

**Culture and Diet: Food Choice  
among Black African and  
African-Caribbean Women with  
Type 2 Diabetes**

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## **ABSTRACT**

People of Black African heritage in the UK have increased susceptibility of being diagnosed with Type 2 Diabetes Mellitus (T2DM) compared to the general White population. Nutrition is central in halting T2DM and the progression of complications such as cardiovascular diseases. However, little is known about the factors influencing the diet of women of Black African heritage with T2DM. In addition, clinical and public health conceptions of the problem tend to be individualistic in orientation.

This study is an exploratory and in-depth inquiry into food choice and the implications of dietary change for women of Black African heritage who self-manage T2DM by diet alone. Eight participants were recruited using purposive sampling. Recruitment sites included Black and Minority Ethnic charities in Norfolk and Suffolk. Data was derived from direct observation using the 'Accompanied Shopping Task', combined with a 'Think Aloud Technique' called a 'Product Choice Reasoning Task'. In-depth interviews were undertaken and transcribed verbatim. Framework Analysis was used to provide a procedure to manage data analysis, which was informed by the PEN-3 public health cultural model which moves beyond overly individualistic conceptions of the issues.

The study showed that six participants prioritised the disease and used what I have called a 'Disease Focused Approach' to self-manage T2DM. Two used a 'Family Focused Approach', as family played a crucial role in T2DM self-management. All participants undertook T2DM self-care by following a culturally appropriate diet. Their

least preferred options for managing T2DM were medical therapy and physical activity. The study showed that although food choice is influenced by many factors, culture was particularly important. Moreover, participants showed greater knowledge than had been anticipated about the role of nutrition to prevent progression of T2DM. Results are explored and presented for three main domains of experience for the participants: first, food shopping and decision-making; second, diet choice and lifestyle; and third, the interface with health services. For each of these the culture was found to be of paramount importance.

The implications of the findings are presented in relation to the importance of culturally appropriate advice; culturally sensitive service provision; and the significance of household composition in managing the illness, especially for people with T2DM who have young children living at home.

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## **COMMON ABBREVIATIONS**

BME	Black and Minority Ethnic
DH	Department of Health
CVD	Cardiovascular Disease
HSCIC	Health and Social Care Information Centre (London)
HSE	Health Survey for England
NHS	National Health Service (UK)
NICE	National Institute for Clinical Excellence
NIDD	Non- Insulin Dependent Diabetes
NSF	National Service Framework
ONS	Office of National Statistics (UK)
PCRT	Product Choice Reasoning Task
SABRE	Southall and Brent cohort Revisited study
T2DM	Type 2 Diabetes Mellitus
UKPDS	United Kingdom Prospective Diabetes Study
WHO	World Health Organisation
UK	United Kingdom

# **Chapter One: Introduction and Background**

## **1.1 Introduction**

The focus for this thesis is Black African and African Caribbean (Black African heritage) women's experience of self-managing Type 2 Diabetes (T2DM) by nutrition alone. T2DM is also known as Non-Insulin Dependent Diabetes (NIDD). The most recent survey data to report on ethnicity and T2DM demonstrated that doctor-diagnosed T2DM was at least three times as likely in Black Caribbean women compared with the general population (Health Survey for England (DH, 2004)). In the United States the increased diagnosis of T2DM observed in African Americans has been attributed, at least in part, to a lack of effective nutritional interventions to help them achieve a healthy weight (Kumanyika, 2005). However, in the UK, while the problem of T2DM among people of Black African heritage has been recognised to some extent, the links with culture and diet have not been highlighted.

People of Black African heritage are not a homogenous group. Considerable differences exist within, and between, people of Black African heritage. The reason why they have been grouped together in my thesis is explained in detail in section 2.2 (page 41ff).

## **1.2 Type 2 Diabetes Mellitus**

In this thesis I use medical terms to define T2DM. (Although I argue in Chapter Two that the medical model is insufficient to assist in public health interventions, there is a medical basis to the condition which needs to be acknowledged). The pathogenesis

of T2DM is complex but insulin resistance is recognised as an early sign (DeFronzo et al., 1992). Although the exact factors in T2DM that lead to insulin resistance are only partially understood, there is evidence to suggest a strong association between insulin resistance and lipid accumulation (Chaturvedi et al 2012, Ferrannini & Camastra 1998). Furthermore, T2DM has long been regarded as a chronic progressive condition, capable of management but not cure (Butler et al 2003, Williams et al 2003, Hanley et al 2010). Crucial findings from the United Kingdom, such as the United Kingdom Prospective Diabetes Study (UKPDS 1991, 1998), demonstrated that lifestyle changes could halt the clinically progressive nature of the disease, for example the dependence on insulin to maintain good glycaemic control. Recent studies suggest that T2DM can be reversed by diet (Lim et al 2011), exercise, weight loss and other lifestyle changes (Taylor 2008, Camastra et al 2007), even after surgery (Isbell et al 2010).

Although major progress has been made in T2DM research and treatment over the years, there still remain gaps in the basic medical understanding of T2DM and – especially - the priorities of an individual affected in relation to treatment choice and self-care. The question of appropriate treatment and care is the topic of this thesis.

A personal reason for initiating this study is my professional experience. It seemed to me that health professionals' advice about diet and physical activity may compete with the individual's expectations and values. My study, therefore, focuses on food choices because being able to choose a balanced diet that is low in calories, fat, sugar and salt is a crucial skill to promote a healthy weight. The key factor in T2DM self-care is to halt its progression and this can only be achieved by maintaining a

healthy weight over a lifetime (NICE 2014). Tackling obesity and weight gain directly contributes to reducing health inequalities which are experienced by most people of Black African heritage. This research study, therefore, investigates the medical condition of T2DM from the perspective of the lived experience, with a particular focus on culture and diet.

### **1.3 Research aims and objectives**

The overall aim of this study is to explore the cultural aspects of food choice at the level of the individual, family and community among women of Black African heritage who self-manage T2DM by diet only.

This aim leads to three main **objectives**:

- to explore key factors that influence food choices and how these interact to inform decisions about healthy eating;
- to identify challenges to dietary change and interventions to support people of Black African heritage with T2DM;
- to gain information which could assist public health and other healthcare professionals to develop culturally relevant nutritional information and interventions for people of Black African heritage in the UK.

These objectives in turn lead to the formulation of the **research questions**. First, what are the main factors that influence food choice in women of Black African descent, diagnosed with T2DM, whose condition is managed by diet? As the study

evolved it became clear that a second research question had to be developed: what is the relative importance of culture, environment and knowledge as key influences on food choice for this target group?

#### **1.4 Thesis outline**

The thesis is presented in six chapters. In the rest of this chapter, I describe T2DM as a public health priority, highlighting the high prevalence of T2DM among Black and Minority Ethnic (BME) people compared to the White population in the UK, and the prevalence of T2DM in the Black African and African Caribbean population. There are several different types of explanation for the prevalence of T2DM in the Black African and African Caribbean population and these types of explanations are often linked to the proposed interventions. For example, public health is traditionally associated with epidemiology and a 'risk factors' approach to health problems. This tends, however, to lead to an individualistic conception of the issues, whether couched in psychological or medical terms. These approaches are generally insufficient, since they neglect culture and social dimensions. So, while the rest of Chapter One describes T2DM in traditional public health terms, it needs to be borne in mind that, following this, I will be emphasizing the importance of a cultural, rather than an individualistic, approach.

In Chapter Two, I outline the importance of understanding the cultural values that are of relative importance to women of Black African heritage. I describe gender, culture and identity theories to explore a collective historical and contemporary experience of women of Black African heritage as a cultural group domiciled in the UK. This is

followed by a discussion on theories used in public health nutritional interventions. I identify the PEN-3 Public Health Cultural Model as the most suitable model for facilitating our understanding of the complexity of how women of Black African heritage make decisions about healthy eating. (I describe the PEN-3 model in general terms in Section 2.5, pages 59-66, and in Appendix 1, page 217 I provide an application of the model to the substantive research area).

Chapter Three provides a discussion of the rationale behind the selected research methodology and the research approach. This chapter maps out the processes and procedures followed in the fieldwork, including ethical approval. The methodological choice for my study was a focused ethnographic approach that included observable patterns of behaviour and knowledge held by the group under study, using the Accompanied Shopping Task and Product Choice Reasoning Task (PCRT) and in-depth interviews. I discuss the procedures for analysing the data using Framework Analysis (Ritchie & Lewis 2003) to manage data. The PEN-3 Public Health Cultural Model (Airhihenbuwa 1995), as discussed in Chapter Two, was used to inform the analysis (See Appendix 1).

The results obtained from my participants are reported in Chapter Four. The analysis identified two main categories for my respondents: those who used a 'Disease Focused Approach'; and those who used a 'Family Focused Approach', which run across three themes and several sub-themes. Both the family and the household are explored in relation to my data. My study defined a family as composed of a woman, spouse and children or a single parent living with children. I have adopted the Social Trends (2004) definition of a household as composed of one or more people who

occupy a housing unit who share a meal and the living accommodation. The data focused on the lived experiences and the meanings attributed to a cultural diet (African food). Additionally, the challenges experienced by the women in managing T2DM, including weight management, interactions with public health services and healthcare professionals in T2DM, are detailed.

In Chapter Five I discuss the findings, drawing in particularly on the Accompanied Shopping Task, the Product Choice Reasoning Task, and interviews. I review differences and similarities in the findings and the evidence from the literature, and draw together the key findings.

Chapter Six draws the thesis to a conclusion by reflecting on its strengths, limitations and the possibilities for further research development. This is followed by implications for policy, practice, the PEN-3 public health cultural model, politics and recommendations.

In the rest of this chapter I turn to examining the prevalence of T2DM among people of Black African heritage in the UK and T2DM self-management in the context of public health. It is important to understand the clinical and epidemiological aspects of T2DM to highlight the growing trend of adult obesity which is a major risk factor for the disease.

## **1.5 T2DM: A public health priority for BME people**

Diabetes is the fifth most common cause of death in the world and accounts for 16 per cent of deaths occurring in England. T2DM is a chronic illness with long-term, incapacitating and terminal characteristics. In recent years, it has become one of the UK's key public health priorities (DH 2002, 2003, 2007; Patients Choice 2005) because of the dramatic increase in the prevalence and the form of its presentation: a silent prodromal period (undiagnosed T2DM with no early symptoms), followed by progressive deterioration of glucose tolerance, leading to severe T2DM (Lim et al 2011). The UK is facing a significant increase in the number of people with T2DM, as the number of people diagnosed with the condition doubled from 1.4 million in 1996 to 2.9 million people fifteen years later (Diabetes UK 2012). It is estimated that, by 2025, five million people in the UK will have T2DM due to the ageing population and the rapidly rising numbers of overweight and obese people (Diabetes UK 2012). It is currently estimated that there are around 850,000 people in the UK who have undiagnosed T2DM (Diabetes UK 2012). Early diagnosis and careful management are therefore vital in order to prevent complications (Charturvedi et al 2012).

The National Diabetes Audit Report, 2011-2012 (HSCIC 2013a, HSCIC 2013b) reported that life expectancy is reduced on average by up to 10 years for people with T2DM. For example, CVD (cardiovascular diseases including heart disease, stroke and other diseases of the heart and circulation) are a major cause of death, accounting for 52% of fatalities (Morrish et al 2001, HSCIC 2011, 2013a). Furthermore, people with T2DM have a two-fold increase in the risk of stroke within



the first five years of diagnosis compared with the general population (Jeerakathil et al 2007, Emerging Risk Factors Collaboration 2010).

The total financial cost of managing T2DM was estimated to be £11.9 billion for the NHS budget in 2010/2011 (Diabetes UK 2012). Because of the prodromal period, most people will already have developed complications such as high blood pressure by the time they are diagnosed with T2DM (Sampson et al 2007). The presence of T2DM complications also results in social care costs for both residential care or home helps for those with disabilities associated with T2DM (Scanlon et al 2008). For example, poor control of T2DM is a common cause of lower limb amputations (Amputee Statistical Database for the UK, 2007). T2DM is also associated with negative emotional well-being and the prevalence of depression has been reported to be approximately twice as high in people with T2DM compared with the general population (Katon et al 2004).

According to the Health Survey for England (HSE) (DH 2004), doctor-diagnosed T2DM among women (see Table 1) was highest among Pakistani women (8.6%), Black Caribbean women (8.4%), and lowest among Black African women (2.1%), compared with the general population (3.4%). In the same survey in 2004, T2DM was reported to be generally rare among those aged 16 to 34 years. T2DM was reported as being highest among Indian men (10.1%) and Black Caribbean men (10%), compared to the general population (4.4%).

**Table 1: Prevalence of self-reported doctor-diagnosed diabetes in England by minority ethnic group and sex**

Minority Ethnic Group	Men (%)	Women (%)
Bangladeshi	8.2	5.2
Black African	5.0	2.1
Black Caribbean	10.0	8.4
Chinese	3.8	3.3
Indian	10.1	5.9
Irish	3.6	2.3
Pakistani	7.3	8.6
General population	4.3	3.4

(Source: The Information Centre, 2006; Health Survey for England (DH, 2004)).

In East Anglia, the area in which my study took place, there is no local baseline data to demonstrate the prevalence of diagnosed T2DM in people aged 18+ from Black African and African Caribbean communities. However, in Norfolk, predictive modelling in 2011 estimated the prevalence of undiagnosed and diagnosed people aged 18+ years from the Black African or African Caribbean population at 9.3%, compared to an estimated prevalence of 8.7% for the White British population (Alabady 2011). These estimated figures for Black African and African Caribbean communities in Norfolk suggest a significant and growing burden.

In 2011, Norwich accounted for 12.26% of the total Norfolk BME population of Norfolk (ONS 2011). Migration to rural areas of the UK is not a new phenomenon, but the rise in migrant numbers has contributed to their greater visibility in these

areas (Wilkinson et al 2010). The increase is partly due to the fact that Norfolk and Suffolk became dispersal areas for asylum seekers, and both are also farming regions and tend to attract a migrant labour force from the EU (Wilkinson et al 2010).

The Suffolk Public Health Annual Report (Suffolk County Council 2012) showed that the recorded prevalence of T2DM in 2010-2011 in Suffolk was 5.3% of the total population (32,361 people). The report highlighted the fact that T2DM was both a national and local priority which carried with it significant morbidity and early mortality. However, there is a lack of local data to demonstrate the prevalence of diagnosed people aged 18+ years with T2DM from Black African and African Caribbean communities.

## **1.6 Public health explorations of the relationship between ethnicity and T2DM**

The standard explanations of the causes of T2DM in people of Black African heritage focus on genetic, lifestyle and migration explanations. These explanations tend to locate the problem in the individual and therefore posit medical or psychosocial solutions, and the public health models which are adopted as a result also assume an individual-level intervention.

Genetic explanations note that the known risk factors for T2DM, such as raised cholesterol, hypertension and obesity, differ between ethnic groups (Charturvedi et al 2012). Most recent data for BME communities in the UK has shown that risk factors may also vary between ethnic groups. Despite all these differences, genetic explanations tend to argue that all BME groups share a tendency towards T2DM,

central obesity and related complications (Chaturvedi et al 2012), and there is currently no data to refute this.

Several authors (Zlot et al 2009, Hariri et al 2006, Annis et al 2005, Chaturvedi et al 2012) have produced strong evidence to support genetic explanations and argued that ethnicity largely alters the risk of T2DM through genes. The authors state that one of the main pieces of evidence is that a family history of T2DM is independently and significantly associated with the development of diabetes itself, even after adjusting for other risk factors (Meigs et al 2000, Chaturvedi et al 2012). Moreover, the UK CHASE Study (Whincup et al 2013) demonstrated the type of genes which can influence the propensity to gain weight, the pattern of weight gained, and the likelihood that body fat will result in insulin resistance. This was thought to cause Black African, African Caribbean and South Asian children to be susceptible to weight gain when compared to white European children.

Viner et al (2003) argued that the evidence highlights the need for targeted nutritional interventions based on parental characteristics. Overweight or obese parents are a stronger predictor of childhood BMI than ethnic origin. Mothers' and fathers' BMIs are predictors of childhood BMI across the ethnic groups studied (Viner et al 2003). Although the correlation between T2DM and BMI remains unclear, the debate does create an opportunity for further research in this area and this will undoubtedly benefit people of Black African descent.

Another explanation for the high prevalence of T2DM in people of Black African heritage is diet influenced by migration. Migration to the UK has been shown to play

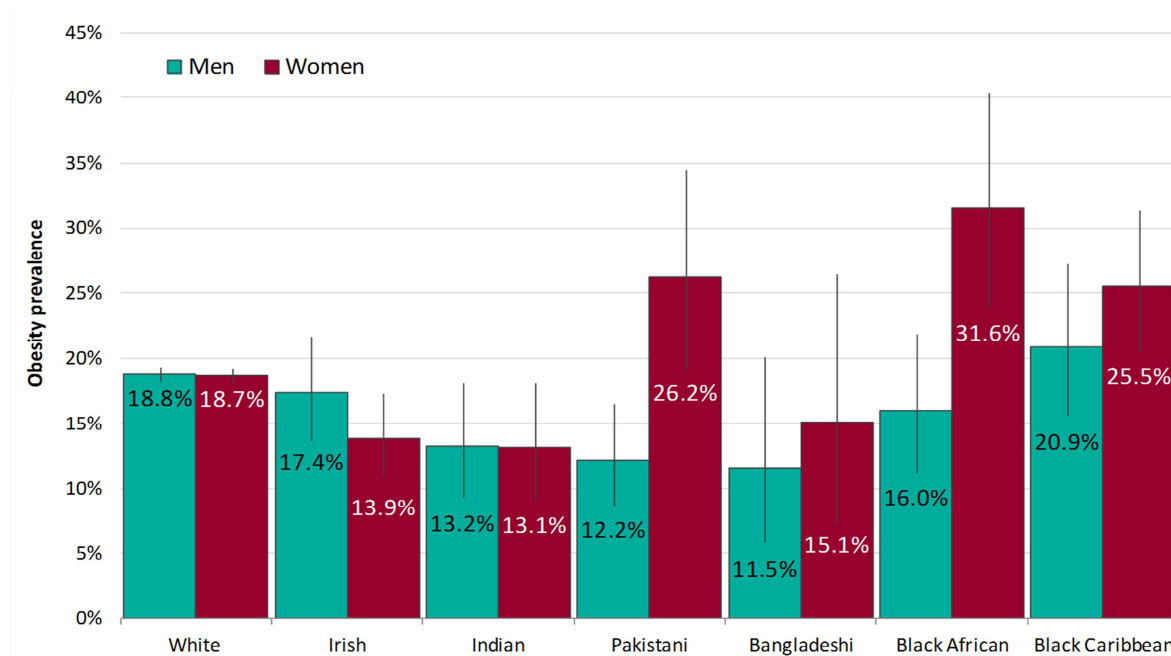
a significant role in influencing dietary change, through the adoption of a Western diet due to the expense and lack of availability of traditional fruit and vegetables (Lawrence et al 2007, Harding et al 2008). It was also revealed that migration to the UK appeared to affect obesity prevalence, resulting in weight gain and obesity in BME children. Oldroyd et al (2005) showed that the prevalence of obesity and being overweight among migrant populations of Black African origin from Cameroon and Jamaica living in the UK was higher compared to those residing in their countries of origin. Moreover, sedentary lifestyles have been found to be central to the increased prevalence of obesity observed among women of Black African heritage (DH 2011).

