, is there any changes you would make moving forward?
Acceptability	Would you recommend this intervention to someone you care about?
Barriers	Were there any difficulties in taking part?

10.6 Qualitative Findings

Overall feedback from participants was positive about the intervention. Thematic analysis (Braun & Clarke, 2006) of free text researcher notes, alongside the prioritised points from the workshop matrix's, identified patterns and responses (see Tables 10.5 to 10.8) are presented below. Priority themes were identified by understanding the most important points to the least important to the SA participants and what they would like to see in the intervention for future interventions. Thematic analysis allowed the researcher to identify patterns and themes in the data. An advantage of this approach is that it allowed the flexibility to identify key themes which provided answers to the research question being addressed.

Table 10.5: Overall performance of the video

Prioritised responses (Ranked) (Most Important to Least Important)	
Good explanations of the issues in the community	Generally, comments were positive and suggested that participants found the intervention processes acceptable.
People featured in the video represent our community	Responses to questions relating to the video organisation demonstrated that the intervention was well structured and delivered. These aspects of the intervention contributed to participants overall satisfaction.
Professional, encouraging and motivating	
Good Pace	

The content of the video was judged to be informative and well explained. It was suggested that they were delivered at an appropriate pace in a supportive environment. They found the speakers in the video to be professional and encouraging, providing good support and motivating participants. Most of all, stakeholders recognised the value in the intervention focusing on SA people, being delivered by SA people. They also acknowledged and valued the range of messages delivered within the intervention and commented on how relevant it was, whom the messages came from (e.g. religious leaders, health professionals, lay public, family members). They felt as though, they could relate to the speakers, e.g. a mother felt she could relate to the mother and children scene in the video. She felt this was a very powerful message for her to change. Therefore, her beliefs towards T2D changed based on her experience of the video intervention, and hence she also reported an intention to change post-intervention.

Table 10.6: Overall satisfaction

Prioritised responses (Ranked) (Most Important to Least Important)	
Improved Motivation	
Well-structured discussions	
Well-explained and informative	
Well-delivered via a video	
Easily accessible	
Could be in different languages	
More variety in the age group	

Stakeholders summarised that the intervention provided appropriate and useful resources that enabled participants to understand their own risk. There is some evidence that the intervention might address the motivation for engaging in lifestyle behaviours for example through changing beliefs in capabilities and improving confidence. The participant reported to be more motivated to make changes in their lifestyle after the intervention. They acknowledged if they didn't change their behaviours, the risk of developing T2D will increase further.

After the intervention, stakeholders discussed various aspects of preventative behaviour which otherwise they had not considered, for example, they acknowledged the importance of PA and reported having greater intentions to become physically active, (as reinforced by the quantitative analysis, study 4a). Participants reported that their intentions of joining a gym to exercise or going out for daily walks with family members were higher post-intervention. Participants understood the link between PA and risk of T2D and being from an ethnic background that is at high risk; they had to become more active. It is possible that these comments indicated that participants might take a graded approach to PA in the future, which may have been encouraged by the video intervention (BCT 8.7 – Graded tasks, Michie et al., 2013). Furthermore, influences on psychological capability were inferred by several references to intervention content. For example, the

stakeholders discussed how the intervention had enhanced their awareness and understanding of the risk of T2D. These responses suggest that the intervention facilitated the acquisition of self-management skills to improve risk behaviour, for example, post-intervention sparked discussion about issues such as: attending regular screening, and how blood tests will help participant monitor their own risk of developing T2D.

Table 10.7: Recommendations to others

Prioritised responses (Ranked) (Most Important to Least Important)	In general, participants reported they would recommend the intervention to others to gain a greater understanding of RP of developing T2D and to improve awareness in the SA community. Stakeholders appreciated the opportunity to take part in the intervention evaluation workshops. Participants were very
Improved understanding risk of T2D and lifestyle changes	
Improved motivation to make a change in behaviour	
Quick and Easy to watch	
Enjoyable	

keen to highlight from their perspectives; there are very few interventions targeting the SA population; as a result, they supported the roll-out of the intervention to the SA population.

Within the video intervention, there was an element of social opportunity that was highly valued by the participants. Participants felt that the people present in the video represented the community, and they felt reassured after hearing experiences from the speakers in the video, especially the religious scholar. Most of the participants found the religious leader the most powerful figure in the video intervention. They felt motivated by the message from the religious leader and felt they could get more support within the community. Furthermore, participants enjoyed being a part of the group watching the

video intervention and then taking part in a discussion (these evaluation workshops). These participants implied that they did not regularly have access to groups such as these and they highly valued the ‘peer-support’ within the group, and hence would recommend both the intervention and this workshop process to others.

Table 10.8: Suggested changes to improve the video intervention

Prioritised response (Ranked) (Most Important to Least Important)	
Need a different version of languages	Having the videos in more than one language was a priority discussion for the stakeholders. Some participants felt the video only English will not be relevant to the larger SA group, as people may struggle to understand the messages delivered by the people in the video. Therefore, participants suggested in the future to have more languages, more predominant in the SA
Different variety of ages in the video	
Need a face to face group programme explaining what to eat and how to exercise	
Need this video to be circulated on social media and other places	

communities, such as Urdu, Punjabi, Gujarati and Hindi. For the purpose of this PhD, the intervention was simplified as a proof-of-concept study only. However, the delivery of this intervention in multiple languages was discussed within the immediate research team during intervention development, although to ensure simplicity and assess proof-of-concept for initial design it was kept to English only. However, it is certainly feasible to produce this intervention in multiple languages.