The Suffolk Public Health Annual Report (Suffolk County Council 2012) stated that deprivation is strongly associated with factors linked to the risk of T2DM in England, and is highest among women and men with the lowest incomes. The most deprived people in the UK are two-and-a half times more likely than the general population to develop the condition at any age (The Health and Social Care Information Centre 2011, ONS 2011).

Obesity is the most significant risk factor for T2DM, accounting for 80-85% of the overall risk of developing T2DM (Hauner 2010). In Norfolk in particular, deprivation appears to be consistently associated with the prevalence of obesity and low levels of physical activity. Several studies (Whincup et al 2013, Thomas et al 2012, Ehtisham et al 2000) and the Royal College of Paediatrics and Child Health Report (2009) have reported an increase in childhood obesity in the UK, particularly among school children in the reception year and in year 6. Moreover, the diagnosis of T2DM among children and adolescents (9 to 16 years) since 2002, mostly in BME

groups such as those of Pakistani, Indian and Black African heritage, has added a public health concern in terms of the distribution of limited resources. The variations in prevalence of obesity by ethnic group and between the sexes within ethnic groups are illustrated in Figure 1. The prevalence of obesity is higher in women compared to men for those of Black African heritage and Pakistani ethnic groups.

**Figure 1: Prevalence of obesity by ethnic group**



**Source: Patterns and trends in adult obesity (Public Health England, 2013)**

The prevalence of obesity is highest among women of Black African ethnicity (31.6%), and higher among those of Black Caribbean (25.5%), and Pakistani (26.2%) ethnicities, compared to the other ethnic groups. Similarly, evidence from the UK suggests that the risk of T2DM is higher for Black African and Black Caribbean women (Diabetes UK 2006), particularly in mid-life. One of the few recent studies on this topic is the Southall and Brent (SABRE) cohort Revisited study (Chaturvedi

et al 2012), which tracked the development of T2DM and revealed the full extent of the role played by ethnic differences in the risk of developing T2DM in the UK. It also provided some answers about the causes of the increased risk. The London based SABRE began following female and male participants aged 40-69 from 1988 to 2011, and recorded those that developed T2DM. It also looked at a number of risk factors across the different ethnic groups, in order to understand the causes of the increased T2DM risk among BME people.

According to the SABRE study, a family history of T2DM is an important risk factor for all ethnic groups. Weight gain and obesity are known factors that can underlie increases in insulin resistance and this was also confirmed by the SABRE study (Chaturvedi et al 2012), which revealed the risk that is posed by fat around the trunk of the body in mid-life, together with increased resistance to the effects of insulin. The SABRE study acknowledged that other unknown factors may also play a part in the observed risk factors across the different ethnic groups, which need to be understood in order to gain further insight into the causes of the increased T2DM risk among BME people (Chaturvedi et al 2012).

The evidence from the SABRE study could help the Public Health NHS Health Check programme (DH, 2009) to target people of Black African heritage in the UK. The NHS Health Check programme was developed to invite eligible individuals aged 40-74 years to attend a screening every five years with the aim of identifying undiagnosed health problems and assessing an individual's risk of developing, for example, T2DM. Monitoring people in this way could create opportunities for GPs to intervene early and reduce individual risk through lifestyle changes, such as taking

exercise or healthy eating. Evidence from the SABRE study suggested that it would be more beneficial if T2DM was picked up at a much earlier stage for BME people.

## 1.7 Perspectives in the management of T2DM

### Clinical aspects of managing T2DM

The NICE guidelines (2001) recommended that all people diagnosed with T2DM must attend six-monthly monitoring for their glycaemic control (see **Table 2**). HbA1c refers to glycated haemoglobin which identifies average plasma glucose concentration levels over a period of time. This helps to predict complications: the higher the HbA1c, the greater the risk of developing T2DM related complications, hence the importance of reviewing all sufferers at 2-6 monthly intervals (Diabetes UK 2012). Other aspects monitored also include blood pressure, lipid profile, urinary albumin, renal function, retinal screening and foot examination, conducted every 6-12 months for diabetes-related risk prevention (NICE 2001).

**Table 2: Glycaemic control**

Below target	Ideal	Above target	Poor control	
Mmol/l	5 – 8	9 – 12	13 – 15+	Blood glucose
mmol/mol	48 – 53	54 – 64	65 – 86+	HbA1c

(Adapted from Home Held record for Diabetes: Norfolk Community Health Care Trust, 2012)



The dataset held by Diabetes UK (2013) contains limited information about T2DM and ethnic minority communities. However, it highlighted a lack of compliance with, or adherence to, treatment among people with T2DM from ethnic minority communities. For example, BME people are less likely to have annual health checks for HbA1c, cholesterol and blood pressure. Their awareness of T2DM and its complications is extremely low: only 37% knew about the risk of blindness and 34% knew about the risk of kidney failure, compared to the average awareness in the White population of 63% and 51% respectively (Diabetes UK 2006). Moreover, six out of ten ethnic minority households were reported as non-English speaking, resulting in more limited access to health information (Diabetes UK 2006). These findings have significant implications for health because higher incidences of long-term chronic diseases translate into rates of premature death which are reported to be three times higher in ethnic minority communities than in the general population (Diabetes UK 2006).

Thus far, I have discussed the clinical aspects and management of T2DM based on early biomedical measurements and treatment. While these may be offered as a solution, they fail to halt the progression of the disease. I will now discuss food choice because the dominant professional paradigm now considers lifestyle choices with a healthy diet as the core of a strategy to manage T2DM.

## **Lifestyle as an option for managing T2DM**

The UK Prospective Diabetes Study (UKPDS 1991, 1998) found that a paradigm shift in the management of T2DM with risk prevention as central to diabetic management had occurred. There was a growing consensus that the focus for treatment ought to be on fat and calorie restriction along with a high fibre intake in order to make an impact upon weight and blood glucose control (Guthrie & Guthrie 2002). The progression of T2DM means that poor glucose control also increases the risk of long-term complications (UKPDS 1991, 1998). The Diabetes Research Group USA (Toumilheto et al 2001) demonstrated that T2DM is a metabolic disorder in which an individual's glycaemic load or carbohydrate concentration is directly influenced by food intake, weight and physical activity. The research showed that preventative care is effective and that the identified risk factors can prevent or halt the progression of T2DM in people of Black African descent.

Good metabolic control of T2DM has been shown to reduce the risk of complications (Lim, 2011; Charturvedi et al 2012). In the United States, Kumanyika (2005) showed that among African-American women, nearly 50% of T2DM cases were due to modifiable risks such as obesity and physical activity levels. Although there is evidence in the UK to suggest that the risk ratios of T2DM are higher for women of Black African heritage than for the general population, weight loss and treatment among Black people has been studied less extensively compared to the White population. Research does not always report findings in terms of an ethnic breakdown or include sufficient numbers of Black participants. Where the figures for Black women have been reported, they are often shown to be less successful at losing weight than White women (Kumanyika 2005). Several studies (e.g. Moore

2000, Obarzanek et al 2001) have demonstrated the effects of energy-restricted diets in people with T2DM, and have shown that even minor weight reductions may have major beneficial effects on subsequent T2DM risk in overweight individuals. Given the extent of this evidence, it can be argued that obesity and excess energy consumption are likely to be the key contributory factors to the risk of developing T2DM in already susceptible individuals.

Self-care of T2DM is considered crucial in halting the progression of the disease. Anderson et al (2003) defined self-care as both the knowledge and a set of skilled behaviour which will influence the disease outcome. According to Anderson et al (2003), the skills needed by individuals with T2DM are diet, exercise and monitoring blood glucose levels, foot care and taking prescribed medicine. However, Devine et al's (2003) explanation of self-care showed that individuals experience difficulties in changing their behaviour. Many factors influence food choice and these are not solely nutritional or physiological needs such as hunger, therefore interventions should be designed to take account of the different groups within the population (Devine et al 2003).

According to Marmot (2010) and Petterson et al (2004), a range of factors affect health and an individual's social and economic status contributes significantly to inequalities in health outcomes. The existence and persistence of inequalities in health has been well documented in several reports (Marmot 2010, Whitehead 2007, Townsend et al 1998, Gray 1982). The Black Report (Townsend et al 1988) was initiated by the Labour Government in the late 1970s but was subsequently completely ignored by the Conservative Government which came to power under

Margaret Thatcher. Inequalities in health have been a matter of public record and commentary in the UK for almost four decades. According to Thomas et al (2012), there is a strong inverse correlation between socio-economic status and obesity, as behavioural risk factors for the incidence of T2DM such as healthy eating and sedentary lifestyle are associated with obesity. Moreover, the largest concentration of obese people are found among the poorest sectors of society and this is demonstrated in eating patterns, for example, individuals of low socio-economic status on low incomes are less likely to adhere to the recommended five portions of fruit and vegetables a day compared to higher income families (Thomas et al 2012).

The HSE (DH 2004) reported that 50% of people in social classes IIIIM to V are likely to lead sedentary lifestyles due to unsafe or hostile environments (neighbourhoods in deprived areas). These environments do not promote jogging, walking or cycling but encourage sedentary lifestyles where people feel protected by staying indoors (Diabetes UK 2006, DH 2004). Moreover, Nazroo (2000) showed that people of Black African descent, like most BME people in the UK, tend to live in deprived neighbourhoods regardless of their socio-economic status. These factors which are directly linked to low socio-economic status interact and result in poorer access to health services for BME communities and may worsen the quality of T2DM care (Grace et al 2008).

All this shows that the relationship between health, the individual and society is very complicated. Nevertheless, public health interventions are nearly always designed at the level of the individual, even where positive health outcomes are shown to be related to socio-economic and environmental factors.

At the policy level, meanwhile, there is recognition of the knowledge gap in T2DM self-management and attempts have been made to address this gap (DH 2007; Diabetes Commissioning Toolkit, 2006; Patient Choice, 2005), yet these solutions are again addressed at the level of the individual. These policy documents have been produced to support people diagnosed with T2DM to navigate their way around local health services and access appropriate services. At a strategic level (i.e. *The Diabetes NSF Delivery Strategy*, DH 2003), both health and local authorities have been required to collaborate with other local bodies to produce local health equality strategies. The Department of Health (2002) NSF standards 10, 11 and 12 focused on multi-agency support for self-management of long-term T2DM complications by promoting regular surveillance, and implementation of protocols for blood glucose and blood pressure control to reduce the risk of disability and premature death that would result from T2DM. However, clinical practice does not always reflect best practice as documented in social policy. There is a greater need to focus on barriers to accessing healthcare as most sufferers will be from disadvantaged communities, who are less likely to access the appropriate services (Dan 2010, Nazroo 2000).

There is limited research into men and women's perspectives on the design and delivery of T2DM treatment and care, for example, opinions on individual versus couples counselling, disclosure, and availability of T2DM services. It is necessary to include these perspectives in order to design T2DM nutritional interventions that minimise adverse consequences due to complications. Moreover, bearing in mind the focus and nature of my study, I needed to be aware of, and to be sensitive to, the

possibility that women can be subjected to adverse consequences within households or communities as a result of living with T2DM.

Public health incorporates many disciplines and this has resulted in a number of models being used to address nutritional interventions. The foregoing discussion on managing T2DM is strongly supported by several public health healthy eating models. The main cognitive and behavioural theories used in public health nutritional interventions include: 'The health belief model' (Rosenstock 1974, cited in Baum et al 1997; Rosenstock et al 1998); 'The theory of reasoned action' (Fishbein & Ajzen 1975); and 'The theory of planned behaviour' (Ajzen 1991); these have been used extensively to explain behavioural aspects in health and lifestyle interventions. However, as discussed already, these individualistically-oriented models and theories are inadequate to explain, treat and self-manage a chronic condition such as T2DM. The main reason for this is that, when used individually, they fail to address all the issues confronted by people of Black African heritage in self-managing their T2DM. The individual level is an important part of the analysis, but a holistic public health nutritional model for healthy eating must incorporate patient empowerment approach to T2DM self-care and the social and cultural context. Thus it should recognise the fundamental right and responsibility of the individual to make the final decisions regarding their own daily T2DM care. Moreover, it should recognise the value of the family, the collective nature of most Black African and African Caribbean communities, and acknowledge the psychological and cognitive behaviour required in order for dietary change to occur. These family and cultural dimensions present a gap in public health knowledge. This is a gap in knowledge which needs to be addressed and which is, therefore, the topic of this thesis.

As I will discuss in the next chapter, the PEN-3 public health cultural model (Airhihenbuwa, 1995) is to be preferred in practice to other healthy eating models that inform public health nutritional interventions. It is favoured because the PEN-3 public health cultural model argues for a collective approach that involves the individual, family, neighbourhood and culture in informing nutritional interventions among people of Black African heritage.

## **1.8 Summary**

This research study focuses on women of Black African heritage who self-manage T2DM by diet only. The study assumes that T2DM can be effectively managed by diet. Early diagnosis and careful management are vital to halt the progression of T2DM complications. Owing to a lack of data from the study sites of Norfolk and Suffolk, data from HSE (DH 2004) was used which demonstrated that doctor-diagnosed T2DM was at least three times as likely to be found in women of Black African heritage compared with the general population. Public Health England (2013) has demonstrated that the prevalence of obesity is also higher in women of Black African (31.6%) and African Caribbean (25.5%) heritage compared to the White population (18.7%). Evidence has identified obesity as a major risk factor for T2DM. The chapter discussed management of T2DM from clinical and lifestyle perspectives.

Overall, a major limitation to understanding a Black African diet and the role of culture is the lack of research conducted in the UK. In my overview of the relevant public health literature I have identified that understanding that food choice can be

interpreted individualistically or culturally. While some individual level data and understanding is needed, this is not sufficient and for a more powerful set of explanations and context for interventions we must examine the cultural and social context. The next chapter provides a review of the key influences on food choices and the importance of a cultural conception of T2DM in public health nutritional interventions.



## **Chapter Two: Literature Review**

### **2.0 Introduction**

My original approach to the literature was to conduct a standard search of the literature via databases. The literature search strategy for this is described in Appendix 2. However, it is important to note that a trajectory of cumulative thinking led to my awareness that the concept of culture is largely missing from nutritional interventions in public health literature in the UK. This led to changes to the research aim and objectives, which had originally focused on a more traditional, individualistic, public health approach to nutritional interventions. The main focus of this chapter, therefore, is an exploration of the relevance of culture to this topic. (The findings from the original literature search are also incorporated into thesis - some of these findings, for example, have been reported as background, in Chapter 1).

### **2.1 Theoretical conceptions of culture and health**

Whilst there may be many kinds of explanations for differences in dietary habits, the concept of culture allows us to explore the experience of food choice behaviour among women of Black African heritage in greater depth. The concept of culture also offers the opportunity to unpack the experiences of eating and illuminate the social elements of food consumption as they operate within the context of the individual, family and community. Culture is a broad concept and can be defined in a number of ways. One of the most famous is by Tylor (1871), who defined culture as follows:

“Culture is that complex whole which includes knowledge, beliefs, arts, morals, law, customs and any other capabilities and habits acquired by a human as a member of society.” (Tylor 1871, cited in Williams 1983 p.87)

Parsons offers an alternative definition which focuses on the way in which culture is passed down through generations:

“Culture consists of those patterns relative to behaviour and the products of human action which may be inherited, that is, passed on from generation to generation independently of the biological genes.” (Parsons 1949 p.8, cited in Hart 2009)

Meanwhile, Mazrui (1986, p.239) defines culture as:

“a system of interrelated values active enough to influence and condition perception, judgment, communication, and behaviour in a given society.”

(Cited in Airhihenbuwa & De Witt Webster 2004 p.5)

These definitions incorporate the patterns of identity shared by members of a social group whilst distinguishing them from those of another group. Moreover, McElroy and Jezewski (2000) defined culture as a system of learned and shared codes or standards for perceiving, interpreting, and interacting with others and with the environment. My study adopted Tylor’s (1871) anthropological definition of culture which implies that culture is learned, acquired, shared, and involves thoughts and behaviour that can be observed within a distinct group of people. It includes observable patterns of group behaviour, characteristics, beliefs and knowledge held by the group under study.

According to McElroy and Jezewski (2000), culture is an integral factor in defining, achieving and maintaining a state of health and treating illness, which forms the normative framework for decision-making and behavioural strategies. The illness experience is inextricably intertwined with the self and others across time because the responses of others are as important in the illness experience as the interpretation of the individual who is ill. This view of illness as a social and community experience, rather than an individual experience, is echoed in some public health research which displays sensitivity to the concept of culture. Chinouya (2007), for example, claimed that, in Black African “tradition”, the art of being human and belonging to life’s network can shape the burden of a disease in a community, where being ‘human’ produces behaviour associated with communal responsibilities, such as families and neighbours looking after the individual who is ill. (Although Chinouya (2007) does also point out the concept of “tradition” is itself problematic – hence the inverted commas).

Furthermore, McElroy and Jezewski (2000) stated that, when people are ill, they respond to health problems through multiple systems. For example, they communicate through culturally distinctive ways of symbolising and presenting symptoms of the illness as it becomes grounded in the social and cultural realities of an individual sufferer. Family members, the community, and health professionals respond by trying to define the problem and effect healing as they become aware of an individual's illness. They also reported that there is an extension of linkages when personal suffering becomes redefined in social and political terms. Culture therefore

acts as a useful bridge linking levels of health experience between the individual who is ill, the family and the community (McElroy and Jezewski, 2000).

What is needed to understand food choice is an understanding of the culture in which it operates. According to Gabaccia (1998, cited in Goody & Drago 2009), food and language are the cultural habits humans learn first and also the ones they are most reluctant to change. Helman (2004) also stated that food is a powerful symbol of cultural identity, meaning that it is more than an object or product to be purchased for routine inclusion in daily life. Food fulfils the human race both culturally and physiologically, because the meaning of food for different cultural groups goes beyond providing sustenance. Food is not just a source of nutrition but, in many societies, it plays a variety of roles and is deeply embedded in the social, religious and economic aspects of everyday life.

However, cultural groups differ markedly from one another in many of their beliefs and practices related to food and there is an implicit set of rules that determine what types of food are consumed. Food consumption is closely patterned by culture, and accepted as a way of life within a community (Helman 2004). There is also a set of rules involved in food preparation such as who does the cooking, which individual groups eat together, where and on what occasions the consumption of food takes place, and how the actual manner of eating the food supports each culture (Helman 2004, Scott 2001).

There is a common cultural belief in many parts of the world that preparation of food is usually the task of women (Ember 1985) and in many societies women are also

closely involved in its production, for example planting and harvesting crops, rearing poultry, and retailing and marketing food. This role played by Black women in relation to food was another reason for my study to focus on women. This was supported by Helman's (2004) argument that before these beliefs and practices can be modified or improved, it is important to understand the way that each culture views its food and the way that it classifies it into different groups. Social foods, for example, signal gender or group identity, relationships, status and occupation (Helman 2004). My interest in T2DM and food choices was aroused because of the central role of food in daily life, in social relationships, dietary beliefs and practices that makes it difficult to change people's diet. This seems to be the case, even when food choice has a negative effect on a person's life. Therefore, it would seem that healthcare professionals such as nutritionists, T2DM nurses, and doctors face cultural challenges when giving nutritional advice to T2DM sufferers from cultures different from their own.

Helman (2004) explored the notion of culture and health further by proposing that doctors and other health professionals should try to see beyond their patients' presentations of symptoms to understand how these relate to their beliefs systems and cultural backgrounds. In his 'folk model consultation', he proposed that patients should be encouraged to represent their experience of illness as a narrative in order to empower them. He argued that the role of the patient's narrative in medical care reveals the inner worlds of both doctors and patients. This could then prompt an understanding of health and social factors, and the relationship between beliefs and practices in relation to certain diseases, both physical and psychological. Therefore, Helman (2004) called for a holistic approach to health that requires all health

professionals to take a lead in promoting and protecting health. This also means working in collaboration across all sectors to tackle the social determinants of health.

Culture is not a fixed entity, but varies across age groups which also vary according to life stage, while the power of one factor will vary from one individual or group of people to the next (Clarke 1998). The second and third generations of migrants to the UK are more affected by acculturation than the first generation, particularly in the case of BME groups (Clarke 1998). Moreover, James (2004) asserted that cultural influences are amenable to change when people move to a new country because they may adopt particular food habits of the host country, especially the second and subsequent generations. Anderson et al (2003) also acknowledged that Western societies have dietary intakes vastly different from those practices traditionally followed by ethnic minority people, for example eating processed food and fast food with little nutritional value in comparison to traditional Black African dietary staples. Therefore, the traditional shift in food consumption may have negative consequences for those already susceptible to T2DM because of family history (Anderson et al 2003, James 2004). This could perhaps partly explain the rise in T2DM among young people in ethnic minority communities (Anderson et al 2003).

According to Brown et al (2007), traditional foods have persisted because food is about identity and there may be a general perception among people of Black African heritage that 'eating healthily' – as promoted in Western public health, for example, means giving up part of a person's cultural heritage and conforming to the dominant culture. This attachment to traditional food seems to be practised despite knowledge about T2DM (Grace et al 2008). Therefore, if culture significantly contributes to food

choice, its aspects may also modify the risk of T2DM through their effect on eating patterns, for example dietary patterns high in salt, sugar, animal fat and carbohydrate intakes, which are a modifiable risk in obesity (DH 2004). NICE public health guidance 35 (2011) for T2DM emphasised the need for a community approach, involving understanding methods of working with local communities, and knowing the appropriate language to use. For example, achieving a healthy weight may be perceived as more acceptable and appropriate to Black African and African Caribbean women than preventing obesity.

## **2.2 Gender, culture and identity**

Historically, within Black communities, strong emphasis has been placed on the roles that Black men and women occupy within the family. Davis (1981) argued that these roles have not only been shaped by cultural values but have also been profoundly influenced by domestication in the context that provision of family care for the sick, children and elderly evolved as a gendered activity. The domestic obligations that Black women have performed in general provide evidence of gendered power relations. Davis (1981) also commented on the interaction between gender and race at the point where there is oppression within the very roles that are played out within the Black family network. For example, a survival technique encourages gender-blindness and this can be observed within the Black communities where younger Black women are inducted into caring roles as part of the “tradition” of caring.

I want to acknowledge that Black African and African Caribbean women are distinct groups with differences because of their countries of origin. Nevertheless, there are

arguments to show that there are significant similarities such that for research purposes they can be considered as one group, women of Black African heritage, as I do in my study.

My study identified three reasons for this. First, gender theorists claim that women of Black African heritage can be grouped together because they argue that the foundation of life for women of Black African heritage is rooted in the experiences of their ancestors from Africa. For example, Collins (2000) argues that groups who share common placement in hierarchical power relations also share common experiences in such power relations. Collins' theory reflects a collective rationalistic view of power, characteristic of the critical theory commitment to justice for one's own group and that of other groups (Horkheimer, 1976), in that relations of power are perceived as a pre-existing hierarchical structure external to the individual.

At the same time, Collins (2000) emphasised that these relations of power have what she called 'shared angles of vision' as well as a 'self-defined' position which reflects the collective realm and the individual realm, giving rise to a group self-definition and 'voice'. Although she acknowledges that the individual has 'unique' experiences that are rooted in their specific social location, reflecting the individual's cognizance of their individuality, which is their identity, she does not abandon the collective secret knowledge generated by groups on either side from which individual self-definitions originated (Collins 2000). The arguments presented by Collins (2000) highlight the pool of knowledge that has emanated from institutional practices which actively grapple with the central questions facing groups of people differently placed in specific political, social, cultural and historical contexts characterised by injustice. It



can be argued that this view illustrates that the experience of multiple oppression is the concern that can be used to unite the differences between Black African and African Caribbean women. My study therefore perceived them as a unified group of women of Black African heritage in the UK who have suffered under a similar system that has privileged one group over another, such as White women from a racial point of view and gender masculinity from a cultural point of view. Therefore, Collins' (2000) theory conceptualised the everyday experience of ordinary Black women as rooted in the Black community in which this perception of women's activities as unequal to men's was nurtured. Thus, the cultural context created by social institutions is simultaneously experienced and resisted at the level of the individual and as the basis of self-definition, and at the group and community level by a standpoint of Black women coming together.

The second reason in favour of grouping women of Black African heritage together in my study is based on a T2DM perspective, namely their susceptibility to T2DM due to heritage because of their ethnicity and genetic composition, family history and the associated risk factors, for example obesity (National Diabetes Support Team 2005, CHASE study). Obesity is caused by an imbalance between energy intake and energy expenditure, which is a major risk factor for T2DM (Cohen-Cole & Fletcher 2008). Kumanyika (2005) attributed the increased diagnosis of T2DM observed in African Americans partly to a lack of effective nutritional interventions to help them succeed in achieving a healthy weight.

The third reason for grouping women of Black African heritage together in my study is that they are associated with similar practices related to their lifestyle. According to

Davies (1981), even during the era of slavery, African Caribbean people retained most of the main staple food of their African heritage and food preparation methods such as fried chicken. “Traditional” African diets are essentially comprised of heritage food such as starchy foods, in their least processed forms, for example foods such as maize (or sweetcorn), rice, cassava, millet, barley, sorghum, plantain and legumes. “Traditional” African heritage meals are based on an abundance of colourful fruits (oranges and other citrus fruits, pineapples, mangoes, papayas, avocados etc.) and vegetables, especially leafy greens; as well as tubers like sweet potatoes, a variety of beans, nuts and peanuts; rice, flatbreads and other grain foods; and minimal consumption of sweets. These foods are known to provide fibre which has been demonstrated to improve cholesterol levels, prevent and treat constipation, as well as aiding weight control. However, it should be noted that the lifestyle of Black Africans and African Caribbean in their native countries is quite different from that of people of Black African heritage living in the UK. This is due to a shift from a rural traditional African heritage diet to a Western urban diet, due partly to a limited availability of traditional African food. It is this difference that might make the African diet difficult to promote.

Nevertheless, overall, there are experiences, common to both Black Africans and African-Caribbean people, of meals (whether “traditional” or not), and of subsequent limited availability of these “traditional” foods, which render the grouping of Black Africans and African-Caribbean women acceptable for my research purposes.

## **Gender norms**

Gender norms and values give rise to gender inequalities that foster differences in the way men and women are treated, which systematically empowers one group to the detriment of the other. The fact that, throughout the world, women on average have lower incomes than men is an example of gender inequality. While the role of women is central both in the workplace and in the management of routine daily order at home for the family, the conscious planned thoughtful work involved in being a mother constitutes part of bringing up both male and female children. However, the extent of women's 'private work' carried out at home is still taken for granted both in the workplace and at home. Moreover, gender inequalities can give rise to inequities between men and women's health status and access to healthcare.

Arber and Thomas (2001) argued that the social construction of gender identity and related gender roles also have a significant effect on health and life expectancy. Maternal mortality has declined in most countries and overall women outlive men; this trend has been observed even in developing countries. An example of a gendered form of health behaviour is smoking. Men have always smoked more than women and this has often been considered an attractive marker of masculinity, while it tends to be frowned upon in women, particularly Black African women. On the other hand, cooking is seen by most men of Black African heritage as a woman's work; therefore gender norms and values result in behaviour that negatively affects health and can be the single most important obstacle that prevents women from achieving effective T2DM self-management. This has led some feminists to argue that the patriarchal discourse which has resulted in the social gendering of the two

sexes has meant that women have not been able to match social expectations in this hierarchy as they are less valued (Scambler 2003). Therefore food choice for women of Black African heritage requires them to be proactive.

Gender vulnerability can also affect differences in decision-making and access to healthcare. For example, while a married man may make an independent decision to see a doctor, a woman may feel obliged to discuss her health decision before accessing the service. Moreover, the vulnerability of women with T2DM in a traditional family household can lead them to neglect their own needs and over-exert themselves in order to meet the family needs. This suggests that for women, T2DM should be a largely self-managed activity, but as women provide care, they are not assured of care from others. In fact, some women are vulnerable because they cannot access the necessary resources to self-manage T2DM, as they live on terms dictated by their husband and, in extended families, by a mother-in-law who hold power because of their matriarchal position within the family setting. Meanwhile, a man may be under pressure to seek treatment for fear of being unable to fulfil his traditional gender role as a breadwinner (Bharat 1996).

### **2.3 Culture and food choice**

The purpose of this section is to discuss some of the identified core influences on food choices among people of Black African heritage. Culture impacts on food choices in two main ways: environment and nutritional knowledge. I discuss each of these food choice influences in turn to develop my second research question: What

is the importance of culture, environment and knowledge as key influences on food choice for this target group?

According to Scott (2001), among people of Black African heritage, special foods have disease-specific medicinal significance and should be appropriately provided for people when they are ill as both a means of supporting health and demonstrating family thoughtfulness. Thus, food recommended for T2DM as healthy diets by health professionals might be perceived negatively and rejected by some women of Black African heritage.

“Traditional” heritage food cultures and customs can be seen in countries where people of Black African heritage have settled throughout the USA, UK, South America and the Caribbean Islands. Luke et al (2001) argued that Africans carried their food and dietary customs into the diaspora and throughout North America, South America and the Caribbean as a result of the European slave trade. However, their descendants represent populations at different stages of a nutritional transition. Luke et al (2001) stated that in the UK, Black Africans are more often in the early stages of nutritional transition, where they face many challenges in adhering to a traditional African heritage diet, and at the same time they are introducing processed foods into their diet. Meanwhile, many African Caribbean populations represent the middle stages of nutritional transition, for example, diets of caloric excess, high in fat and animal products. The consequence is that, in the UK, the Black population suffer most from obesity, T2DM, high blood pressure, coronary heart disease, and certain cancers which have become prevalent and are now beginning to emerge in younger Black African populations that have never had to face these diseases before, as

diets become more Westernised (Luke et al 2001). The key evidence for conducting this study is the current evidence from England which shows that a significant number of women of Black African heritage are obese (Gatineau M et al 2014).

## **Environment**

Environment, which includes peoples' cultural background and the activities required to obtain traditional food, is not merely a means of getting food for nourishment, but rather a way of sustaining relationships and distinct cultural characteristics (Scott 2001). Therefore, the concept that some food may not contribute to health can be culturally difficult to grasp. This is made more complex by the term 'environment' being used in relation to healthy eating because it embraces a collective of determinants in the context of food consumption which influence eating behaviours. These include a wide range of contextual environmental factors such as the interpersonal environment created by family and social networks, the physical environment which determines food availability and accessibility, the economic environment in which food is regarded as a market commodity at the local supermarket or food store, and the social environment in which indicators of social status such as income, education and gender mediate (Glanz et al 2005).

The term 'environment' is used in my study to refer to a collective of determinants which illustrate that eating is a socially-constructed activity that is embedded not only in the individual behaviour of healthy eating that is drawn from national guidelines and marketing of products, but also in physical and economic environments. This also includes material factors and physical settings (geographical neighbourhood as

defined by Power 2004), income, and the cost and availability of food that influence what people eat, for example homes, stores, restaurants, and transport. At the neighbourhood level, food environments can also refer to the availability and accessibility of food to residents within a neighbourhood (Story et al 2008, Larson & Story 2007, Larson et al 2009). According to Glanz et al (2005), the cost and availability of different foods in a neighbourhood are often associated with what its residents eat and their health. It is therefore not surprising that environmental determinants of food choice address the complex operative external and internal forces found in the health inequalities literature.

Weinsier et al (2002) and Crespo et al (2000) also showed that access to food is determined by available income, and that food costs are the prime determinants of food choice for individuals on low incomes. In addition, Weinsier et al (2002) and Crespo et al (2000) found that the eating behaviours of those who reside in deprived neighbourhoods are more likely to involve the 'default choices' on offer, for instance healthier foods cost more in small local shops situated within poorer neighbourhoods than in shops in wealthier areas. What is of great significance is that poor diets and low levels of physical activity contribute to poorer health outcomes in general, and this in turn can create a cycle of disadvantage which may be transmitted to the next generation (James 2004). Hence women have been selected for this study as they have a significant influence on the development of lifestyle habits in their families and children, including those that may contribute to the maintenance of a healthy diet. For example a mother's knowledge of nutrition, food-purchasing practices, cooking and eating patterns, and physical activity choices provide models for her family's knowledge and behaviours.

Behaviour interacts with the environment and, according to Raphael (2003), much of the T2DM literature wrongly assumes that behavioural patterns are adopted through voluntary lifestyle choices (see chapter 1). Raphael (2003) argued that environmental influences which show the interconnection network of how income influences the quality of life, levels of stress, availability of food and quality of diet, participation in physical activity, and degree of social exclusion, appear to call for new ways of thinking about lifestyle choices and redirecting research activities in regard to T2DM. According to Lynch et al (2000), material deprivation refers to the differences individuals experience in exposure to both beneficial and damaging aspects of the physical world. Individuals who suffer from material deprivation have a greater exposure to negative events such as lack of quality food and poor environmental conditions at home and at work (Lynch et al 2000). In addition, individuals suffering from material deprivation have less exposure to recreational activities, as well as poor social networks and connections to the community (Raphael 2003, Lynch et al 2000). Social and community support have been found to be extremely important facilitators for physical activity and leisure opportunities that contribute to better health (Lynch et al 2000).



## **Nutritional Knowledge**

Knowledge is considered to be a crucial influence on food choice. It can be convincingly argued that best decisions can only be made if people know how to interpret the information that is given to them. Since the 1980s, evidence has shown that a higher intake of fruit and vegetables protects against development of T2DM (Snowdon & Phillips 1985, Feskens et al 1995, Sargeant et al 2001). Several reports (WHO 2003, World Cancer Research Fund 1997, International Agency for Research on Cancer 2003) have confirmed that fruit and vegetables are important components of a healthy diet.

Furthermore, regular consumption of fruit and vegetables at the recommended daily intake of at least five a day or more is needed to reduce chronic disease risks, such as cancer (oesophageal, gastric, colorectal, lung, pharyngeal and laryngeal) and cardiovascular diseases (DH, 2005; WHO, 2004) and T2DM. Parmenter et al (2000) commented that the knowledge required by an individual involves, at minimum, knowing the prevailing nutritional recommendations and being able to apply those to the food products which they are considering, and combining these with the recommendations to make the best food choices. The World Health Organisation (WHO 2008) reported that people also need to understand the links which have been established between diet and disease. Parmenter et al (2000) found that knowledge about diet and disease was poor among the general public, for example regarding high fat and salt intake and high blood pressure, and the links between a diet lacking in fruit and vegetable consumption and some cancers. Lack of knowledge is an obstacle, particularly to those with limited educational attainment and those with limited English language skills, as most nutritional information is available in written

format (Grace et al 2008). Furthermore, the 2011 Census showed that six out of ten BME households do not speak English as their main language at home, which might have significant implications in terms of accessing health services and information leading to dietary change.

Scott (2001) and Leung (2010) indicated that a Black African and African-Caribbean diet is generally closer to a healthy pattern than that of the general population in terms of fruit and vegetable consumption. These authors argued that perhaps what needs to be addressed in the Black African and African Caribbean food culture is the preparation of food. The Black African and African Caribbean food culture remains embedded in many of the recipes and food “traditions” from Africa, for instance the staple African and African Caribbean foods remain largely unchanged: rice, fried chicken, salty fish, yams, fried plantains, sweet potatoes, green bananas, etc. are common foods that are rooted in African culture and have been passed on from generation to generation, just like other African rituals (Scott 2001). If this is the case, the challenge to dietary change for this target group lies in the alteration of habits that have been built over a lifetime and over generations. An example, Black African women with T2DM would be asked change their cooking method such as to boil skinless chicken instead of the much loved fried chicken.

That said, several authors (Ranger 2004; Chinouya 2007) have argued that “traditions” which appear or claim to be old are often recent in origin and sometimes invented. “Invented tradition”, according to these authors, suggests a set of practices, normally governed by overtly or tacitly accepted rules and of a ritual or symbolic nature, which try to instil certain values and norms of behaviour by

repetition, which automatically implies continuity with the past. Ranger (2004) maintained that what actually happens is that people who uphold “tradition” normally attempt to establish continuity with a suitable historic past. In any event, whatever the origins and status of “tradition”, it is clear that public health interventions require a much deeper analysis than individualistic models presuppose.

In the next section, I discuss some of the healthy eating models widely used in public health. I show the strengths and limitations of public health nutritional models from the literature and explore why the PEN-3 public health cultural model is suitable for my study. I explain why the PEN-3 public health cultural model for practice is relevant and most useful to inform my study. A subsidiary part of the study evaluates the PEN-3 public health cultural model (see Chapter Six).

## **2.4 Healthy eating models**

The healthy eating models used in public health are critical to improving people’s capacity to self-manage chronic conditions, and in the case of T2DM the success of halting the progression of complications means improving the sufferer’s quality of life. The healthy eating models found in public health nutritional interventions include community development empowerment approaches and social support. I will show both the strengths and limitations of public health nutritional models that are evident from the literature and why the PEN-3 public health cultural model is more suited to my study.