Some of the participants suggested improvements by having other resources rather than just a video. Participants felt they had no other directions after watching the video,

i.e. where to find other support, therefore wanted more ‘hands-on’ approach whereby, they can attend physical classes for exercise or learn about food and diet, which they can bring family members with them, and they can learn together. However, this is important as it could be used as a promotional tool prior to an invitation/referral to the NDPP (or other formal intervention).

The overall aim of this qualitative study was to gain an understanding of the acceptability and feasibility of this intervention in the SA community. Overall, the aim was achieved in this study, based on the SA community, this intervention was deemed acceptable and could make a significant difference as part of a community T2D prevention strategy (within a high SA area).

10.7 Combined Discussion Study 4a and 4b

The overall aim of this intervention evaluation was to complete a PoC study and to assess the acceptability and feasibility of a RP intervention for SA people in the real world. This evaluation was completed through a mixed-method approach, using both qualitative and quantitative data. The quantitative study (4a) indicated that the intervention was successful in suggesting the preliminary effectiveness of the intervention changing RP towards T2D such as, SA participants had higher internal locus of control, lower external locus of control, higher RP scores and higher intention to adopt healthy behaviours after watching the intervention. These results were reinforced through the acceptability and feasibility study (4b) which suggested that SA participants thought the intervention was both relevant towards their population, feasible to implement within their community and would encourage them to think differently about their RP towards T2D.

Prior to the intervention, many of the participants tended to have low RPs of developing T2D. However, post-intervention, the RP scores increased. According to the HBM (Becker, 1974), in order to make a behaviour change, individuals will take action to prevent, to screen for or to control illness if they (a) believe that they are susceptible to that illness, especially if they view the illness as potentially having serious consequences to them, (b) believe that by following a recommended health action (e.g., diabetes screening), they would reduce their susceptibility to the illness and (c) believe that the benefits of taking the recommended action outweigh the perceived barriers or costs for doing so (Joseph, Burke, Tuason, Barker & Pasick, 2009). Based on quantitative and qualitative data, our findings are in line with the HBM, as SA participants were more aware of their own risk of developing T2D and after watching the video, they may have felt more susceptible to T2D therefore, their RP score may have increased. Furthermore, SA participants were more intent on following a health action. The findings in this study have shown that the intervention was acceptable and feasible to a range of stakeholders, chiefly to SA population. SA participants had more knowledge and awareness around the risk of T2D, and this was evident based on the quantitative findings, whereby, SA participants had higher RP score post-intervention.

In the present study, there was a significant relationship between I-LoC and time of intervention (pre and post). Participants had higher mean scores post-intervention. Those with I-LoC have greater control over their health, i.e. those who believe that the main reason of their health is in themselves pay more attention to lifestyle behaviours. Thus, the I-LoC increases the person's ability in self-care behaviours. Brannon & Feist (2007) showed that individuals with internal control had a better quality of life and health than a control group. Results of other studies demonstrated that educational interventions increase self-efficacy (Yehle & Plake, 2010), self-management (Fardaza, Heidari &

Solhi, 2017) and health assessments (Taghdisi, Borhani, Solhi, Afkari & Hosseini, 2012). Therefore, the designed intervention is useful to increase I-LoC. Furthermore, within this study, as peoples I-LoC increase post-intervention, their E-LoC decreased, P-LoC, C-LoC, OP-LoC and D-LoC. This was an exciting finding, as previous studies (Chapters 12 & 13) found that SA participants tend to hold an external control over their health behaviours, and this is deeply rooted within their culture and religion. However, post-intervention, these views changed whereby, these individuals viewed their health behaviours as more internal. An explanation for this was found through the qualitative data (study 4b), whereby SA participants valued the religious leader in the video to be the most influential figure. This is reinforced by previous findings, as Ali, Gilani & Patel (2017) found that religious leaders have a pivotal role in the community, as they are a key source of information and support. Therefore, the message given by the religious leader may have had a positive impact on the SA participants and reduced the misinterpretation of fatalism and externality, therefore decrease E-LoC and increase I-LoC.

Finally, there was significant evidence to suggest that SA participants were more likely to engage in health promotion behaviours as there was a significant relationship between all the TPB variables and time of the intervention (pre/post). Participants had higher scores on subjective norms, attitudes, behavioural control, intention, planning and behaviour post-intervention. These findings reinforce the TPB model by indicating that participants had a favourable evaluation of T2D, and due to this, there was stronger intention to perform a certain behaviour, the more likely the behaviour will be performed. In addition to this, SA participants had higher subjective norms, and they perceived that a particular action is more likely to be approved by their peers. Therefore, they had higher perceived behavioural control. Due to all these variables increasing in the post-

intervention indicated that SA participants are more likely to carry out certain behaviours.

In this case, more PA and improved dietary intake.

Changes in RP following population health interventions have rarely been measured (Tate et al., 2003). The findings here (studies 4a & 4b) significantly improved RP following a health intervention, which suggests that this type of research is worth considering when assessing the effectiveness of an intervention to improve health.

Given the increasing focus on setting approaches to health promotion (Jeet et al., 2018) or population health promotion (Kumar & Preetha, 2012) and given the recognition of the desirability of indicators that reflect community perceptions, this line of inquiry deserves consideration in planning evaluations of multisectoral, community health-based promotion intervention such as this.

10.7.1 Further Evaluation of the intervention

The next step for the evaluation of the current intervention is to design and carry out an RCT across a larger sample across the SA population. The RCT should evaluate if the intervention changes RP and subsequent lifestyle behaviours are that a) seeking additional health advice, b) changing lifestyle behaviour, c) preventing the onset of T2D.

The potential addition of an intervention follow-up must be considered, to understand whether there is a short term or long-term change in RP within the SA participants.