In considering the public health nutritional models, Campinha-Bacote's (2002) cultural competence model offered an understanding of the relationship between the cultural food practices of BME communities and T2DM, by arguing that healthcare professionals should develop cultural competence. According to Campinha-Bacote (2002), 'Cultural Competence' in healthcare means recognising and forming one's attitudes, beliefs, skills and values, and levels of awareness to provide culturally appropriate, respectful and relevant care and education. This is important in T2DM self-care of BME groups because they maintain their cultural identities with their food practices, values, and beliefs. Campinha-Bacote (2002) and Sucher (2007) argued that this also includes behaviour and policies situated within a system, agency and institutes. According to Sucher (2007), each culture has attitudes, beliefs, practices, and values about good health and disease prevention, the care and treatment of the sick, whom to consult when ill, and the social roles played by the patient and healthcare professionals. Furthermore, there is a difference in how disease is defined by healthcare professionals who perceive disease as physiological and psychological processes (Campinha-Bacote 2002, DeCoster 2005, Davies et al, 2006). On the other hand, most people of Black African heritage would perceive disease of the individual as an illness which has a psychosocial meaning and experience. Therefore, healthcare professionals are trained to manage the disease, whereas patients of Black African heritage seek care to manage their illness. As a result, a cultural discordance occurs because the management of the disease differs from the management of illness (Campinha-Bacote 2002, Goody & Drago 2009). This model offered the opportunity of a cultural encounter which occurs when healthcare professionals acknowledge that a meaningful relationship can be

achieved by interactions and dialogue with BME communities. Cross-cultural encounters can assist in exploring similarities and differences among cultures.

Another healthy eating model found in the realm of public health is the community and empowerment model used to improve people's capacity (Rissel 1994). This has been achieved by drawing attention to key components of environment (physical and social setting), and the culturally regulated customs and practices and beliefs of individuals affected by a chronic condition, which are greatly influenced by others responsible for their care. These key components are not static but are continually changing.

Rothman (1987) proposed a community development model which recognizes the importance of the social environment in which supporting the individual and advocating for changes leads to better health and a higher quality of life. The strength of the community development model is the concept of empowerment which is incorporated as a core element of the model (Rothman 1987). Empowerment has been described as a process by which individuals and communities gain mastery over their lives by becoming enabled to take power and then to act effectively to transform or change their environments (Rothman 1987). Empowerment operates on two levels at the same time. First, the individual who is involved in the community mobilisation effort may experience increased social support which may result in a more generalised sense of control (Rothman 1987). An increased sense of control (empowerment) could have positive benefits for the individual's health. The second and broader level of the community development model is its perceived contribution to community-level empowerment which leads to increased community competence

(Rothman et al 1987). The health practitioner or community leader is seen as playing a crucial role in helping communities to increase their problem-solving abilities.

Several researchers including Gregory (2005), Gallant (2003), and Gary et al (2000), agree that social support is beneficial to an individual's overall health and well-being and can be crucial in promoting middle-aged adults' and older adults' physical health. In particular, the criteria that have to be incorporated include: support from family and next of kin, for example spouse/partner/children; support from a group of people/friends; guidance from a healthcare professional/advisor/coach; and the opportunity for nurturance.

However, there are a number of factors that may hinder social support, and it might not always be readily available when it is needed and can also cause a lot of stress as individuals might feel they are a burden to their family and friends. Furthermore, individuals are not in control of what happens in their lives and it is important to acknowledge that the availability of social support might be limited due to a lack of time necessary to develop and maintain healthy social support.

While partnership and social support models of care are increasingly promoted, Helman (2004) argued that the top down approach still prevails. The authority of the physician's role and that of other health professionals is based on the expert knowledge of clinical management of the condition, for example blood glucose levels, and does not acknowledge the patient's culture (Helman 2004). The result is that healthcare professionals end up trying to direct the daily conduct of their patients' major lifestyle areas such as diet and physical activity. Anderson and Feste

(1995) critically asserted that in the medical model the physician is viewed as powerful, knowledgeable, and in control of the care process. The medical model perceives the patient as a passive recipient, accepting, compliant and dependent on the physician; it is therefore a top down approach to healthcare delivery. This can cause problems because a lifestyle change poses a challenge to T2DM sufferers. Patients might want the advice, but there are major complex behavioural issues that interact to make it difficult for patients to comply with lifestyle changes, for example poverty may inhibit access to healthy eating. Although knowledge of the clinical management of T2DM is crucial, and patients often feel a sense of powerlessness, behaviour change skills, assertiveness and communication skills are necessary to enable them to participate effectively in T2DM self-care. This requires a high degree of psycho-social self-awareness so that T2DM sufferers are able to make informed decisions about recommended care treatments.

Health-related behaviour theories based on social constructs have been used a great deal in public health interventions to explain T2DM self-care decision-making for successful self-care. The Transtheoretical Model is one example of a theoretical model that has been used to empower individuals with T2DM to move through the stages of change, becoming more motivated to alter their behaviours and sustain them in the long term (Green et al 1999, Stickland et al 2010, Gorczynski et al 2010). The TTM was used by Grace et al (2008) to identify problem areas of self-management, explore the individual's emotional state associated with these problems (motivational interviewing), develop goals and strategies to overcome problems and achieve objectives, and create and implement behavioural change plans in T2DM self-management.

However, knowledge about how to support behaviour change and put these principles into practice is insufficient. Heisler (2006) and Paulweber et al (2010) suggested that motivating individuals to change their behaviour includes providing opportunities to change, but evidence for the success of such individualistic approaches is limited and remains unclear. Paulweber et al (2010) argued that for individual support to be successful, the attitude and skills of healthcare professionals would have to change. If individuals are to be more involved in decision-making, GPs for example would need to spend more consultation time with their patients, encouraging them to make positive healthy lifestyle decisions. According to Paulweber et al (2010), if people have more knowledge about their condition and care, this could increase their ability to cope on a daily basis and to develop better self-management skills. A study by Wetzels et al (2004) of GPs in eleven European countries showed that GPs defined their patients narrowly and had limited time to engage with them.

The PEN-3 public health cultural model (Airhihenbuwa 1995) has attempted to incorporate the main features of the models I have mentioned, as well as existing theories and frameworks, while drawing on theory and application in cultural studies. The PEN-3 takes into account the multiple factors that determine health status and is helpful in developing a comprehensive theoretical framework that is culturally sensitive to Black and minority ethnic cultures.

The PEN-3 public health cultural model incorporates the nurturing experience of social support to self-care of a chronic condition within the individual, family and

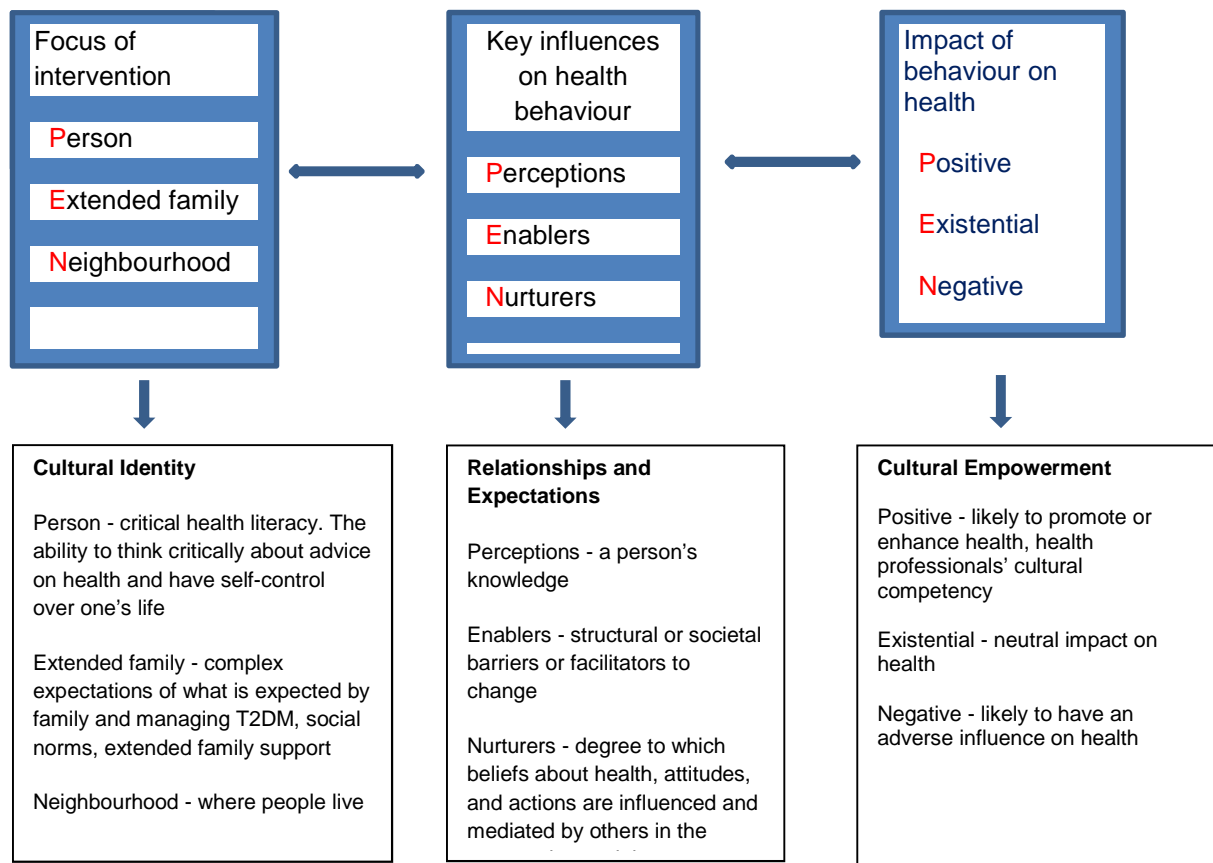


community context. Although the role of the physician is important in disease management, only patients can be experts in the conduct of their behaviour (Airhihenbuwa 1995). The PEN-3 public health cultural model demonstrates that from healthcare professionals' perspective, it is important to gain an appreciation of a patient's culture, for example through cultural awareness, which means having a willingness to extend oneself to the patient (Airhihenbuwa 1995). The strength of the PEN-3 public health cultural model is its identification of cultural logic, as the focus is on the collective for BME communities; behaviour occurs in the context of culture that can either be reinforced or resisted through family and spiritual institutions. It helped to inform my study by providing a holistic vision that has traditionally been fragmented by competing disciplinary paradigms.

## **2.5 Overview of the PEN-3 cultural model for public health practice**

The PEN-3 public health cultural model goes beyond any individual discipline in synthesizing public health nutritional models and theories. It offers a realistic model which seeks to reveal the dynamic interrelations of culture and diet in order to understand how women of Black African heritage with T2DM self-manage their diet in order to make decisions about a healthy diet. The PEN-3 public health cultural model consists of three domains, which are interdependent and interrelated, namely: Cultural Identity; Relationships and Expectations; and Cultural Empowerment.

**Figure 2: Multidimensional PEN-3 public health cultural model (Airhihenbuwa, 1995; adapted from Grace et al., 2008)**



Each of these domains contains three categories which form the acronym PEN (see Figure 2). In the following sections I provide an explanation of each category in the PEN-3 public health cultural model.

**PEN-3 public health cultural model: Domain 1 Cultural Identity**

The first Domain of the PEN-3, Cultural Identity, consists of the Person, the Extended Family and the Neighbourhood. I now discuss each of these in turn.

### ***The Person***

The first category, 'person', examines self-management of a chronic condition, such as T2DM which is largely the responsibility of the 'person' or individual with T2DM (Airhihenbuwa 1995). T2DM stresses changes in lifestyle to prevent complications, for example adherence to dietary variations, regular physical activity at the recommended level and clinical monitoring of blood glucose levels which are all crucial to keep the disease under control (Collins-McNeill et al 2009). These are the challenges for the individual T2DM sufferer who has to obtain the knowledge, skills and the motivation that are needed daily for a lifelong regimen in order to maintain a healthy body weight and good metabolic control (Weinsier et al 2002).

### ***Extended Family***

The 'extended family' category proposed that not only the affected individual or 'person', but also both the nuclear and 'extended family', play a pivotal role as a supportive network for both healthy and unhealthy behaviours. Individuals belong to many different groups and these social networks can shape the burden of the disease.

Lawrence et al (2007) defined the nuclear family for people of Black African heritage in terms of blood and marital ties as a self-contained unit which consists of two generations of family members (parents and children) living in the same household. In most societies, the institution of marriage leads to the formation of the family. However, the extended family for most people of Black African heritage also represents non-traditional forms and includes multiple caregiving family systems such as friends and other forms of extended networks (Lawrence et al 2007). Thus,

the PEN-3 public health cultural model highlights the importance of involving the 'extended family' to promote treatment adherence and change in nutritional behaviour.

### ***Neighbourhood***

The 'neighbourhood' is the third category of the Cultural Identity domain (Airhihenbuwa 1995). Power (2004) showed that there is a strong correlation between vibrant local communities and the presence of families who have deep roots and have lived in the same neighbourhood (geographical area) for a long time. This leads to the formation of 'communities', which are groups of people that may or may not be spatially connected, but share common interests, concerns or identities (Laverack 2008).

### **PEN-3 public health cultural model Domain 2: Relationships and Expectations**

The second domain of the PEN-3 Relationships and Expectations, consists of Perceptions, Enablers and Nurturers, as I now discuss.

### ***Perceptions***

The 'perceptions' category relates to values and beliefs held by women of Black African heritage in relation to T2DM and self-management. Health professionals may give out information on healthy eating to T2DM sufferers to support self-management of T2DM. However, this might be perceived by sufferers from the target

communities as disruptions in meaningful cultural food practices and changing the balance of various foods that were thought to be beneficial to general health.

### ***Enablers***

The second category, 'enablers' of Relationships and Expectations, of the PEN-3 public health cultural model, refers to cultural or structural influences that may enhance behaviour change (Airhihenbuwa 1995). Enablers include the accessibility of resources, for example, neighbourhoods that have open/green spaces to facilitate physical activity such as walking or cycling. Consequently, by identifying 'enablers' health professionals have the potential to address environments that support self-care of T2DM, for example improved management of adverse food environments. It has been found that a sedentary lifestyle, for instance watching television for hours without moving, leads to obesity, a major risk factor for T2DM (Blackwell 2009). Individuals who live in adverse physical and social environments (environmental inequity) are at higher risk of developing obesity and T2DM and suffer more from its complications, and it is the case that most people of Black African heritage live in these types of environments (Blackwell 2009).

### ***Nurturers***

The third category 'nurturers', relates to extended family, friends and the neighbourhood (Airhihenbuwa 1995). These groups of people can reinforce or nurture health beliefs, attitudes and behaviour. Evidence also shows that T2DM

tends to cluster in families (Vaxillaire & Frogue 2010); therefore, supporting self-management may be achieved by altering patterns of behaviour and service use.

### **PEN-3 public health cultural model Domain 3: Cultural Empowerment**

The third domain of the PEN-3, Cultural Empowerment, consists of the factors which impact on Cultural Empowerment in Positive, Existential or Negative ways.

Positive, Existential, Negative. This brings a cultural focus to the foreground. In the original PEN-3 this cultural focus was presented as a paradigm shift in diabetes management in Western countries (Airhihenbuwa 1995, Grace et al 2008). Culture is acknowledged as a difficult and contested concept in the social sciences and humanities (as I have discussed earlier in this chapter). The PEN-3 tended to adopt sociological perspectives, for example that a child learns the lifelong process of its own cultural norms, customs and ideologies, providing the individual with the necessary skills to function in his/her own society (Giddens 2006). This process of socialisation is passed on from generation to generation and is therefore an integral part of racial or ethnic heritage (Hall 1997); and, as Jenkins & Barrett (2004) argued, culture is not static. The conception of culture in PEN-3 is, therefore, compatible with the definitions I used earlier in the chapter.

#### ***Positive***

The first category of Cultural Empowerment, 'positive', refers to factors that influence patterns of treatment-seeking behaviour. These are critical to forming a comprehensive approach to public health nutritional interventions for people of Black African heritage in the UK. The most important positive response to T2DM is that

sufferers observe the regimen required by T2DM, such as following a healthy diet, attending blood glucose monitoring appointments and foot care, etc. This requires service users to undergo an empowerment process (Gallant et al 2002). This is seen to depend on the role of physicians in strengthening a T2DM sufferer's capacity to positively self-manage the condition, which can only be achieved by adopting a culturally sensitive approach (Helman 2004).

### ***Existential***

The second category, 'existential', describes unique or cultural behaviours or harmless responses while discouraging responses known to be harmful. Thus 'existential' is about gaining a better understanding of the healing and spiritual "traditions" of people of Black African heritage, rather than dismissing the values and practices that they have towards T2DM self-management strategies.

Traditional healing practices include a variety of health practices, knowledge and beliefs incorporating plant and spiritual therapies, applied singularly or in combination to maintain well-being, as well as to treat, diagnose or prevent illness (WHO 2002). While others are aligned to mainstream religious groupings, such as Christianity or Islam, some incorporate specifically 'African' elements, linked to the wider cultures and religions of the countries from which they derived (WHO 2002).

### *Negative*

The 'negative' aspects in health-related cultural practices, beliefs and actions that are harmful to T2DM self-care and which could lead to risk of complications due to poor self-management. These include delayed diagnosis and treatment. There may be attempts by the T2DM sufferer's family members to contain the problem within the family and within the community (Helman 2004), for example by resorting to traditional remedies and faith healers, thereby delaying proper medical care (Helman 2004). However, criticism of many complementary and alternative therapists may be less about the practices themselves, but more about the failure by traditional therapists and religious leaders to recognise when the problems they are addressing are within, or outside, the remit of their practices and faith-based healing (Bird, 2004). Thus, 'negative' potential for harm and 'existential' no harm as components of the PEN-3 public health cultural model, within health beliefs and cultural practices, have different implications for control strategies to minimise the risk of T2DM complications.

## **2.6 Summary of Chapter Two**

This chapter has looked at the key influences on food choices and the importance of a cultural conception of T2DM in public health nutritional interventions. Several studies have shown that healthy eating behaviour patterns are the result of culture, socio-economic status, knowledge and environment, but the precise relationships are not clear-cut. People of Black African heritage place culture at the core of their diet and therefore the norms that constitute a healthy diet are highly culturally influenced. In this chapter I argued that public health nutritional interventions, which



are based on Western culture and promote the individual approach to healthy eating are inadequate, and I have therefore proposed the PEN-3 public health cultural model as it offers a holistic approach and the ability to address the limitations of the other models. Effective nutritional interventions seem to be those making progress in incorporating an understanding of how culture informs diet for people of Black African heritage. Overall, the individual level of analysis is necessary, but not sufficient for public health, in both explanatory theories and models for practice.

## **Chapter Three: Methodology**

### **3.0 Introduction**

This chapter outlines the overall methodological framework of the study, describing the steps and the processes that were followed and making explicit the connections between the philosophical issues, the choice of methodology and the research questions. Ethical issues are outlined and addressed. The study design can be defined as a focused ethnography. I explain how I gained access to participants from different locations of the study sites. The data collection was achieved by a focused ethnographic approach which involved an Accompanied Shopping Task, a Product Choice Reasoning Task (PCRT) and in-depth semi-structured interviews. Having collected the data, I analysed it using Framework Analysis as outlined by Ritchie and Lewis (2003). I also describe how I overcame various challenges encountered in the fieldwork and finish the chapter with a discussion about methodological rigour, encompassing trustworthiness, generalizability and positionality.

### **3.1 Philosophical considerations**

This research was guided by an interpretative phenomenological approach. Phenomenology, as the study of social and individual phenomena, is about the 'appearance of things' (Cohen 1987 p.31). Interpretive phenomenology asserts that social reality is perceived in various ways by people who interpret events differently, producing multiple perspectives of an incident (Bryman 2008). A key tenet of interpretative phenomenology is that reality can never be objectively observed from

the outside; rather, attempts must be made to observe it from inside through the direct experience of research participants as far as possible (Cohen 1987).

Participants in my study provided a powerful understanding of their subjective experiences, giving insights into their motivations and actions. This was achieved by observation and by asking questions (through in-depth interviews) to uncover the decisions behind their food choices. This method of questioning and observation attempted to reduce misperceptions arising from taken-for-granted assumptions and conventional wisdom regarding the reasons why the participants chose their food products. The use of in-depth interviews and an observation method allowed information and perceptions to be gathered through inductive, qualitative methods, and the representation of these from the perspective of the participants.

Van Manen (1997) maintained that a powerful phenomenological text thrives on a certain binding tension between what is unique and what is shared and between the reflective and the pre-reflective spheres of the life-world. According to Van Manen (1997), every researcher also starts at the pre-reflective level. At this level a researcher knows what he/she has observed, facts and judgment are not differentiated, and personal beliefs are seen as equally valid. A researcher then needs to engage in reflection which is about an awareness of how they think about their actions, the introspective and self-conscious activity and how it is linked to daily practices and their uniqueness (Van Manen 1997). Reflection then enables a researcher to make links between evidence and beliefs. New understandings become clearer through the process of reflection by allowing the researcher to critically evaluate self-responses to practice situations. I did so by having a period of

reflection and writing field notes after each interview. This self-debriefing was particularly effective when emotive topics were discussed, in that it enabled some distance to be created between the interviews and allowed me to interpret the data, for example, when some participants were talking about their struggles with weight management or loss of a parent or sibling due to T2DM complications. This elucidated emotional discomfort from some of the participants, but it was also significant for me because I had lost an elder sister to T2DM complications a year ago. The personal tragedy I had experienced enabled me to be empathetic while I still needed to retain my equanimity. I also managed to resolve these ethical dilemmas with sensitivity by achieving a balance which involved not prolonging or ignoring the participants' discomfort. I acknowledged their expression of pain by either pausing to allow the participant the opportunity to take a break or to terminate the interview. This eased the situation and allowed the participant to continue.

Writing field notes immediately after an interview allowed me to manage these tensions by engaging in reflexive analysis, which means having an ongoing conversation about the experience while simultaneously living in the moment. I strove to make sense of actions and situations or understand the connections between the lived world and food decision-making processes by which the participants and food choices influence and co-constitute each other (Van Manen 1997). The key was to try to capture the complexity and ambiguity of the lived world of Black African and African Caribbean women who self-manage their T2DM by diet only. The value of using an interpretative phenomenological approach was established by honouring concrete individual experiences and demonstrating some fidelity to the phenomenon. For example, I used verbatim excerpts from the

participants, providing an opportunity for readers to judge the soundness of the research analysis (Van Manen 1997).

### **Analytical approach**

Interpretive analysis is concerned with meaning and context and is focused on the experience of 'understanding something'. It aims to confirm and re-confirm the world under study, and this involves taking into account the perspectives of participants (Cerbone 2006). This process was achieved through examining details of experience with the goal of creating meaning and achieving a sense of understanding (Cerbone 2006). It moves from part of the experience to the whole experience, and back and forth again to increase the depth of engagement with, and the understanding of, words or texts. In my study, it was by using a variety of methods such as observation and in-depth interviews that I managed to maximise the depth of engagement with participants. This gave me, as a researcher, an understanding of how participants constructed their identities as T2DM sufferers, as mothers and as members of a family or community. I also learnt that people construct identities, however multiple and changing, by locating themselves or being located within a selection of their experience (Cerbone 2006). This was revealed through the interviews, as participants tried to make sense of what had happened and is happening to them by attempting to assemble or, in some way, integrate these happenings within their narratives.

### **3.2 Research design**

From a Black African heritage position, it was critical to understand the participants' experiences and how they gave meaning to their cultural beliefs about diet and T2DM self-management, sense of connectedness, interdependence and collective activities, and this could be best achieved by using a focused ethnographic, qualitative research method.

#### **Focused ethnography**

It is important to clarify that this study represents a focused ethnography design rather than full-scale ethnography. According to Roper and Shapira (2000) ethnography is the work of describing culture, using a process of learning about people by learning from them. The difference between a typical ethnography and focused ethnography is the data collection methods. In a typical ethnography the researcher develops a close relationship with the participants. This requires extensive cultural immersion of at least six months or more of time spent by the researcher with participants in their natural environment (Cruz & Higginbottom 2013). While focused ethnography offers the researcher the time to observe how a distinct cultural group derive meaning from everyday experiences for a shorter period of time, episodic participation observation (Holloway & Todres 2006). Focused ethnography has been identified as a good method for revealing contextual issues that are crucial for a more in-depth understanding of a cultural group (Holloway & Todres 2006). I adopted this focused ethnography approach which enabled me to observe and learn from participants the meaning of their activities, behaviours, knowledge and rituals. In adopting a focused ethnography I need to acknowledge my own ethnicity, gender

and class (Davis 1981); that is, my own professional identity as a public health professional and Black African researcher. Overall, I feel this had advantages in terms of access to the women with whom I wanted to undertake this research, although others may come to a different view. I discuss in more detail the issue of my positionality in this research study towards the end of this chapter.

I conducted intermittent and purposeful field visits and my data collection methods were carried out in two main phases. The rationale for using different methods was to gain information which would lead to a holistic understanding of the research topic, that is, to provide triangulation, which is crucial in addressing different aspects of a phenomenon (Creswell et al 2003). This study topic used observation methods to deal with issues of human complexity by exploring directly the nature of the phenomenon, so as to gain insight into people's shopping behaviours and how they undertake complex decision-making processes that lead to food choices.

### **3.3 Sampling processes and characteristic of the sample**

#### **Sample selection**

Denzin & Lincoln (1994) described several types of purposive sampling procedures which make data more 'information rich' such as intensity sampling and maximum variation sampling. The study used maximum variation sampling which aims to select a heterogeneous sample of participants based on their commonality of experience relating to the topic under study. In this study, a maximum variation

sampling of adult women of Black African heritage with T2DM was chosen to explore the phenomenon of influences on food choices in T2DM self-management by diet alone. To ensure that the data was 'rich', a heterogeneous sample of women included single-person and family households, different ages and employment statuses. The commonality of experience was women from Africa and the African Caribbean who identified with their Black African heritage, living in the UK, all of whom had T2DM which they self-managed by diet only.

Purposive selection was used for the sample, with inclusion and exclusion criteria. The eight participants were purposely chosen since they were likely to have sufficient information relating to the research question: What are the primary factors that influence food choice among women of Black African descent diagnosed with T2DM whose condition is managed by diet? The inclusion criteria consisted of adult Black African and African Caribbean women whose ages ranged from twenty-eight to sixty-eight years old (See Table 3, page 75). All the women had been diagnosed with T2DM which they self-managed by diet alone. Diagnosis of T2DM had to be of at least eighteen months or more duration with an absence of T2DM related complications, for example cardiovascular complications. In addition, participants had to be fully engaged in both family and household food shopping as well as meal preparation.

All participants lived in the counties of Norfolk or Suffolk in the UK. These are rural and agricultural counties in the east of England. People of African descent have settled in Norfolk and Suffolk since the 1960s. They live mainly in the urban areas of Norwich in Norfolk which had a total BME population of 12.26%, while



Ipswich in Suffolk reported 4.8% of its population as being from BME groups (ONS 2011). This is due to migration into the areas by Black Africans and other migrants and not natural birth. Moreover, the areas had an advantage as I worked and lived in the study areas and had already established links with BME communities. Financial implications and practicalities of the study also limited the geographical spread of the project. The geographical area also posed an interesting contrast to urban areas such as London which have been studied in more detail. The rural setting might have posed more challenges regarding the experiences of people of Black African descent living with T2DM, a chronic condition which requires regular contact with healthcare services. For example, although Norfolk and Suffolk have a relatively small BME population compared to larger cities like London, the burden of disease may be increasing above that of the general population (NHS Norfolk 2011).

The sample of eight participants was selected from these geographical areas based on the conviction that the appropriate application of a qualitative paradigm is enhanced by the manageability of a smaller number of participants. A fundamental dimension of contextual, naturalistic research is the quality of the relationship between the observer and the observed. The data are grounded in the relationships which were established with participants and this was achieved by working with a small number of participants. For example, I was able to establish rapport and trust with them, which permitted direct observations (in the case of the Accompanied Shopping Task and the PCRT) and a greater level of participation (in the case of the interviews).

The exclusion criteria were women with any limitation that would prohibit full participation, women who did not speak English and those who did not wish to participate in the study. The decision to exclude those with limited spoken English language was based on the researcher's limited resources for the practical task, the Accompanied Shopping Task (See Appendix 3 and 4) and the PCRT (See Appendix 5), for example, the cost of using trained interpreters for those who do not speak the English language was beyond the scope of a student researcher on a small budget. There were two particular cases of individuals excluded from the study. Firstly, a woman whose English was so limited that she could not fully participate in the Accompanied Shopping Task and the PCRT. Secondly, a woman who was accompanied by her partner or spouse and insisted that it would not be possible for her to take part without him being present and fully involved in the study.

The resultant small sample size of eight participants also meant that the type of information and data gathered was rich in detail and, in order to do justice to these and explore them in depth, the sample size had to be manageable. When analysing the data, the recruitment of participants stopped when it became evident that new participants were not contributing any new evidence, and thus increasing the sample size would not have yielded new evidence (Charmaz 2006). Moreover, Hammersley & Atkinson (2000) argued that, in observation research, small groups are studied on the supposition that they have their own truth, which should then make the research study more valid. My study aimed to understand the experiences of food choice for Black African and African Caribbean women, specifically those who used diet to

manage T2DM. I was not, for example, trying to generate a broad generalisation about all Black African and African Caribbean T2DM people in the UK.

**Table 3: Participant Characteristics**

<b>All female Participants</b>	<b>Age</b>	<b>Marital status</b>	<b>Country of Birth</b>
Veronica	50	Single-person household	Kenya/Black African
Liz	28	Married, no children	UK
Tamulah	62	Married, children left home	Uganda/Black African
Vera	68	Married, children left home	Jamaica/African Caribbean
Maria	47	Married with children	Tanzania/Black African
Danya	42	Single-person household	Trinidad & Tobago/African Caribbean
Rita	41	Single-person household	UK
Resy	38	Married with children	UK

### **Gaining access to participants**

Gaining access to participants was achieved by enlisting the help of established contacts who acted as gatekeepers to accessing this target group (Hammersley & Atkinson 2000). This involved working with key contacts such as diabetes nurses, BME community and faith leaders, and the BME voluntary sector who assisted by displaying posters and short adverts in their newsletters. Posters were also displayed in GP surgeries and at key venues accessed by people of Black African

heritage, for example hair salons, etc. I set aside a budget to reimburse participants for their travel expenses and time. This worked to my advantage as I was then able to find other service users who were willing to participate through word of mouth.

However, the problem of obtaining access to the data was very acute at the negotiation stage and this persisted in varying degrees throughout the data gathering stage. For example, a key contact passed on the details of a potential informant. I contacted the informant who agreed to see me and we arranged a meeting. On the day of the meeting, the informant arrived with her husband who turned out to be the only person who does the household food shopping and there was no negotiation of this role. What I learnt from this encounter was that it disproved a preconception that food shopping in Black African and African Caribbean households is the exclusive domain of women. This added a different dimension in terms of food choice for a woman with T2DM. Therefore, it highlighted that nutritional interventions and campaign messages should target, not only the individual, but the whole family<sup>1</sup>. I anticipated recruiting participants from GP surgeries or local Diabetes Centres but this failed and became a source of frustration and considerable anxiety. The main reason for this was that GPs prescribed medication as soon as a person was diagnosed with T2DM, in accordance with NICE guidelines (2006) and did not consider the role of lifestyle choices such as diet in managing T2DM, as argued by the UKPDS (1991, 1998). Therefore, patients who came into contact with T2DM nurse facilitators were referred by GPs and most were already on medication.

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<sup>1</sup>Family in my study referred to the nuclear family of parents/parent and children. A household is referred to as composed of one or more people who occupy a housing unit and who share a meal and the living accommodation (Social Trends, 2004).

Respondents were given a copy of the 'Study information Sheet for Participants', (See Appendix 6 and Appendix 7) detailing the nature of the study and the use of tape recording as well as the option to leave at any point in the research process. Following the suggestions by Harris & Roberts (2003) regarding the challenges of recruiting from BME or 'hard-to-reach' populations in qualitative research, I took measures to address a range of specific issues such as cultural and gender barriers to participation in the interviews (i.e. being of Black African heritage and a woman). I was aware that some participants might need permission from their husbands to participate in the research because of the gender and power relations that operated in some households.

### **3.4. Data collection**

The data collection was carried out in two phases: Observation (The Accompanied Shopping Task) and the in-depth interviews to validate the observation. The Accompanied Shopping Task involved two modes of data collection: recording the Product Choice Reasoning Task (PCRT); and observational field notes.

#### **Observation**

I commenced by conducting a pilot study involving two participants to test the validity of the design and to fine-tune the research issues. This is an organic process involving making sure the protocols used in the Accompanied Shopping Task worked with a view to making them applicable to the target group.

The first phase of data collection which was an Accompanied Shopping Task (See Appendix 3 and 4). The Shopping Task was non-participatory observation which involved me passively observing and following a participant while they conducted their food shopping. At the same time, participants were also asked to “talk aloud” about their thought processes – described in the next section (“Product choice Reasoning Task”, PCRT).

### **Accompanied shopping task**

I had significant concerns about the Accompanied Shopping Task as this clearly required a large amount of time and commitment from participants. It was therefore with great relief that I welcomed and greeted each participant as they turned up at the agreed time.

I used non-participatory observation, which involved me passively observing and following a participant’s activities. Merkens (1989, cited in Flick 2002) described the observer’s interpretations of the observed as occurring from a distance, and explained that the observer constructs meanings for the behaviour of the actors inferred from the observed actions:

“The observer here tries not to disturb the persons in the field by striving to make himself as invisible as possible. His interpretations of the observed occur from his horizon — the observer constructs meanings for himself, which he supposes direct the actions of the actors in the way he perceives them.”

(Merkens 1989, cited in Flick 2002 p.138)

The main advantage of me as a non-participant observer was that it allowed me to record 'action' as it happened which informed me about things that other methods of data collection would not have been able to do. For example, through non-participant observation I was able to observe participants actually choosing food products as it happened, as opposed to being told about it afterwards or getting someone else's perception of what they bought, but the action of the participant choosing food was perceived. I initially recorded events and then interpreted them at a later date. The main aim was to record significant behaviour rather than recording everything that happened. The way this was dealt with was to observe certain behaviours of the participant, listed below:

- a. did the participant use a shopping list to guide food shopping?
- b. reading of food labels
- c. method of payment
- d. interaction with staff

These activities were recorded as field notes. For example, with regards to reading food labels (See Appendix 8), which is a crucial part of food shopping for T2DM sufferers, I recorded whether or not the participant looked at the product in detail. Participants' interactions with their immediate shopping environment (noise, busy atmosphere, food adverts displayed) were also recorded. For example, I noticed that older participants who used public transport preferred to conduct their food shopping in the mid-morning when the supermarkets were less busy and this also coincided with bus times to make transportation easier. In contrast, participants in employment had less flexibility and conducted their food shopping in the evenings after work or on Saturdays during peak hours. However, busy shopping environments created

tension for me in an observation situation when trying to record significant behaviours. These observations formed part of my data gathering process.

### **The Product Choice Reasoning Task (PCRT)**

The PCRT (See Appendix 5) was the primary data collection method and I used field notes to supplement the data from the Shopping Task. The PCRT involved a participant 'thinking out loud' to explain why they picked a particular food product for purchase and later consumption in relation to their T2DM diet.

The Product Choice Reasoning Task is a direct observation method used in consumer food research designed by Barnett et al (2010), which was adapted for my study to be used during the Accompanied Shopping Task. This allowed a more detailed exploration of the reasoning behind participants' food shopping decisions (T2DM consumers). The PCRT technique was used to encourage participants to 'think aloud' in relation to a shopping task about food products that they put into their trolley/basket. The PCRT has its roots in cognitive psychology theory (Vygotsky, 1962, cited in Barnett et al 2010; Ericsson and Simon, 1980). The research technique aims to understand the relationship between thoughts and words. The goal of the 'think-aloud technique' is to give an insight into the processes of working memory, which is challenging because the mechanics of human thought are complex (Sugirin, 1999). Cooper (1999) argued that there are many thought processes that cannot be verbalised in working memory, either because they are automatic, such as recognition of familiar words and images, or because their



intermediate processing passes through so quickly that there is no time to verbalise. I recorded the PCRT which I later transcribed verbatim. Writing field notes soon after the Accompanied Shopping Task became very useful later on as some of the information contributed to my analysis, for example it revealed participants who had used the shopping list and those who had not and eventually facilitated understanding of the significance of planned and unplanned food shopping in T2DM self-management.

The PCRT offered a further advantage of the possibility of tape recording the reasoning behind the participants' decision-making about food choices. If I had been persistently questioning and communicating with the participants during food shopping, I would not have been able to capture the same depth of detailed information from the setting. Silverman (2006) argued that a researcher should not rely solely on notes or recollection of conversations because depending on memory is a difficult task as people cannot remember events and conversations accurately from start to end; therefore using the PCRT is an advantage. Thus using a discreet tape recorder (e.g. during PCRT) is seen as an ideal thing to do when conducting non-participant observation in a natural setting (Patton 2002). However this could only be made possible if participants allowed me to observe them and accepted my presence. I conducted the research with the full consent of the participants (See Appendix 9), who were provided with information (See Appendix 7) about the nature of the study and were fully informed that they had the right to withdraw at any stage of the research process. Therefore all participants who took part in the study agreed to be observed and cooperated with the recording of the food shopping PCRT (Patton 2002).

I was aware that one of the limitations of the PCRT is that it involves a degree of prompting, which had to be kept to a minimum to avoid over-influencing the participants and to encourage their natural thought processes. My choice of the Accompanied Shopping Task activity for the target group was appropriate because it allowed more than an automatic response and was not cognitively overwhelming for participants. I was also aware that bias might be introduced into the 'think-aloud' reporting (Ericsson & Simon 1980). I tried to minimise bias by maintaining minimal contact with the participants during the PCRT to avoid interrupting their thought processes, for example mouthing the prompt, 'keep talking', whenever I noticed that a participant had gone silent. This was very effective in keeping the participants engaged in verbalising their thoughts.

I incorporated a follow-up interview into the PCRT five days later as a measure designed to minimise reactivity, which involved retrospective questioning, i.e. in-depth interviews (Qi 1998, Rankin 1988, Charters 2003). This added to the richness of the data on participants' thought processes (Barnett et al 2010). The research questions emphasised the need to understand people's lived experiences and the meanings they attributed to life events. Therefore, interviews were considered to be an appropriate means of following up the Shopping Task and the PCRT.