10.7.2 The implication for clinical practice

We are aware from previous research (Chapters 1, 4, 5, 6, 10) that SA individuals have limited engagement and retention rates in diabetes prevention services (Khunti et al., 2013). SA individuals are less likely to use and report more difficulties accessing diabetes healthcare services. We have outlined the reasons why this may occur (Chapters

4, 5 & 6) such as individuals from SA background may have lower RP in terms of developing T2D. Therefore, with the initial success of the intervention, current services might consider using this video as a starting point with SA participants and their risk of developing T2D.

For example, in clinical practice, GPs may advise high-risk participants to watch this video before advising them on other lifestyle programmes. If the SA participants can reflect on their own risk and change their initial beliefs, they may be more likely to participate and retain other diabetes prevention services such as the NDPP. In addition to this, the intervention can have future implications (new model of prevention) and can contribute to the NHS five-year forward view.

The intervention also has scope to reach the SA population through community and religion settings if adopted by the local communities. PHE have specific population focussed strategies and tackling inequalities (PHE, 2018), and this intervention can be used within this strategy. Predominately in areas across the UK where local authorities have a high SA population and may need to adapt their prevention strategy to change perceptions and attitudes towards diabetes risk (Better health for all: A new vision for prevention, PHE, 2018).

10.7.3 Conclusion

To my knowledge, this was the first video intervention to investigate RP and LoC variables in SA participants. Overall, the findings from this study were successful in achieving the aims and objective. The intervention was proven success within the SA community. The intervention processes were well received by the participants, who reported suitable structure and appropriate delivery of content and materials. Suggested improvements related to other languages and other modes of delivery for future interventions.

This intervention should now be considered for further evaluation within a full RCT testing effectiveness at changing RP and thus influencing subsequent T2D preventative behaviours (e.g. visits to GP; engagement in NDPP; changes in lifestyle behaviours)

11 Chapter 11: Discussion

11.1 Chapter Overview

This discussion summary brings together this PhD's key contribution to new knowledge and key findings. Followed by a section on research strengths and limitations. In addition, the dissemination of research findings and considerations for future research are also explored.

11.1.1 Overview

This PhD used a mixed-methods approach to comprehensively examine RP and fundamental psychological beliefs in lay SAs living in the UK. This PhD has solely focussed on the general SA population who are not diagnosed with T2D. This was a vital part of this PhD because the aim was to try and change RP prior to a diagnosis as an important preventative measure. Implementing a broad range of methods (e.g. literature review, self-report questionnaires and semi-structured interviews), significant new evidence has been produced and added to the understanding of SA communities. In particular, the literature review highlighted the importance of RP, and without the firm understanding of how people perceive and react to risks, there is no way of knowing what sort of interventions would be most effective. Furthermore, the literature review revealed the complex nature of socio-cultural beliefs within the SA population and the limited amount research examining RP in the lay SA population, provided justification for this research, as there was a clear need to address these gaps in knowledge around SAs and how their RPs could affect their behaviours.

This final chapter highlights the main findings from the studies in this PhD. Furthermore, a discussion of the results for practice and future research is also provided.

11.1.2 Contribution to new knowledge

The unique contribution of this thesis includes using a mixed methodology approach to provide a more complete and comprehensive understanding of RP within the SA population. Previous research may have flagged socio-cultural issues (migration, acculturation and family roles) that may affect SAs behaviours (Greenhalgh et al., 2015). However, this PhD is the first to go beyond merely identifying factors that can impact diabetes prevention, and this new research suggests meaningful explanations as to why these issues may occur. Furthermore, whilst this PhD has created new evidence, it also

goes beyond and moves the findings into a practice-based evidence, by applying a ‘person-based’ (Yardley et al., 2015) approach intervention for the SA population, with the ultimate aim of changing RPs and thus has the potential to make real-world impact to improve diabetes risk within the SA population.

This intervention aimed to change RPs and intent on behaviour change (using TPB variables such as attitude, intention, planning, used from the DIAB-Q). The intervention designed has attempted to adhere to and apply various recommendations for intervention design (Ankhush, Granlund, Odgaard-Jensen, Oxman & Flottorp, 2015) and evaluation.

A comprehensive approach towards investigating the difficulties around SA RP for T2D has been presented as a unique contribution to new knowledge and evidence base. This thesis interconnects new empirical findings; previous research across a range of domains (public health, health psychology, health), and topics (prevention, lifestyle behaviour change, T2D, risk perception, actual risk, interventions); and indeed, considered of a range of theoretical approaches towards the intervention content and delivery, has been a unique aspect of this PhD thesis.

11.2 Overview of findings

11.2.1 Summary of research findings: Study 1

As revealed in the literature review (Chapter 1), T2D has increased over the last few decades and particularly in the UK, T2D is increasing significantly year on year. People of SA descent are vulnerable to T2D, and this risk is expected to increase further in the coming years. With the burden of T2D in the UK, NHS and PHE introduced the NDPP in 2016 to help reduce T2D by providing lifestyle support to high-risk participants. Although lifestyle interventions have shown to have success. Such success has been limited within the SA population, and programmes have reported low levels of

recruitment and retention (Khunti et al., 2013). Therefore, it was imperative to explore health-related RPs and behaviours among UK SA individuals. Although limited research has investigated RP in the SA population, none of the previous studies has used a theoretical framework to explain the complexities of RP. Therefore, Study One used GT methodology to explore risk perceptions in the SA population. Overall this study found several psychological concepts which impact SAs RPs. For example, the concept of LoC, whereby SA individuals hold an external view on the outlook of life, the diminished responsibility of looking after one's health, instead it is based on the concept of fatalism and fate and finally, the socio-cultural barriers between SAs. Within this GT framework, it brought together various theories such as the HBM, LoC and SCT to bring a more profound understanding to the complexities of RP in the SA community (see chapter 4 for more information). The GT found a collation of elements which inform their view on T2D and these may be relevant to the whole population. However, there was a need to investigate if these concepts are more specific to SAs or other populations as well.