## **Interviews**

The Accompanied Shopping Task, which constituted the observation, was followed by in-depth interviews which I conducted after a short interval of five days (See

Appendix 10), which I later transcribed verbatim. The in-depth interviews provided me with an opportunity for further analysis of participant statements, reasoning and observed behaviour. In the observation, my role had been to observe and learn while maintaining a distance. The in-depth interviews were used to allow participants the opportunity to explore cultural issues that are important to them and to allow me to pursue significant issues.

I found the interviews to be particularly valuable in seeking to understand how the participants made sense of the situation they were in and the identification of issues that were crucial to them. I used an interview topic guide with previously planned open ended questions. Questions needed to be open ended to elicit rich data, and overlapping to facilitate going back to a topic that required more information. Moreover, ready probes also helped to elicit necessary information (Charmaz, 2006). This is considered by Paton (2002) to be an advantage of using open questioning techniques in interviews, as it demonstrated interest and actively encouraged the interviewees to elaborate by opening up and talking as opposed to giving 'simple answers', as with questionnaires.

I conducted follow-up interviews a week after the PCRT to seek confirmation of, and explanations for, the participants' actions. According to advocates of the PCRT (Sugirin 1999, Cooper 1999), information is held [in the brain] very briefly and can disappear quickly; therefore, to overcome this limitation, a short interval was required between the PCRT and the interviews. The interviews therefore offered me with the opportunity to discuss both general issues relating to T2DM as well as specific questions arising from the observation of the Accompanied Shopping Task.

The interviews were semi-structured with a few broad areas identified for discussion. Past research, relevant literature and my own knowledge of the research topic were synthesised to develop the research questions. Some participants did not necessarily respond in the same order in which the questions were presented, which meant that I had to use prompts to alert them to questions that had already been discussed and those that required more information. As I became more familiar with the subject matter and gained confidence in interviewing participants, I was able to reduce the number of prompts. During the interviews, participants' answers were rich in detail as open questioning around the topics allowed them to feel more relaxed and elicited personal responses informed by personal experience. For example, some participants disclosed sensitive information such as the loss of a parent, sibling or family member due to T2DM complications. Information such as this can only come to light through an interview in which a participant feels it is safe to talk about personal issues (Gillham 2000).

Given the complexity of the research questions (to explore the influences of food choice) and inclusion of sensitive topics (for example T2DM, weight-management), more than one method was needed to gain a comprehensive understanding of the phenomenon under study. Therefore, I would argue that this could be best achieved by methods that included in-depth interviews to allow the researcher to build up a more complete picture (Gilham 2005). At times, it was difficult to conduct an interview whilst simultaneously giving my utmost attention to the participant in order to maintain the flow of conversation and ensure that all areas were covered. Every

possible effort was made to ensure that the study was as robust and rigorous as possible despite the various methodological challenges.

### **3.5 Ethical issues**

The research commenced after ethics approval had been granted by the Ethics Committees from each PCT area and the University of Essex (See Appendix 11). Throughout the research, the principles of the NHS Research Governance Framework were adhered to, for example, when managing sensitive issues, respecting the autonomy of the individual and their time commitment to the project

There are six ethical principles that place a moral and ethical obligation on a researcher to avoid causing harm, to show respect and to allow people to be self-determining. Ethical consideration focused on each stage of the research process from its inception to its end. The ethical standards of Beneficence, Non-maleficence, Fidelity, Justice, Veracity and Confidentiality (Parahoo 2006) convey a duty on the researcher to use these standards to benefit those who have contributed to the research. My study placed greater emphasis on 'beneficence and non-maleficence', which are "a fundamental ethical principle that seeks to maximize benefits for study participants and prevent harm" (Polit & Beck 2008 p. 748). The researcher has a duty to use the research to benefit those who have contributed to it by showing respect, applying values and using the findings to enhance and develop the target communities and reduce powerlessness. The study had no potential for physical harm (i.e. non-maleficence). However, due to the exploratory nature of the interview (Parahoo 2006), I offered a referral counselling service and details of this were provided on the participants' information leaflet (See Appendix 6). Confidentiality was

also very important. All data collected for the study purposes was stored in a locked cabinet where access was restricted to the researcher only. Any data stored on a computer was password protected. The privacy and confidentiality of all study participants was maintained at all times. I did not try to find out personal information about participants that was not related to the study.

### **3.6 Data analysis**

The study generated a large quantity of data, such as interview transcripts, field notes, and PCRT tape recordings, all of which had to be analysed. Furthermore, the analysis was cluttered as the data did not fit neatly into categories and I ended up with many ways of linking between different aspects of the observations and interviews. I used Framework Analysis (Richie and Lewis 2003) to bring some order to the cluttered data.

Data was managed manually using Framework Analysis, a qualitative approach that has thematic analysis at its core and consists of five key stages. Every attempt was made to make the process as transparent as possible (See Appendix 12 for a detailed description of this process).

The Framework Analysis was carried out inductively and this allowed data to be used for emergent concepts, such as in relation to coding. Framework Analysis was particularly germane to the research topic as it allowed for the capture and explanation of the social worlds of the participants under study. This required me to stay close to the original data, following the recommendations of Richie and Lewis

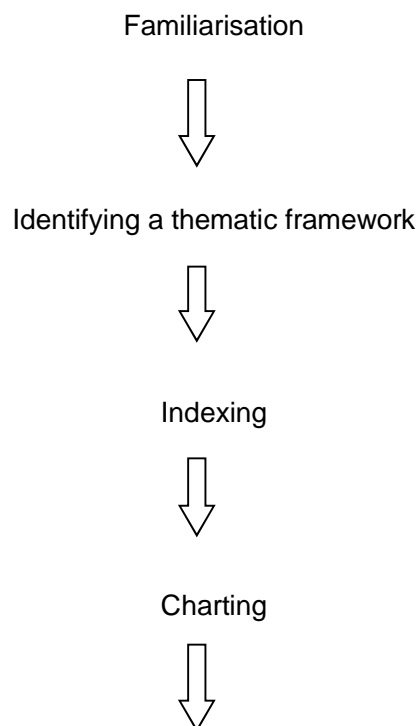
(2003) who stated that whatever approaches a researcher uses, there is a need to become thoroughly familiar with the dataset, as this is a crucial step that takes place at the start of the analysis.

Framework Analysis was an appropriate way to analyse data for my study because the topic has a pre-designed sample (Black African/Caribbean women with T2DM/target group) as well as some *a priori* issues (key influences and food choice), which needed to be explicitly addressed.

The five stages of Framework Analysis which were used in the study are shown in Figure 3, below. Although separate, the stages are interlinked as I was able to go back and forth between them.

**Figure 3: Five Key Stages of Framework Analysis (Ritchie and Lewis, 2003)**

**Data Management in Framework Analysis**



## Mapping and interpretation

Stage 1 of Framework Analysis involved managing and getting close to the data. I retained the key terms, phrases and expressions used in the participant's own language. I kept the interpretation to a minimum at this stage so that there was always the opportunity to revisit the original expression as the more refined levels of analysis were conducted.

In Stage 2, I made connections between two sets of data (Accompanied Shopping Task and interviews) to identify patterns and confirm participants' lived experiences. I used the notes from observing the Accompanied Shopping Task and transcribed the PCRT reasoning data about why participants bought certain food items during the PCRT to confirm and expand on their knowledge when they were asked about it during the interview. The PCRT data was particularly effective when describing the traditional Black African diet to which participants attached meaning. This type of creativity within the interview process enabled data to be gathered that reached into the experiences of the group and permitted me to uncover consistent themes while taking into account variations within the group. For example, participants were asked a specific question about why they selected a particular product and the answers revealed a variety of influences on food choice such as income, culture (expressed as heritage food in the PCRT when picking a sweet potato or pineapple, etc.) In this way, it was possible to build a connection between the two sets of data (observations and interviews) at this stage of the analysis.

In Stage 3, Indexing (Strauss and Corbin, 1990), I used labelling or tagging to identify sub-themes, which were grouped under five main substantive headings with



an additional 'other' category to provide an identifier for any uncovered issues that emerged within the broad subject area under investigation. This helped to ensure conceptual clarity within the framework and identify areas of overlap or gaps in the level of conception used. I performed this as a multi-stage process to generate a set of themes and concepts. I had to reflect on, and return to, the data for clarification of transcripts, observation notes gathered during the PCRT, and summaries of interviews, and I also re-listened to the tape recordings.

In Stage 4, Charting, I used the headings from the thematic framework to create charts of the data so that I could easily read across the whole dataset. I constructed charts by case for each respondent across all themes and included textual examples, shortened quotations and key words as a reminder of what was being referred to.

In Stage 5, Mapping and Interpretation, I summarised or synthesised the original data. I searched for patterns, associations, concepts and explanations in my data. I also created typologies, identified associations within the data and provided explanations. This depended on the themes that emerged from the data and the original research question: What are the main factors that influence food choice in women of Black African descent diagnosed with T2DM whose condition is managed by diet? I had to visually display ideas, which was useful for exploring data in the context of Framework Analysis.

The primary concern of the study was to explore beneath the surface of 'reality', making meaning out of participants' data, and out of their experiences, for example of making dietary choices, and understand how the broader social context impinges

on those meanings, while still retaining a focus on the material and other limitations of reality.

During the framework stage of analysis, it became crucial to understand the data in the most effective way possible. My rationale for using the PEN-3 public health cultural practice model to inform the analysis was that it was crucial to keep the distinctive cultural aspect of the study. For example, the themes that were being extracted from the data demonstrated how cultural values supported the 'family' in food shopping decision-making for participants with young children at home, and also kept all the family connected at extended family gatherings and social events. Connections were made between the PCRT recordings that had been transcribed verbatim and the interview data. The PEN-3 public health cultural model integrated all aspects of the data and provided cultural insights, which were eventually incorporated into the findings (See Appendix 1).

### **3.7 Methodological rigour**

In this section I discuss trustworthiness, generalisability and my own positionality as a researcher. Rigour was ensured by identifying the methodological issues outlined above and below and addressing them as far as was possible. According to Tobin (2004), the essential test of validity of a finding in a positivist paradigm is not feasible when using a flexible design involving human interactions.

Bryman (2008) argued that, despite a long history of using qualitative research, and the undeniable contribution made by qualitative research, there has been criticism

that qualitative research methods are subjective and therefore not rigorous. However, I would like to argue that my study showed trustworthiness in various ways, principally by following criteria recommended by Arminio et al (2002) which included the suggestion that a researcher should state their philosophical underpinnings to provide context and inform the study. My study also demonstrated how data collection (methods) was conducted explicitly and how it was managed. The philosophical position chosen was the interpretive paradigm using observation and in-depth interviews to collect qualitative data.

Tobin (2004) stated that trustworthiness is central to qualitative research and needs to be demonstrated through credibility, transferability, creating an audit trail, conformability, peer debriefing and triangulation. My study maintained an audit trail to enhance conformability. This was achieved by electronic storage of all the raw data from the PCRT and interviews. All research activities, including field notes and meetings held with my supervisors to discuss the study are available in hard copy and electronically

Arminio et al (2002) also stressed the importance of the process of reflection on the relationship between participants and the researcher, which is made evident throughout my study. Arminio et al (2002) placed emphasis on gaining new insights and recognising implications for professional development. The data presented in this study may assist public health professionals in making nutritional interventions, as the findings are representative of the food shopping experiences, and explanations for these, of most T2DM people of Black African heritage.

My study also demonstrated recognition of issues regarding validity by using triangulation in order to strengthen rigour. Two sources were used to collect data to investigate the study topic, which were observation and in-depth interviews. These methods facilitated the collection of data from two different perspectives or sources of the same phenomenon. Various researchers, including Guba and Lincoln (1981, cited in Graneheim & Lundman 2004), have proposed considering applicability and transferability, which represent the extent to which the research findings of a particular study may be applied to similar contexts. Triangulation also helped to clarify meaning and verify the repeatability of an observation.

Peer support was used throughout the project, as I discussed and presented my study to my supervisors, peer groups and colleagues who work in the research department.

The aim of all research is to generalise in some form or another, but in qualitative research generalisability can only be achieved in a strictly limited manner. I acknowledge that the findings were derived from a small sample and therefore may not be a true representation of the population from which the sample was taken. However, the educational level, socio-economic status and age differences between the participants reflect those of Black African and African Caribbean communities in Norfolk and Suffolk.

## **My positionality**

I had to be aware and remain fixed in the researcher's mind throughout the whole process, to try to attain objectivity both in regard to data collection and analysis. My reference point was not only in relation to ethnicity and gender, but was also subtly linked to the relationship between ethnicity, gender and class (Davis 1981).

I considered that my own ethnicity played a positive part in understanding some of the identity experiences of women of Black African heritage in the diaspora. I understood what the female participants meant when they mentioned difficulties they experienced in relation to food shopping for the family and social eating at family gatherings. Thus, when participants used a phrase such as, "you know what I mean", during interviews, I knew that this was drawing on shared meanings as I clearly understood that the desire to maintain a normal life for a female T2DM sufferer may be problematic in families of Black African heritage.

Yet, as a Black African researcher, I also encountered the problem of defining the participants by their cultural group. Furthermore, a cultural approach, important as it is for my study, tended to focus on differences from the dominant culture without accounting for common elements, thus setting up false irreconcilable differences. It was therefore important that I periodically stood back and reflected on the situation and themes which characterise the phenomenon under study.

At the same time I had to maintain my status as a female professional and researcher. It was this dynamic relationship and a contemplative interaction with the process of analysis that emphasised the reciprocal reflective stance I retained. This required that I acknowledge my presence in the research as a Black African woman and as an experienced public health professional working in the NHS. This reflective

process seeks to create a certain truth and depth of meaning, while retaining the ambiguity of experience. As a public health professional of Black African heritage, my position was to increase awareness of the need to promote approaches that supported the role of men as care-givers in the family and community, and provide adequate support and guidance to enable male participation, which will lead to progress in addressing gender equity issues (this is discussed in chapter 5) in T2DM care for women of Black African heritage.

### **3.8 Summary**

This chapter has described the qualitative methodology used in the study, which is underpinned by an interpretive phenomenological approach. Focused ethnography was used which involved two methods of data collection carried out in phases. The first phase involved non-participatory observation in order to identify decision-making in relation to food choice in an undisturbed way. The second phase involved conducting in-depth interviews that identified specific questions to ask so that each interview had the same basic content. The observation illustrated connections with participants' behaviour, during the Shopping Task and PCRT, while subsequent interviews provided further assessment when discrepancies occurred between their statements and observed behaviour. Framework Analysis was used to manage the data. The PEN-3 public health cultural model was used to synthesise and to discuss the data and how it revealed the interrelations between culture, gender and identity in order to understand how women of Black African heritage construct decisions about a healthy diet. The outcomes of the data collection and analysis are presented in the next chapter.

## **Chapter Four: Results**

### **4.0 Introduction**

The purpose of this chapter is to present the findings relating to the eight women who participated in, and made a significant contribution to, my study. I begin by examining the two overarching categories that emerged from the data, the 'Disease Focused' and the 'Family Focused' approaches to managing T2DM. These categories might be construed as rather mundane but there are far-reaching implications for the experience of women living with T2DM – and, therefore, for public practice.

Following the brief elaboration of these categories, I describe several aspects of the lived experiences of the women which are expressed through their voices as they offered specific knowledge on nutrition. In so doing, I make connections between their lived experiences; I identify three main domains of their experience of diet. The domains of experience – themes – are each closely tied with culture. The first theme, 'Food shopping and decision-making', showed how the participants dealt with challenges involved in their food shopping habits and in-store decision-making. The second theme, 'Choice and lifestyle', demonstrated factors influencing food choice and showed how participants prioritised nutritional needs. Behaviour appeared to be driven not only by health concerns, family, and personal preferences, but also by environmental and socio-economic situations. The third theme, 'Interface with health services', captured and defined the significance and nature of culture and kinship in T2DM self-management to inform practitioners and public health nutritional

interventions from a Black African heritage perspective. This chapter ends with a summary and leads into a discussion of the findings in Chapter Five.

Cutting across the three themes, and also emerging from the data analysis, were two overarching categories. When the data from the eight participants was analysed, the two broad categories that emerged were: a ‘Disease Focused Approach’; and a ‘Family Focused Approach’. Six participants prioritised their disease and used what I call a ‘Disease Focused Approach’. The other two participants whose T2DM self-management behaviours were influenced primarily by their family situation used what I call a ‘Family Focused Approach’ (a summary is provided in Table 4).

**Table 4: Participant Characteristics and Behaviour**

<b>All female Participants (pseudonyms)</b>	<b>Age</b>	<b>Marital status</b>	<b>Behaviour observed related to shopping and lifestyle</b>
Veronica	50	Single-person household	Disease focused
Liz	28	Married, no children	Disease focused
Tamulah	62	Married, children left home	Disease focused
Vera	68	Married, children left home	Disease focused
Maria	47	Married with children	Family focused
Danya	42	Single-person household	Disease focused
Rita	41	Single-person household	Disease focused
Resy	38	Married with children	Family focused

The first overarching category identified was a ‘Disease Focused Approach’. This was used by six participants, two of whom had children who had left home, one of whom was married but had no children, and three of whom lived in single-person households. A ‘Disease Focused Approach’ conveyed the idea that participants



behaved in a way that prioritised their disease and were able to self-manage T2DM. A 'Disease Focused Approach' resulted in proactive attitudes towards managing harm that was imminent and visible as opposed to harm that was invisible (Rosenstock et al 1988).

The second overarching category identified was a 'Family Focused Approach' which indicated that two out of the eight participants with children living at home prioritised family care over their disease. They tended to sacrifice their own need for self-management if there was a conflict between performing social roles and self-management of T2DM. A 'Family Focused Approach' involved an awareness cognition which resulted in harm reduction behaviours that were strongly dominated by interaction with family members.

The impact of the category for each participant was generally significant in relation to theme (1) Participants' food shopping and decision-making, and theme (2) Choice and lifestyle, but seemed to have less impact on theme (3) Interface with health services. The implications of these categories are discussed within each theme.

The findings suggest that the participants' food shopping behaviours were shaped by individual and family preferences and also by the women's culture, economic and environmental situations.

The subsequent three sections look at each of the three themes that were identified from the data collection and analysis, as illustrated in **Table 5**.

**Table 5: Categories and Themes identified within the study**

<b>Cross-cutting Categories: behaviour and lifestyle</b>	<b>Themes (domains of experience related to T2DM)</b>	<b>Sub-themes</b>
Family Focused Approaches	<ul style="list-style-type: none"> <li>• Food Shopping and decision-making</li> </ul>	<ul style="list-style-type: none"> <li>• Dietary knowledge</li> <li>• Planned and unplanned shopping</li> <li>• Health promotion / nutritional Information</li> </ul>
Disease Focused Approaches	<ul style="list-style-type: none"> <li>• Choice and lifestyle</li> </ul>	<ul style="list-style-type: none"> <li>• Culture and food preparation</li> <li>• Access to food and affordability</li> <li>• Cultural influences on food choice</li> </ul>
	<ul style="list-style-type: none"> <li>• Interface with health services</li> </ul>	<ul style="list-style-type: none"> <li>• Self-management</li> <li>• Collaborative pathways of care</li> <li>• Raising awareness</li> <li>• Culturally appropriate service provision</li> </ul>

#### **4.1 THEME 1 - Food shopping and decision-making**

Theme (1) ‘Food Shopping and decision-making’ and its three sub-themes ‘Dietary knowledge’, ‘Planned and unplanned shopping’ and ‘Health promotion and nutritional information’ were derived from the PCRT and field notes. Data from the interviews also confirmed consistencies in participants’ responses to information mentioned during the PCRT (for example, about the knowledge of, and justification for, why identified food items were picked). Participants demonstrated how they coped with the challenges involved in applying dietary knowledge to in-store decision-making.