This study makes a significant contribution to the understanding of the role of culture and psychological beliefs on RPs within the SA population, highlighting key variables which may be influencing SAs behaviours. To our knowledge, this was the first study to attempt to develop a GT framework by bringing several psychological theories together to understand the complexities of RP in this population.

11.2.2 Summary of research findings: Study 2

Study 2 (Chapter 5) of the thesis was designed based on the key findings of Study

1. As suggested in Study 1, SA participants presented significant variations in understanding the risk of T2D and identified barriers to implement change were used as justification for Study 2. Study 2 aimed to explore specific constructs of RP, so to understand whether these constructs were explicit to the SA population (as a vulnerable

high-risk group) or if these issues, surrounding RP, were relevant to the general population as a whole (hence SA vs White population comparisons were made).

Very few studies have examined RP vs AR, in more than one ethnic group and explored how ethnicity may influence diabetes self-management behaviours and public health preventative initiatives. While SA might be more statistically vulnerable to developing T2D, we need to understand why they may not engage with preventative intervention to modify their lifestyle behaviours. Hence, we proposed there's a social-psychological barrier in beliefs towards developing T2D, and this is manifested as a gap between their calculated AR (which is what NDPP referral and other health professionals focus on), and the individuals RP towards T2D.

Based on findings, it suggests that individuals that were categorised as moderate to high risk of T2D scored greater on their RP scores. However, when this was investigated further, this trend was more apparent in the White's compared to the SAs. This was further explained by the different RP constructs, whereby White's had higher levels of Personal Control, Optimism, Personal Disease Risk compared to the SAs who had higher levels of Worry/Anxiety. Overall the hypotheses were accepted in this study. Given that in the HBM context, the greater the RP, the more likely an individual is to engage in a behaviour. However, in this study, even though the SA participants were classed as 'moderate to high risk', this didn't translate into behaviour change. This is because SA participants had lower levels of Personal Control, Personal Disease Risk and Optimism compared to the White group, therefore, these constructs may have reduced the SAs RP. This study provided a unique contribution to new knowledge as the findings reflected a low RP of diabetes for SA participants compared to the White participants. Given there is less engagement in health services/healthcare within the SA community, these findings provide unique evidence for future research/intervention.

This study provided much-needed information to address the gap in knowledge around RP and AR by using the validated RPS-DD.

11.2.3 Summary of research findings: Study 3

Study 3 (Chapter 6) of the thesis was designed based on the key findings of Study 1 and Study 2. Study 2 revealed there is an interaction between ethnicity, AR and RP whereby SA that were at a high actual risk of developing T2D had lower levels of RP compared to the White population. Of the limited previous research, on diabetes risk, RP and diabetes prevention, it has tended to focus on attempting to change modifiable behavioural lifestyle factors (Yang et al., 2018). Interventions do not typically focus on supporting individuals to change their psychological wellbeing. Limited research has explored how psychological traits such as anxiety, depression and stress may influence actual health behaviour.

It can be concluded that HLoC and DASS made a significant contribution to the variance in RP. The implication of this conclusion is that HLoC and DASS constructs can have an impact on an individual's T2D RP. More specifically, it was found that Powerful Others, Chance and Other People were the HLoC dimensions which directly influenced RP. Within these findings, the hypothesis was accepted, indicating HLoC and DASS will have a significance to RP. When considering the psychological-emotional traits, anxiety was a significant predictor of T2D RP. This means individuals that were more anxious with their risk of developing T2D perceived themselves to be at higher risk of developing T2D.

The findings provided in this study provides a strong foundation when designing an intervention targeting to improve RP in the SA community. Therefore, based on Studies 1, 2 and 3, there appears to be a need to focus on efforts in intervention design towards External LOC and the role of the SA community, such as Powerful Others.

11.2.4 Summary of Phase 2: Intervention Design and Evaluation

The intervention itself was designed by a comprehensive volume of new knowledge presented via a number of empirical studies (1, 2 & 3) which included theoretical applications (presented separately within studies and the combination of all findings together); and consideration of the previous evidence base. The next stage of intervention development was designed in continuous collaboration with a range of stakeholders. The content of the intervention was also delivered directly by SA people (e.g. religious leaders and community leaders; SA lay population). As a result, of this detailed preliminary work, a RP video intervention was designed based on the preferences of SA individuals in the community and previous research informed by a theoretical framework. Having developed this new intervention, it was necessary to model the intervention processes and explore acceptability and proof- of -concept to identify the interventions strengths and weaknesses.

The intervention evaluation was presented via two studies: the first Study 4a a proof of concept study considered the preliminary effectiveness of the intervention. Results found that SA individuals RP increased from pre to post-intervention, alongside I-LoC and furthermore reductions occurred in all constructs of E-LoC. Moreover, SA individuals had higher scores on TPB constructs such as Planning, Intention and Behaviour. Overall, this intervention was successful in its aim to change RP within the SA community and hence is a viable intervention for future roll-out as a real-world public health intervention. Based on these findings, the intervention seems to be influencing RP via an intent to change behaviour. The TPB proposes that the more positive people's attitudes and subjective norms, and the greater their PBC, the stronger are their intentions to perform the behaviour. This is what was observed in this study. Participants post-intervention increased in all the constructs of the TPB, therefore, their intention to perform the behaviour was increased.