These findings are important because they relate to an everyday situation that is faced by T2DM sufferers, that is, a busy supermarket. In this PCRT participants were required to ‘think aloud’ about why they were buying the food they picked in relation to their knowledge of T2DM and their understanding of public health recommended nutritional guidelines. They also revealed their ability to apply health promotion and nutritional information such as reading and understanding food labels to guide food choice.

The data showed that, while participants had the knowledge about which food to buy, they demonstrated a very different perception and application of dietary knowledge in their food shopping behaviour. Participants who used a shopping list demonstrated that it acted as an effective guide to avoid unintended purchases

#### **4.1.1 Dietary knowledge**

The food shopping behaviour of the two participants who had children living at home illustrated that the role of a mother, as opposed to the role of a T2DM sufferer, was paramount. Despite showing awareness of a healthy diet, both participants engaged in a ‘Family Focused Approach’ to food shopping behaviour and paid more attention to their children’s needs than their own:

*“I buy lots of fizzy drinks because my kids like it. I like Coke too and I do not buy Diet Coke because it tastes disgusting, not good but we buy it anyway.”*

*(Resy 8, PCRT, Professional P/T)*

Another participant also stated:

*"I am looking for the bread. I will buy some bread. I should have brown bread for sandwiches. My sons refuse to eat it, so I buy white bread."*

*(Maria, PCRT, Assistant Social Worker)*

Although these participants were not accompanied by their children at the supermarket, children exerted influence over food that was purchased by participants whose children were living at home. Furthermore, where motherhood played a role, it was found that the task of executing the required diet was compromised. For example, a participant with two young children demonstrated how a healthy lunch was accompanied by a treat:

*"I pick cucumber; it is good to have in children's packed lunch. I also pick cherry tomatoes again to put in their salad. I pick chocolate, for kids packed lunch, not good but they like it. I have chocolate with my lunch too" (Resy, PCRT, Professional P/T)*

The response of Resy demonstrated that she had acquired knowledge about healthy food but she clearly stated that she also consumed unhealthy food that she bought for the children such as chocolate. It is also evident from the comment above that a parent's attitude can have a key role to play in their children's nutritional needs. Most primary school age children have limited knowledge of food and the ingredients that would make a good, healthy lunch.

In families with children at home, it was this deep-rooted sense of family that was also instrumental in T2DM self-management. Maria reported that as a parent she faced challenges in deciding on a healthy meal for herself because of her two young teenage boys (aged 11 and 13 years). The participant's predicament was illustrated in the following statement:

*"I pick some chips, my children do not like the food that we diabetics eat. They want their chips and sausages all the time, all the food I can't eat. They don't want the salads, the fruit, and all the food that I can eat." (Maria, PCRT, Assistant Social Worker)*

The comment above illustrated that the ability to self-manage T2DM for this participant was further complicated by trying to reconcile her knowledge of the recommended diet and her children's nutritional preferences on a daily basis during family meals. It is necessary, therefore, for health professionals to consider how individuals' dietary knowledge might be moderated by their family situation (especially women with families at home).

However, the other six participants, who engaged in a 'Disease Focused Approach' to food shopping, were able to prioritise self-management of T2DM. One of these six participants disclosed how she prioritised her disease while food shopping:

*"I just got some salad but I have only two so far. For me to have more salad, I like something on my salad, pepper not salt or salad dressing on my salad because I can't eat a green salad plain, it's too bitter for me. I still have a*

*sweet tooth. I do look at the sugar labels but on some things I don't. It depends, like I didn't look at the sugar labels on salad dressing but they don't have too much in them. Because sugar levels in the food will get the diabetes up.” (Rita, PCRT, Unemployed)*

This statement showed how a T2DM patient becomes the key person for achieving the expected outcome. The participant demonstrated that she knew about food labels and linked sugar content in food with blood glucose level, thereby demonstrating the ability to self-care for T2DM by diet. It has been confirmed elsewhere (Thomas-Hawkins et al 2005) that diet in T2DM self-care relies on patients' behaviours: this can be difficult to manage by healthcare professionals alone. In T2DM, as in other chronic illnesses, a patient is expected by health professionals to be competent in self-management at home.

Three participants in single-person households appeared to prioritise their food purchases differently than if they lived in a family household. They tried to economise their food-buying habits and took into account practical considerations, such as ready-made meals or easy to cook meals that included a variety of vegetables:

*“I am buying the vegetable stir-fry that is already pre-packed. There is a combination of vegetables and the fact that I live alone and for budgetary reasons I cannot buy them separately.” (Danya, PCRT, Unemployed)*

Participants in single-person households also reported that they went food shopping more frequently because they felt restricted in their food choice in terms of quantity for perishables. They could not buy items like milk, vegetables and bread in large quantities to save money, as these go off quickly:

*“I pick milk, the green low fat milk. Because I live alone I buy the 2 pint one because, if I open it, it can go bad if I buy a big one.” (Veronica, PCRT, Care Worker)*

The participant also demonstrated her knowledge of the type of milk she needed to manage her weight by buying low fat milk, thereby putting theory into practice. T2DM sufferers need to be aware that the levels of calcium and potassium in food help to keep blood pressure down by countering the sodium which is a component of salt, and these minerals are therefore important in their diet (Food Standard Agency 2012). Skimmed and non-fat milk offer more potassium than higher fat, whole milk.

There are many factors that can influence impulse buying because stores are full of different stimuli: participants are met with a busy environment containing in-store colourful displays, perfectly aligned packages of snacks on end-cap displays and advertisements (Helgesen et al 2010). Nevertheless, the in-store stimuli and food advertising seemed to have little effect on those participants who adopted a ‘Disease Focused Approach’. This was demonstrated by two participants who actively looked for vegetables:

*"I am still struggling here with my potatoes (laughs). I am still trying to look for the best value ones!" (Danya, PCRT, Unemployed)*

And another participant said:

*"You know they have changed the vegetable arrangement. I don't know where they put them now. They change everything. I am going to look that way."  
(Veronica, PCRT, Care Worker)*

More importantly, the focus on food that the participants wanted to buy seemed to limit the extent to which the store cues might be noticed. They also demonstrated that they consumed vegetables as part of their diet.

Another participant demonstrated how she planned her meals to guide shopping for a healthy breakfast:

*"I don't use cow's milk so I will go up further on where I can get some soya milk. I use soya milk for my cereal, I'll have to go round and get some cereal. So we go round now, and I get my soya milk." (Vera, PCRT, Retired Professional)*

This illustrates that the participant was focused on buying a particular food product that she used on a daily basis. She also demonstrated her knowledge of a good source of protein, soya milk, which is often used by vegetarians as an alternative to cows' milk.



#### 4.1.2 Planned and unplanned shopping

Two types of food shoppers were observed: those who used shopping lists and those who did not. The first type consisted of the six participants who followed a 'Disease Focused Approach' and produced a shopping list to guide their food shopping and aimed to engage in planned shopping. One of the six had a shopping list but did not use it. The second type consisted of two participants who used a 'Family Focused Approach'; neither had a shopping list.

The five participants who used their shopping list seemed to avoid impulsive decisions and also opted for lower-priced items:

*"I have to be careful with what I decide to buy. Next on my list I'm going to have sweet potatoes because they are less starchy. I am looking normally for a pack with four which is probably just in line with what I can afford right now."*

*(Danya, PCRT, Unemployed)*

And another participant also said:

*"One remaining thing on my list is butter. I like to use this olive oil spread because it has 0.1g sugar and 0.12 g salt. So it's better for me".*

*(Veronica, PCRT, Care Worker)*

And another stated:

*“And broccoli is good for cholesterol, actually it’s cheaper here so I got some because I, (checks shopping list) I got some linseed soya bread, brown bread good bargain again. You know that’s great value £1 ok.” (Tamulah, PCRT, Charity Worker P/T)*

Thus, following a food shopping strategy with a list may lessen the stress of food shopping and make living with T2DM more manageable. The participants took time to check the prices and to read food labels. The shopping list could therefore be construed as a guide to help participants make planned purchases and avoid impulsive buying. This was particularly true for two vegetarians, for example:

*“I’m just going up this aisle here, where the vegetables are because I want to buy some butternut squash. I buy butternut squash because I am going to make some soup. I eat a lot of soup; I carry a lot of soup with me so I don’t have to buy lunch as well.” (Vera, PCRT, Retired Professional)*

The five participants who used a shopping list also visited fewer aisles and therefore decreased their exposure to in-store stimuli and the likelihood of looking at store displays. They were committed to a course of action and seemed to be focused on getting those food items on their list. Self-control is generally goal directed towards a certain performance or outcome.

Another participant had developed a food shopping strategy which she used to manage planned shopping. She had learnt to prioritise her disease in selecting food

products, and she described how she avoided food products for which she knew she had a craving:

*“I am now walking past. I avoid the confectionary aisle; I ignore it because it’s got the products I like. I try to ignore the bakery side of it as well. That’s the treat of the week!” (Liz, PCRT, Lecturer)*

Limiting exposure was very important for this participant as she used self-imposed constraints on behaviour by planning ahead, which assisted her in-store decision-making.

In contrast, one participant who generally adopted a ‘Disease Focused Approach’ and had a shopping list, did not use it. She did not use the shopping list perhaps because she preferred to wander along the aisles looking for bargains. The other possible reason could be that her shopping was just for one person. Abandoning a shopping list is less efficient and leads to spontaneous shopping; as she later stated:

*“Oh, I can’t get more food because my basket is full up. Can you hold the onion rings for me? Here is the shopping list. I picked up things that weren’t on the list.” (Rita, PCRT, Unemployed)*

As she did not use a shopping list this may have led to her demonstrated inability to resist the craving to buy sweet food, or more food:

*"I am going to have Coke. I like Coke. I do still drink it because I can't get out of my "dizziness" for Coke. It is on offer, buy one get one free. I saw it the other day on the local news advert that came through the door." (Rita, PCRT, Unemployed).*

This particular participant displayed behaviour that fluctuated from being a very 'Disease Focused' individual with a mind-set geared to using a shopping list, only to lose control when exposed to shelves of food. She clearly had the knowledge about her nutritional requirements in relation to her disease but it seems that the local advert highlighting a special offer on food she liked contributed to her decision to purchase an unhealthy food item. In this instance, it seemed to be the case that the individual's willpower and locus of control which can play a crucial part in making healthy decisions and avoiding risk-taking behaviour, was diminished. She dropped her guard and lost concentration on T2DM management as she seemed overwhelmed by the food in the supermarket, which she articulated as follows:

*"I pick some humus. I pick some sweet onion caramelised humus. I buy this mango and chilli sauce. They do different sauces here at Sainsbury's. They do some new things all the time. That is why I like coming here; it is not my usual shop. I shop at my local. " (Rita, PCRT, Unemployed)*

This excerpt also demonstrates that supermarkets offer a wider range of food products than small shops. However, it may be that exposure to a variety of food products can work against a person's original intention, for example, leading the participant to abandon her shopping list. Using a shopping list requires a lot of effort,

but it can be helpful for people with T2DM as they need to stay focused and on budget.

The second group of shoppers engaged in unplanned shopping were the two participants who used a 'Family Focused Approach' and did not have a shopping list. They perhaps illustrate the difficulties experienced by the participants when children and large households are added into the food shopping, particularly if these include special needs and fastidious eaters. For example, in the words of one participant:

*“Sometimes they are not happy because I go shopping and buy things they don't want. It's different kind of food for them and me. They want different food. I do, I buy things that I think are healthy for them too.” (Maria, Interview, Assistant Social Worker).*

It is therefore important from a health promotion point of view to engage with other family members in relation to nutritional interventions and not just the individual with the disease.

At the same time, one of the participants who used a 'Family Focused Approach' was troubled and stated that she had difficulty managing her T2DM in the way that she did. She reflected on this as she conducted her shopping, as she tried to consider and enact strategies to help regulate her current behaviour to foster long-term goals that are nutritionally healthy. Her thoughts are illustrated in the following excerpt:

*“I am buying sweets. I buy junk food at times as a special treat. I would like to buy food that is low on sugar, pulses, lentils, beans. I am looking at fruit and vegetables that are going to benefit me, vitamins and nutrients. I would like to buy that all the time.” (Resy, PCRT, Professional)*

This reveals the real challenges faced by an individual T2DM sufferer when trying to make the right food choices. She was able to acknowledge and recognise that she had succumbed to perceived immediate short-term needs.

My observation notes also identified that the two participants who engaged in unplanned shopping visited more aisles looking at products, putting them back on the shelf and deliberated over making a decision about what product to buy. They also showed an interest in special offers and reduced items. As a result, time spent on the shopping task and the PCRT with these participants was considerably greater than with the participants who planned their shopping.

My data from the field notes illustrated that participants’ method of payment was important, in that it was also a deciding factor in terms of what food to purchase. Shoppers have multiple means of paying for products. The receipts I collected from participants at the end of the shopping task demonstrated that participants’ shopping behaviour was associated with their payment method. All participants who planned ahead and used shopping lists were able to pay by cash because they ended up with just the amount of shopping they had wanted to buy. By contrast, the two participants who used a ‘Family Focused Approach’ and engaged in unplanned food shopping used debit cards to pay for their shopping.

#### 4.1.3 Health promotion and nutritional information

Within this theme of 'Food shopping and decision-making', the sub-theme of 'Health promotion and nutritional information' emerged. This allowed for detection of participants' reasons for choosing particular types of food and exploration of the sources of the knowledge informing these choices. Limited resources could affect their learning about this topic, thus possibly leading to the purchase of unhealthy food which could have a negative impact on their lives.

A participant who used a 'Disease Focused Approach' demonstrated why she had bought cabbages and broccoli and also showed how she had been proactive in looking for information:

*"I bought cabbages and broccoli, because recently there was an article about broccoli seeds, and broccoli leaves are meant to have a chemical, I forgotten the name of it but I will let you know some other time, but that chemical apparently is helping people with cholesterol levels and with diabetes and heart diseases." (Tamulah, Interview, Charity Worker P/T)*

Another participant who used a 'Disease Focused Approach' also showed her knowledge of how a diet rich in vegetables could prevent T2DM complications such as cardiac heart disease:

*"As I mentioned while I was picking up the food at the supermarket is that, with vegetables, I occasionally buy beetroots, cucumbers and things like that to juice."*

*I always recommend vegetables all the time because it tends to sort of get into the system a lot better and you have a combination of nutrients that would benefit you. You are not at risk of developing a heart disease somehow.”*  
(Danya, Interview, Unemployed)

These excerpts revealed that the participants seemed to have adequate knowledge about T2DM and how to self-manage it through diet. A liquid diet rich in nutrients can also help with weight management.

While nutrition can be a complicated area to understand, the participants in my study demonstrated that they were well-informed. Participants who had decided to self-manage using diet alone needed to have a basic understanding of concepts such as ‘nutrient density’ and its contribution to diet. Nutrient density is concerned with the knowledge of essential micronutrients (vitamins and minerals) in relation to the energy they provide; macronutrients are mainly ‘high density’ carbohydrates that constitute a large part of most diets (WHO 2003).

Most participants, particularly those who used a ‘Disease Focused Approach’ revealed a practical understanding of this fundamental knowledge base:

*“I’ve quite bad eyes and, normally growing up, I’ve been told that carrots are good for your eyes. So that sort of sticks with me. So I bought carrots.”* (Danya, Interview, Unemployed)

Another participant stated:



*“I bought low fat, low salt Bachelor’s vegetable soup. It’s better for me.” (Maria, Interview, Assistant Social Worker)*

Thus ‘high’ or ‘low’ nutrient density should be considered in terms of what it seeks to achieve, for example a high nutrient density of vitamin A may be important for preventing conditions resulting from deficiencies of these nutrients (for example carrots and sight), whereas a relatively low density of fat or sodium (salt) is desirable to lower the risk of T2DM and its complications (for example high blood pressure), and reduce fat and weight gain. The following examples illustrated this point:

*“I bought vegetable oil actually. I use oil to shallow fry sometimes. Also, because of my weight I have to be careful with oil.” (Veronica, Interview, Care Worker)*

This also demonstrates that the participant was aware of micronutrients, such as vitamins, minerals and trace elements which are now recognised as important constituents of dietary intake. Vitamin E is associated with a reduced risk of chronic diseases, and sources include vegetable oils, soybean, sunflower, corn, seed oils, nuts, whole grain and wheat germ.

Some participants were also aware of macronutrients and this was confirmed by the way that they managed carbohydrates which represent the main energy intake:

*“With carbohydrate type of food, being West Indian I buy sweet potatoes, yam and sometimes green bananas if I can get them, because it is food that I used to eat in Jamaica. I would only eat one type carbohydrate at a time, just one,”*  
(Vera, Interview, Retired Professional)

This participant understood that she had to reduce her consumption of carbohydrates (high density) food as it might affect T2DM metabolic control. The statement also showed that she preferred traditional African food.

Moreover, another participant who used a ‘Disease Focused Approach’ demonstrated her awareness of health promotion dietary guidelines:

*“I choose food on the basis that it is something that will add to my five a day.”*  
(Liz, Interview, Lecturer)

Participants were also aware that consumption of fruit in large amounts was not good for T2DM metabolic control:

*“I bought bananas because it has potassium but is also slow acting carbohydrate and I mustn’t eat a lot of them as they will increase my blood sugar levels.”* (Maria, Interview, Assistant Social Worker)

Therefore, several participants demonstrated that an understanding of the nutritional value of food is vital for the management of T2DM by diet.

#### **4.1.4. Summary of Theme 1**

It is evident from the data that household composition had a significant impact on the participants' shopping behaviour. Two groups of food shoppers were revealed: those women who had children at home, who prioritised family commitments above their own needs and used a 'Family Focused Approach'; while the other group consisted of participants whose children had left home, or were without children, and those living in a single-person household who were primarily concerned about their disease and used a 'Disease Focused Approach'. With the exception of one participant, those individuals who adopted a 'Disease Focused Approach' also visibly planned their shopping, used a shopping list, paid by cash and were proactive in making in-store decisions. In contrast, one participant who used a 'Disease Focused Approach' and two participants who used a 'Family Focused Approach' practised unplanned shopping and were exposed to stimulus cues while food shopping. It may be that shopping for a family fostered a mindset that is not organised, or – more likely – a busy lifestyle (for example, picking up children from school, school activities and work) which might not leave time to use a shopping list compared with those participants whose children had left home and those without any children.