Although the TPB provides a useful basis for interventions to promote behaviour change, it is also clear that changing intentions and PBC does not guarantee action – there remains a substantial ‘gap’ between intentions and behaviour change (Sheeran, 2002). In addition to this, given the proof-of-concept study didn’t follow-up actual behaviour (such as visiting their GP to be assessed for diabetes, or changing their diet/exercise behaviour to reduce risk), findings must be interpreted with caution (see limitations section 11.2.5 for further discussion on intention – behaviour gap).

In addition, acceptability and qualitative feasibility study (4b) were conducted which suggested that SA people believed the intervention to be acceptable to watch; was relevant to their community; emphasized the importance of RP and acknowledged the seriousness of T2D in the SA community. This evaluation also highlighted areas for intervention improvement. For example, the intervention could be delivered in various SA languages such as Urdu, Punjabi and Gujarati, which would increase reach to a broader SA audience.

The overall aims of the intervention studies were to test the effectiveness of the intervention and were to engage key stakeholders in the process of intervention validation. The aims and objectives were deemed to have been achieved, as the intervention increased RP within the SA community. The stakeholders provided valuable reflections and information on the acceptability and feasibility of the intervention in the real-world. These evaluations echoed the quantitative findings further supporting the effectiveness of the intervention.

Policymakers commit numerous errors when they set out about changing health-related behaviour (Kelly & Barker, 2016). The response to and understanding of worldwide epidemics involve human behaviour (Funk, Salathe & Jansen, 2010). However, it is not just individual behaviour which drives epidemics such as T2D.

Behaviour takes place in social environments, and efforts to change it must, therefore, take account of the social context and the political and economic forces which act directly on people's health (Glasgow & Schrecker, 2016). The policy default has traditionally been behaviour change, abstracted from the contexts within which behaviour occurs. Foregrounding behaviour achieves two things. It avoids having to think about the complexity of the external factors such as social and political factors which influence people's health and sidesteps confronting the powerful vested commercial interests. Moreover, in addition to social, political and economic factors, community and individual psychological understandings which influence behaviours have also been neglected.

Although a great deal is known about the science of how to change health-related behaviour and much has been achieved, e.g. the scientific literature is extensive and evidence-based guidelines from NICE (2014), for example, carefully describe how health behaviour change interventions can be made part of standard health and social practice. Yet over the years, most efforts at getting people to change behaviour have had only limited success (Marteau, Hollands & Kelly, 2015). Therefore, there is a need to think about the limitations of merely focusing interventions on behaviour change (as single outcomes), but here this PhD demonstrates and argues, there is also a need to change cognitions and perceptions relevant to subsequent outcome behaviours. For this PhD, the cognitions and psychological understanding relate to toT2D RP. The findings in this thesis could be considered more broadly within public health preventative interventions, targeting the general public (not just SAs) and could be considered for other prevention topics (beyond that of T2D).

11.2.5 Strengths and limitations

A significant strength of the PhD was using a mixed methods research design to examine the intersections of RP, LoC, TPB and psychological traits within the SA

population. To reiterate the rationale made in the methodology section, the integration of quantitative and qualitative methods effectively enabled a more comprehensive understanding of RP of developing T2D in this population. As illustrated in Chapter 3, the sequential design was effective in meeting the research objectives in the studies. Specifically, the first, quantitative phase of the study successfully provided substantial evidence. After selecting a subset of significant results from these findings, the second, qualitative, phase of the study was then able to capture rich insights into the explanatory and contextual factors underlying of the key significant findings for the studies.

This PhD did not only adopt a mixed methodology and analysis (Terrell, 2012) throughout the studies, but also throughout the PhD the researcher has sought to review the previous evidence base, and develop an intervention taking account of the key theoretical constructs. However, above all, this PhD has incorporated a “person-based” (Yardley et al., 2015) approach throughout, highlighting the focus on understanding and accommodating the perspectives of the people who will use the intervention. This allowed the ‘person-based’ approach to ground the intervention design in a rigorous, in-depth understanding of the psychosocial context of the people derived from iterative in-depth qualitative research (See table 11.1 for a full overview of the person-based approach in the PhD).

Table 11.1: An overview of how the person-based approach has been incorporated at each stage of the development of this T2D risk perception intervention

PhD Stage	Target output of the person-based approach	Specific person-based approach processes undertaken	Activities undertaken as part of a wider intervention development context
Planning	Identification of key behavioural issues, needs, and challenges the intervention must address	Carry out primary qualitative research using open-ended questions to elicit user views of the planned behaviour changes (including relevant previous experience, barriers and facilitators)	Consultation with experts, members of user groups, other stakeholders (e.g., religious and community leaders)
			Examination of relevant theory and evidence from previous trials (complex intervention development)
Design	Creation of guiding principles to help summarise and easily refer to features of the intervention identified as central to achieving the intervention objectives	Create guiding principles, comprising key intervention design objectives (addressing key behavioural issues, needs, challenges identified in Step 1), and key (distinctive) features of the intervention needed to achieve objectives	Theoretical modelling (MRC framework), e.g., creation of a logic model describing behavioural determinants and behaviour change techniques

Development and evaluation of acceptability and feasibility	All intervention components evaluated in detail and optimised from a user perspective	Elicit, observe and analyse user reactions to every intervention element (e.g., using think-aloud techniques), iteratively modifying the intervention to optimize from the user perspective	Development of detailed procedures for intervention plus information/advice, scripts etc., for SA participants
		Carried out a detailed mixed-methods study to evaluate and optimise usage of the intervention	Mixed methods evaluation of acceptability, feasibility (complex intervention development)
Implementation and trialling	The intervention evaluated in a real-life context(s), modified to improve implementation in future contexts	Use mixed methods process analyses to identify further modifications to improve acceptability, feasibility, and effectiveness of intervention for future implementation, or for use in different contexts	Mixed methods process analyses of implementation (reach, fidelity, context effects, etc.), mediators, and moderators of intervention effectiveness

Furthermore, another key strength of this PhD was that it utilised the MRC framework (Craig et al., 2008) in conjunction with the ‘person-based’ approach as a strategy for intervention development. However, it is noteworthy that a recent paper on “Guidance on how to develop complex intervention to improve health and healthcare” has just been published in the British Medical Journal (BMJ) (O'Cathain et al., 2019). The table below highlights these recommendations and, despite the PhD research and intervention design commencing prior to this paper’s publication, it summarises how this PhD has adhered to these key actions emphasising the relevance and comprehensive approach this PhD has offered in consideration to the issue presented (see table 11.2).

Intentions capture both the level of the set goal or behaviour and the person’s level of commitment. Although most behaviours are habitual or involve responses that are triggered automatically by situational cues (Bargh, 2006), forming intentions can be crucial for securing long-term goals (Baumeister & Bargh, 2014). The concept of intention has proved invaluable for researchers concerned with behaviour change, and interventions designed to promote public health, educational and organisational outcomes rely on frameworks that construe intentions as a key determinant of behaviour change (Ajzen, 1991; Bandura, 2002).

However, a meta-analysis of experiments that manipulated intention showed that a medium to large-sized changes in intentions led to only a small to medium-sized changes in behaviour (Webb & Sheeran, 2006; Rhodes & Dickau, 2012). Findings from statistical simulations also converge on the conclusion that changing intentions do not guarantee behaviour change (Fife-Schaw, Sheeran & Norman, 2007). This is further reinforced by a meta-analysis which has shown that, intentions explain only a 36% of the variance in behaviour (Rhodes & de Bruijn, 2013) and that changing behavioural intention does not necessarily engender behaviour change. Therefore, with these

limitations, future studies can look at investigating the SA participants who participated in the PhD studies and to test whether greater intention leads to behaviour change in the long term (full scale RCT), and this can be done by understanding how many participants visit their GP for regular screening, changes in dietary and physical activity and practices.

'Hard to reach' is a term sometimes used to describe those sections of the community that are difficult to involve in public participation. In health research, hard to reach often appears in relation to the ability of health services to reach out to certain difficult to contact, segments of the population. Hard to reach is also equated with the 'underserved', which can mean that either there are no services available for these groups, or more often, that they fail to access the services that are available (Barlow, Kirkpatrick, Stewart-Brown & Davis, 2005). This PhD aimed to accommodate the hard to reach by including the SA population to understand their risk of developing T2D to able to provide more services in the future to tackle these issues in this particular ethnic group.

There are certain barriers to participation in research which can affect the representativeness. Language is a frequently cited issue. Language compatibility is reported to be great importance to SA people (Quay, Frimer, Janssen & Lamers, 2017). Jolly et al. (2005) observed a significantly higher proportion of SA individuals being excluded from participation in research due to literacy and language barriers compared to other ethnic groups. To acknowledge this, attempts were made to be inclusive as possible and recruited participants from various languages such as Gujarati but restricted by not being able to speak a broad mix of languages relative to the SA community (such as Punjabi, Urdu which are common in the UK SA). The intervention itself was conducted in English, as a proof of concept study, this was deemed acceptable although important to recognise the language requirements of this population and thus a recommendation for wide-scale rollout would be to consider developing the intervention in other languages,

as appropriate for the wider The use of multilingual researchers, with language or cultural competency training is proposed as a possible strategy to overcome language barriers. This approach also allows for a larger recruitment pool and this would allow greater representativeness of the SA sample. Therefore, future studies may look at targeting SA individuals speaking different languages and different levels of literacy in order to get full representativeness of this population.

In particular, the demographics of the sample in Study 4 were lower in age and a higher proportion of the sample were females compared to all the other studies. This could be the explanation for the differences in RP compared to the other studies within this PhD. Further evaluation is required testing the application of the intervention with an appropriate sample size to reflect power, effect and p-value as appropriate.

Table 11.2: Overview of the “Guidance on how to develop complex intervention to improve health and health care” and how it’s been included in this PhD

Action	Consider the relevance and importance of the following	How this PhD adhered to the key actions
Plan the development process	Identify the problem to be targeted and refine understanding of it throughout the process. Assess whether the problem is a priority. Consider which aspects of the problem are amenable to change. Ask whether a new intervention is really needed and if the potential benefit of the new intervention justifies the cost of development. Determine the time needed to undertake intervention development. Obtain sufficient resources/funding for the intervention development study. Draw on one or more of the many published intervention development approaches, recognising that there is no evidence about which approach is best and apply flexibly depending on the problem and context. Involve stakeholders during the planning process (see next Action). Produce a protocol detailing the processes to be undertaken to develop the intervention.	Conducted a literature review and empirical studies to identify and understand the issues around RP in the SA population. Involved key stakeholders from the planning process (from study 1 onwards)
Involve stakeholders, including those who will deliver, use and benefit from the intervention	Work closely with relevant stakeholders throughout the development process: patients, the public, the target population, service providers, those who pay for health and social services or interventions, policymakers and intervention design specialists. Develop a plan at the start of the process to integrate public and patient involvement in the intervention development process. Identify the best ways of working with each type of stakeholder, from consultation through to coproduction, acknowledging that different ways may be relevant for different stakeholders at different times. Use creative activities within team meetings to work with stakeholders to understand the problem and generate ideas for the intervention.	Several meetings were taken places with key stakeholders, supervisory team and wider SA community members. Discussions took place around getting better understanding around RP in the SA community, what interventions would work and why and planning of the intervention.
Bring together a team and establish decision-making processes	Include within the development team individuals with relevant expertise: in the problem to be addressed by the intervention including those with personal experience of the problem, in behaviour change when the intervention aims to change behaviour, in maximising the engagement of stakeholders and with a strong track record in designing complex interventions. It may be hard to make final decisions about the content, format and delivery of the intervention, so only some team members may do this. There is no consensus about the size or constituency of the team that makes these final decisions, but it is important early on to agree on a process for making decisions within the team.	The team included the researcher (from a SA background, links with the community), the supervisory team (relevant expertise from own professional background), key stakeholders (religious leaders, community leaders) and the wider SA community.

Review published research evidence	Review published research evidence before starting to develop the intervention and throughout the development process, for example, to identify existing interventions, to understand the evidence base for each proposed substantive intervention component. Look for, and consider, evidence that the proposed intervention may not work in the way intended.	Conducted a literature review on various dimensions on SAs, such as prevalence of T2D, current lifestyle and prevention interventions.
Draw on existing theories	Identify an existing theory or framework of theories to inform the intervention at the start of the process, for example, behaviour change or implementation theory. Where relevant, draw on more than one existing theory or a framework of theories for example, both psychological and organisational theories.	Based on the empirical findings from studies 1-4, various theories such as the HBM, TPB, LoC and SCT were implemented to get a deeper understanding and key target behaviours (BCTs) were assigned to certain theories. In addition to this, Yardley's et al., (2015), a person-based approach was implemented.
Articulate programme theory	Develop a programme theory. The programme theory may draw on existing theories. Aspects of the programme theory can be represented by a logic model or set of models. Test and refine the programme theory throughout the development process.	The intervention development chapter provides a programme theory around the causal pathways between the content of the intervention, immediate outcomes and future goals.
Undertake primary data collection	Use a wide range of research methods throughout, for example, qualitative research to understand the context in which the intervention will operate, quantitative methods to measure a change in intermediate outcomes.	This PhD used a mixed-methods approach to understand the context in which the intervention will operate and measure any intermediate outcomes.
Understand context	Understand the context in which the intervention will be implemented. Context may include population and individuals; physical location or geographical setting; social, economic, cultural and political influences and factors affecting implementation, for example, organisation, funding and policy.	Parts of the discussion in the meetings with key stakeholders were about the implementation of the intervention. Including certain populations, geographical areas and certain factors affecting implementation were discussed and based on these recommendations; study 4 was disseminated in a suitable way.
Pay attention to future implementation of the intervention in the real world	From the start, understand facilitators and barriers to reaching the relevant population, future use of the intervention, 'scale-up' and sustainability in real-world contexts.	The researcher understood the difficulty in implementing the intervention within the SA community. Therefore, a proof-of-concept study was vital to understand whether the intervention is successful in this community and future refinements. Next steps test the intervention in RCT study to the wider SA community.
Design and refine the intervention	Generate ideas about content, format and delivery with stakeholders. Once an early version or prototype of the intervention is available, refine or optimise it using a series of iterations. Each iteration includes an assessment	The intervention development chapter provides the details on the content, format of the intervention. A proof-of-concept study was conducted to understand

	<p>of how acceptable, feasible, and engaging the intervention is, including potential harms and unintended consequences, resulting in refinements to the intervention. Repeat the process until uncertainties are resolved. Check that the proposed mechanisms of action are supported by early testing</p>	<p>any potential harms, unintended consequences and refinements of the intervention.</p>
End the development phase	<p>There are no established criteria for stopping the intensive development phase and moving on to the feasibility/pilot or evaluation phases. The concepts of data saturation and information power may be useful when the assessment of later iterations of the intervention produces few changes. Describe the intervention to facilitate transferability of an intervention outside the original team and location in which it was developed. Write up the intervention development process so that judgements can be made about the quality of the process, links can be made in the future between intervention development processes and the subsequent success of interventions, and others can learn how it can be done</p>	<p>The details of the intervention were written up, and studies were taken place to understand its success for future implementation in clinical practice and research. However, more testing is required such as RCT to understand the effectiveness in more detail.</p>

11.2.6 Design

A cross-sectional design was used to collect data for studies 2, 3 and 4 of this PhD. This was an efficient and cost-effective method of collecting data in the time available. The overall aim of these studies was to explore and describe the associations between the variables, not to imply causality. Thus, significant results in these studies have been treated with caution or as exploratory results, requiring validation in further confirmatory studies. From a methodological perspective, it would have been preferable to use longitudinal, prospective design to determine the direction of causality or assess change over time. However, due to PhD time constraints, this was not possible.

11.2.7 Recruitment

The researcher was responsible with the undertaking of recruitment and built up a close working relationship with the more extensive research team and guaranteed that there was on-going and standard correspondence, particularly with respect to recruitment. Full group meetings took place week after week toward the beginning of recruitment and afterwards at least fortnightly and month to month gatherings all through data collection. Utilizing strategies for recruitment, for example, leaflets have demonstrated troublesome and less effective in enrolling members from the SA population (Rooney et al., 2011). Nonetheless, in this investigation utilizing a blend of non-verbal and verbal recruitment procedures demonstrated to be fruitful in arriving at the required sample size for each study. Furthermore, in order to reduce researcher bias, having an ethnically diverse team of supervisors helped to reduce such bias. For instance, DoS promoted a deeper understanding and encouraging reflection when analytically coding the qualitative data.

11.2.8 Representativeness of the sample

A key strength of this PhD was the success in recruitment whilst being aware of the problems of recruiting people from the SA community into research, especially using impersonal technique such as random sampling, as reported by other studies (Alam, Speed & Beaver, 2012). Different arrangements were made to recruit people by going out into the community using purposive and snowballing sampling to recruit people from a range of local community and religious groups. The primary aim of this research was to explore factors influencing RP about developing T2D in SAs generally.

Drawing on the key findings and the strengths and limitations of the studies outlined above, the following sections put forward a number of recommendations with relevance to future research and practice.

11.2.9 Implications for practice

Current UK policy for T2D prevention does not explicitly account for the needs of the SA population. Therefore, in view with the findings reported in this thesis and the estimated prevalence and rise in T2D, it would be worthwhile and cost-effective for policymakers to consider planning strategies which include intervention and assessments to change RP within the SA population and develop targeted programme not only to modify their lifestyle behaviours but also change their psychological beliefs. Furthermore, the development of the pilot intervention could be standardised and rolled out as a RP intervention for the SA population within health care services, for example, individuals that are diagnosed as high risk of developing T2D may be advised to watch the RP intervention to assess their own risk before referring them to a national diabetes programme.

11.2.10 Dissemination of research findings

The research will be submitted to various peer-reviewed journals relevant to health psychology, diabetes and public health dissemination. The studies have to date been presented at a number of academic conferences, including Liverpool John Moores University Research Day and at applied health conferences, such as Diabetes UK, 2017 & 2018 and the National Diabetes Prevention Programme conference, 2017. It is noteworthy that in March 2020, I will present at Diabetes UK 2020 for a session as an invited speaker. Further disseminated of the findings have been communicated (presentations and reports) to health professionals, NDPP services and community venues across the areas where the research was conducted.

11.2.11 Recommendations for future research

Findings from the different studies in this PhD suggest a need for future research to explore RP beliefs toward SAs vary across different parts of the country, with larger, more varied SA sub-groups. This is important, as the participants that took place in the aforementioned studies were residing in the North-West of England, therefore may not be generalisable to other diverse areas in the UK.

In addition to this, the PhD solely focussed on the SA group as a whole. However, there are several subgroups within SAs. Therefore, future research could aim to explore different ethnic subgroups to understand whether individuals from a certain subgroup hold different RP beliefs. However, we were mindful of the overall public health strategies (PHE, 2018) and to further segment a population may actually reduce the viability of it being adopted and rolled out.

Findings from Study 3 (Chapter 6) suggest a need for future research to explore other psychological traits other than Depression, Anxiety and Stress or indeed it may be that a more varied sample in SA with higher DASS scores. Unlike previous research, our study did not suggest SA people had overall higher levels of DASS, and this may have

influenced the findings. It is understood that apart from the aforementioned traits, differing personality traits may influence individuals RP (Skot, Nielsen & Leppin, 2018). Therefore, future research could examine personality traits to see if there is a specific need for an intervention targeting varied personalities.

Finally, the intervention was designed in conjunction with key stakeholders, including SA laypeople. The intervention design was collated via the empirical findings, previous literature and consultation with stakeholders. The study 4 quantitative proof-of-concept study suggested the intervention achieved its goals of increasing HLoC and RP within the SA community. Moreover, the qualitative study (4b) suggested SA groups deemed the intervention acceptable and feasible. Largely supporting the roll-out, with a few recommendations for future improvement. It is feasible that this intervention should be tested via a full-scale RCT, which could target SA people across the UK (perhaps via a social media public health campaign within dense SA population areas); or could be used within specific health strategies, such as within NDPP programmes that need to recruit in high SA areas.

11.2.12 Reflection

Within the context of this PhD research, I was an insider. Based on Nowicka and Ryan's (2015) definition of an insider, researchers share a cultural, linguistic, ethnic, national and religious heritage with their participants. With this definition in mind, I am a UK SA Male aged 29 years old living in an area of high ethnic diversity and I am from the Muslim faith, actively engaging in my cultural and religious community. To this extent being an insider has been beneficial to this research in that it has aided recruitment processes as I was able to approach various individuals known to me and requested their support for snowball sampling. As participants perceived me to be an insider I was able to access a large and varied pool of SA individuals, this was advantageous given other

researchers have suggested SA people are hard to reach or fail to participate in research (Waheed et al., 2015).

Moreover, being a SA, Male I have been able to engage with participants, speaking various languages and engaging through cultural processes, this was also helpful for example during the interview studies whereby I was able to quickly build rapport and trust, a keen element of successful qualitative data collection.

However, as a PhD student, highly educated with a research interest in diabetes RP and having secondary employment as a deliverer of the National Diabetes Prevention Programme my knowledge, insight and approach to this topic may have been skewed from that of the participants. Which could have hindered my interview style but indeed could also have helped me develop a rounded picture of the situation for my participants. Certainly, within the qualitative studies, I used the process of reflection and supervision to balance any (positive or negative) bias that may have brought to the data analysed.

Moreover, I recognise that I did not focus my research towards exploring personal characteristics in-depth and as such it may have been helpful to have further explored the complexities of various levels of anxiety stress and depression in the SA cohort, however, this would have gone beyond the scope of the original PhD aims.

11.2.13 Conclusion

Using a mixed-method approach, this thesis has highlighted the importance of RP, LoC and the current psychological state towards SA beliefs of developing T2D. The contribution to new knowledge of this thesis suggests that in order to change SA individuals' risk of developing T2D, there needs to be a focus on changing psychological beliefs, before aiming to change modifiable risk factors. As current diabetes prevention programmes have a 'one size fits all' approach, with the SA population (consisted a vulnerable high-risk group), there needs to be more a culturally specific approach and

interventions not just focussing on behaviour change but to change perceptions and cognitions before the behaviour. Therefore, applying the RP intervention developed in this thesis to current prevention health services is a starting point to help with changing perceptions to improve risk behaviour in the SA population.

12 References

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