#### **4.2 THEME 2 – Choice and lifestyle**

The second theme, 'Choice and lifestyle' and its sub-themes, 'Culture and food preparation', 'Access to food and affordability', and 'Cultural influences on food choice' show how participants integrated knowledge about food from various sources to inform their lifestyle, thereby integrating theory into practice. The participants had

a strong preference for an African traditional diet. They tried to maintain the African traditional diet despite the many barriers they faced in terms of the limited availability, cost of food, and transport.

My data also confirmed that some participants' behaviour appeared to be driven not only by family, extended family and personal preferences, but also by environmental and economic considerations (for example, the neighbourhood where they lived and their income). Accessibility was a major feature among environmental factors, for example, the prices of food in stores affected where participants conducted their food shopping. Accessibility also had an influence on what type of food group participants could purchase, for example, in the case of two unemployed participants who, despite numerous strategies designed to budget their income, could not afford to purchase a healthy diet. Accessibility also affected the availability of culturally relevant nutritional information.

#### **4.2.1. Culture and food preparation**

The sub-theme, 'Culture and food preparation' illustrates how participants integrated nutritional knowledge and health promotion messages to inform behaviour. All respondents were aware of the importance of portion size and reducing their intake of salt, sugar and fat.

All participants disclosed that they had acquired specific knowledge, and cooking skills, relating to their self-care activities, for example, knowing how to cook food which is going to help sustain health. The following statement, from a participant

who used a 'Disease Focused Approach', demonstrated awareness of applying knowledge to practice:

*"I know when it's not quite healthy. Like I prepare food from scratch if I have more time and not in a rush, I obviously have the National Guidelines on salt and fat, so I think you need to think more about how you cook it to support your body system. I make my own bread using whole-grain flour even if it takes three hours." (Liz, Interview, Lecturer)*

This statement also revealed how the participant prioritised nutritious food, although it was time-consuming to prepare. She was willing to make the extra effort to meet her dietary needs. Furthermore, bread bought from a supermarket is known to contain more salt than most people realise (Food Standard Agency 2012). Cooking from scratch gave the participant maximum flexibility in the choice of ingredients, and thus allowed National Food Standard Guidelines on salt, saturated fat and sugar to be followed more rigorously, to help achieve a healthy diet (See Appendix 8).

Participants were also aware that micronutrients are affected by heat treatment in the cooking and processing of foods so they avoided over-cooking of vegetables and were careful about the type of cooking oil they used. The following excerpts show how participants managed healthy cooking:

*“I don’t tend to fry or cook my food. I tend to like most of my food raw, as a vegetarian. When I do use oil, it’s mostly vegetable oil or olive oil.” (Tamulah, Interview, Charity Worker)*

Another participant reported:

*“I think it all depends on the preparation, how you prepare your food, it is not only because you are diabetic. I now steam my vegetables not boil them.” (Maria, Interview, Assistant Social Worker)*

This comment from participant (5), who used a ‘Family Focused Approach’, indicated an awareness of food preparation and a change in her behaviour, shifting towards more of a focus on her T2DM.

Determining the correct portion size was reported to be problematic by most participants; they shared the same concern about maintaining a small portion size, particularly with carbohydrates at meal times:

*“You can eat most food but it depends on the portion, how much you are eating, because you think this one will not change into sugar, increase my sugar in the blood, but it will, maybe you have taken a lot of it.” (Maria, Interview, Assistant Social Worker)*

The above statement from a participant illustrated her awareness of portion size, which can be easily achieved in the home environment. Marginal participation by

family members provided evidence of the significance of home food preparation in contrast to eating out and family gatherings, to which I will now turn.

### ***Eating out, family gatherings and family support***

Since dining together is the most significant social activity among people of African heritage, dietary behaviour is highly vulnerable to social influence, as illustrated by the following excerpt:

*“They expect you to fill your plate, because it’s like respect when somebody offers you food, you eat and then go for more and more and they say, “She really likes our food.”” (Maria, Interview, Assistant Social Worker)*

Nevertheless, portion size was often a problem when eating out or at family gatherings. This was the case not only for participants who used a ‘Family Focused Approach’, but even for some participants who used a ‘Disease Focused Approach’ to manage their condition:

*“I think sometimes when I eat out; normally I eat out with friends and family because I prefer eating social food. So when I go out to eat with other people and my family, I tend not to worry about the portion size and eating healthily. I tend to lose control, I break the rules.” (Liz, Interview, Lecturer)*

While another stated:

*"I last ate out once in May. I went to a pub lunch and had scampi and chips which were deep fried and, I shouldn't really have it, for the fat content. It had lots of fat in it. I was with the church group." (Rita, Interview, Unemployed)*

These statements reveal tensions between knowledge and practice. The participants faced challenges on social occasions and ate more food, regardless of their awareness of the importance of portion size. However, this risk-taking behaviour may occur because T2DM remains as an asymptomatic disease for years before chronic complications develop, which may cause sufferers to overlook the importance of self-management as an ongoing process.

On the other hand, a participant who generally used a 'Family Focused Approach' demonstrated a determination to self-manage her condition:

*"We went to Nando's with my youngest son's football team. They were celebrating. There were platters of chips, chicken and they were all eating. Before I could also easily eat a plate of chips, but now I am watching what I am eating. And later, other people were admiring my salad." (Maria, Interview, Assistant Social Worker)*

This comment illustrated that good health outcomes can be achieved even when under social pressure.

Participation and support by family members can lead to stability and cohesion within the extended family network. One of the vegetarian participants, who used a



'Disease Focused Approach', was able to demonstrate a meal prepared for her extended family which consisted of a nutritionally balanced diet with higher intakes of fruit and vegetables. She described how she managed her extended family meal in the following statement:

*"If it's my family, I know what type of food they would like. So I choose for them the food they like. I will also cook vegetarian type of food, I do a fruit salad, because they are other people in my family that are vegetarian, so I will choose vegetarian type of food that I know that everybody would like." (Vera, Interview, Retired Professional)*

This reveals how she exercised her own dietary needs even at a family gathering. It also shows how an individual can use this opportunity to enhance family healthy eating behaviour by sharing what they consider to be good food for all. This is important because food is an integral part of family gatherings where positive health can be encouraged in a relaxed family atmosphere as members share stories, jokes and past experiences and essentially enjoy each other's company by participating in broad-ranging discussions.

However, not all families offer appropriate support and this was demonstrated by a participant who used a 'Family Focused Approach':

*Unfortunately recently we had a lot of take-away, MacDonald's and KFC, my husband's treat, which needs to be reviewed. It is difficult for me because my*

*children like to eat what I am eating, particularly my youngest daughter. My cupboard is full of sweets and all sort of food. I didn't buy them. My husband did. He has been doing most of the shopping lately. (Resy, Interview, Professional P/T)*

This showed that an individual's needs are not always acknowledged by family members. The participant revealed that her husband's attitude or lack of understanding of a T2DM diet made it difficult for healthy food choices to be achieved. Family members can therefore be unhelpful when they act as a barrier to achieving good metabolic control or weight management. Thus, a lack of participation by family members and inability to respond to T2DM dietary needs is a limitation to bear in mind.

On the other hand, a participant who lived on her own revealed that the absence of a family in her life led to poor nutritional habits and irregular meal patterns. This was demonstrated by a care assistant who expressed the difficulties she encountered with an irregular meal pattern:

*"Sometimes I have done a night then I don't wake up to eat lunch. I work two nights a week but again I am agency (staff), they call me whenever it's convenient." (Veronica, Interview, Care Worker)*

It seems that the pattern of shift work can be a contributory factor to meal patterns.

Another single participant, who used a 'Disease Focused Approach', also reported her experience of cooking for one:

*"I find cooking for one quite difficult and expensive because I always make a lot of food which I have to chuck out. So I keep eating." (Rita, Interview, Unemployed)*

Single-person households therefore face a challenge in terms of food choices that is different from family households. It is important for health professionals to be aware of these differences because people who live alone may require more support.

The family context has been found to underlie social support although the motive for this ranges from a sense of duty or love, to a lack of choice and concern. My data also demonstrated that social support from family and friends can be a positive experience, as articulated by three participants:

*"My youngest son is a footballer so all the time he will tell me to sit down on the carpet and he will show me different things to do for my body, to shape up my body." (Maria, Interview, Assistant Social Worker)*

Another participant also reported:

*"A friend of mine who is aware that I have been diagnosed with high blood sugar levels sends me some interesting links and I also have another friend*

*who sends me a link which I subscribe to called daily alerts.” (Tamulah, Interview, Charity Worker P/T)*

Meanwhile, another revealed that:

*“My husband normally does the food shopping with me. I tend sometimes not to get the very healthy food. I need someone to be physically there to help me. We also do the eight mile run on Saturdays.” (Liz, Interview, Lecturer)*

These statements revealed that families and friends can be sources of support if they have the factual knowledge about a chronic condition and how it should be managed. The emotional bonding from a son or a husband could result in supportive, caring behaviour. This familial orientation described above, which includes friends, reaffirms the collectivist nature of the Black African and African Caribbean communities (Chinouya 2003).

Unfortunately, some participants did not consider risks related to diet and T2DM seriously, such as weight gain, until they actually happened. Risks tended to be taken seriously only if they were perceived to be life-threatening or seriously compromising an individual’s quality of life. Two participants shared their experience in the following statements:

*“I have put on two stones. I used to be size 8 and size 12 is a big jump for me. I am trying to lose weight and you are going to eat the kind of food that would make a difference.” (Liz, Interview, College Lecturer)*

*“I did go to Weight Watchers but I didn’t stay, they put pressure on me because I was not meeting my target. So I ate more and more. Some people were losing weight but I wasn’t and so I stopped, for a while. I have started going again.”*  
*(Rita, Interview, Unemployed)*

These statements illustrate that effort and confidence is needed by individuals for effective weight-management. This supports Rosenstcock’s (1974) theory of health promotion as dietary knowledge, and how harm that is imminent may propel an individual to be proactive.

Complications of T2DM usually become more severe with age. The two vegetarian participants showed that they were prepared to self-manage T2DM on diet alone as long as they could:

*“And for about pretty much five years, I have used diet and homeopathy. I understand that if I take care, I have a good chance, so I am prepared to go down that path. I am also now a vegetarian, which means I need to see what proteins I am eating and understand my diet more. It would be beans or lentils or things like that. I eat a lot of vegetables and I have cut down on cheese, cut out fatty cheeses these kinds of things.”* *(Tamulah, Interview, Charity Worker P/T)*

Another vegetarian participant also highlighted her successful self-management of T2DM:

*“I managed to keep my sugar level down for quite a number of years, and it’s been keeping down quite a bit now, quite a lot now, because, (PAUSE) blood sugar level it’s about 6, it’s always been about 6 something. The most it’s ever gone up to is 6.” (Vera, Interview, Retired Professional)*

Perhaps this was possible for them because they did not have to change their food eating behaviour significantly, which is an integral part of maintaining weight management. In contrast, four other participants who also adopted a ‘Disease Focused Approach’ struggled at times with their food eating behaviours. They reported that they now followed a reduced meat diet to maintain a healthy weight. This was captured in the following statement:

*“When I was diagnosed I stopped eating meat for a while. I introduced myself to meat again because I was low on iron levels. I have only started eating white meat, fish and chicken.” (Liz, Interview, Lecturer)*

While it might be assumed that maintaining a healthy weight would be easier for those who used a ‘Disease Focused Approach’ than a ‘Family Focused Approach’, this was found not to be the case: maintaining a healthy weight was a challenge for most of the participants. The main difference between the two categories was that participants who used a ‘Disease Focused Approach’ seemed to be more proactive in adopting strategies to manage their diet and weight, whether or not these strategies were ultimately more successful.

#### 4.2.2 Access and affordability

Participants reported supermarket accessibility and food affordability as major factors affecting food choices. I use the term 'food environment' to refer to the accessibility to healthy food in the participants' neighbourhoods and the cost of food. All participants paid for their trips to the supermarket, whether it was in the form of fuel for their cars, a bus ride or getting a lift from a family member/friend. However, those women who walked reported being restricted in what they could carry and this in turn led to more frequent trips for smaller, higher priced food products because buying in bulk tends to be cheaper.

Transport provided access to a supermarket and affordable food but was an issue for some participants. Meanwhile, many supermarkets were located out of town leaving them with little choice but to buy food at local neighbourhood shops at a high cost. Often, neighbourhood shops did not offer a variety of affordable vegetables. This was more evident to some of the women:

*"I tend to find when I am shopping locally that price can be prohibitive in terms of fruit and vegetables, so I make a trip to the supermarket. I have found cheaper alternatives like the value range; I buy the value range just so we can have healthy stuff." (Resy, Interview, Professional P/T)*

Another participant stated:

*"I don't normally shop here, at Sainsbury; it is not my usual shop. It's too expensive. I'm on benefits. I don't drive and I'll have to catch the bus. I only*

*come here to buy vegetables, potatoes because my local shop doesn't have them. I go to my local every day. I go and buy my newspaper and then I pick up what I want to eat, milk, stuff like that. I only buy enough for two days."*

*(Rita, Interview, Unemployed)*

The local shop was seen by the participant as the best place for food consumed on a daily basis and not throughout the month. One of the participants stated that her local store did not stock vegetables. These findings confirm those of van den Horst (2010) and Larson et al (2006), who showed that families on low incomes or benefits, who reside in deprived areas, are hindered by their environment in maintaining a well- balanced and nutritious diet.

However, some participants were prepared to travel further out of town, relying on family for transport to access African/Caribbean food outlets in order to buy traditional African food:

*"I buy green bananas, pineapple, yams and things like that. I have to go out of town and my son comes and picks me up once a month. It cost too much so I just go once a month."* (Vera, Interview, Retired Professional)

Health professionals may lack awareness of the needs of Black African and African Caribbean communities and their food shopping habits, as well as the challenges this community faces. This may lead to their needs being overlooked and yet such knowledge may help to provide information and services that reach out proactively to these communities in general.



In contrast, a married participant without children who used a 'Disease Focused Approach' was not in favour of shopping at out-of-town shops catering for BME. She expressed this difference in the following comment about family and friends who go to London to buy African food on a regular basis:

*"I wouldn't because by the time you have paid for the petrol and the time it takes to get there, you might as well buy more for your money locally." (Liz, Interview, Lecturer)*

Clearly she felt that the costs were too high. Theoretically, availability of food could account for a large proportion of the food choice process. Participants mentioned that walking to shops prevented them from buying vegetables because they are bulky and heavy to carry, which also contributed to increasing the frequency of food shopping trips. However, despite having a car, one of the participants who used a 'Family Focused Approach' explained her strategy to incorporate physical activity into her food shopping once a week:

*"I try to do exercise, I like walking and what I do, I can get a car from my house to the supermarket, but instead I walk rather than take a car and then going back I take the bus because I am carrying some heavy vegetables, potatoes and cabbages, tomatoes and onions and some things. I take a bus going back." (Maria, Interview, Assistant Social Worker)*

So although transport can be an issue, choices can be made which promote an active lifestyle when integrated with a daily activity such as food shopping.

The affordability of food was mentioned by all participants regardless of socio-economic status. For example, all participants perceived healthy food as an expensive option. However, income as a barrier to increasing fruit and vegetable consumption was illustrated more vividly in the case of participants who were unemployed and lived in deprived areas of Norfolk and Suffolk. Two unemployed participants who used a 'Disease Focused Approach' stated that their low incomes led to a greater tendency to consume an unbalanced diet and low intakes of fruit and vegetables, for example:

*"I find myself buying a lot of fat type and starchy foods, breads because those things are normally cheaper and I get more for my money, things I would normally buy less of. So I tend not to properly consider the healthier options fruits and vegetables which are more nutritious for me." (Danya, Interview, Unemployed)*

This excerpt also demonstrates that the participant had knowledge and understanding of what type of food groups she should not eat in large quantities (carbohydrates) in order to successfully manage T2DM. However, due to a limited income, she sometimes looked for cheaper alternative food to avoid hunger rather than prioritising the disease. This then leads to over-nutrition due to excess energy consumption, resulting in weight gain and obesity. Another comment from the same participant (Danya) showed how she struggled with weight-management:

*“I find losing weight difficult. I know what to eat to be fit and healthy, but whatever I have for lunch, which is mainly bread, I tend to have in the evening. It’s not necessarily different. So basically, I don’t have the money, I don’t have the options. ” (Danya, Interview, Unemployed)*

Therefore it is often difficult to ensure that a healthy meal becomes a priority for an individual over the disease. Although the participant was aware of the benefits of a nutritious diet for her condition, she was unable to choose her preferred food on a limited budget.

Thus, those with insufficient resources are restricted when purchasing food of their choice. Another unemployed participant, who adopted a ‘Disease Focused Approach’, confirmed this view:

*“I tend not to have weight at the forefront of my mind when I am shopping; it’s more what I can afford. Affordability is an issue with me. Before when I was working, I could afford to buy quality food, I also had a gym membership.” (Rita, Interview, Unemployed)*

This reveals how financial means constituted a barrier to the participant’s preferred healthier lifestyle.

In contrast, another participant who also adopted a 'Disease Focused Approach' but who was employed and could therefore afford to make a healthy food choice expressed her ability to exercise this choice:

*"I tend to buy wholemeal flour, wheat flour, brown rice and pasta, again it is quite expensive food but it is good for the fibre. In a way healthy food is a very expensive option." (Liz, Interview, Lecturer)*

The statement also demonstrates how the participant was prepared to pay more for a healthy diet. Furthermore, she also perceived the quality of natural produce as important when choosing food:

*"I will go for that brand, Innocent smoothies, it's a natural product and they are selling two for £4, there are more expensive here but I go for the quality and these suit me better." (Liz, Interview, Lecturer)*

This excerpt demonstrates how the cost of buying healthy food for the health conscious becomes increasingly expensive, pricing out poorer consumers. Pricing interventions such as subsidising the cost of fruit and vegetables have the potential to increase consumption.

#### **4.2.3 Cultural influences on food choice**

Culture has a strong influence on the diet preferred by the participants. The food they selected was also the food that formed their regular dietary pattern in most

households and therefore was subject to similar food choice influences. This provided answers to my second research question: What are the importance of culture, environment and knowledge as key influences on food choice in this target group?

A participant who used a 'Disease Focused Approach' showed how the advice she received from an NHS nutritionist did not match her culturally preferred diet.

*"I became aware that the diet did not match up with my understanding, was quite different from our culture. My visit to the nutritionist who gave me some information about diet, but it was not comprehensive enough because she just talked about how much rice to eat and portions and I just could not get my head around it because the diet advice I got was not cultural specific enough for me." (Tamulah, Interview, Charity Worker P/T)*

Another participant who adopted a 'Family Focused Approach' also revealed how important it was for her to have an African diet

*"I buy sweet potatoes to have as a complement with the meal. It's nice to have as a staple but I don't just buy it all the time. That's what I have grown up with, it's heritage food. The food choices I make is familiar, my mum will have bought some sweet potatoes. I only bought the sweet potatoes because they were on special offer. I couldn't afford them at any time." (Resy, Interview, Professional, PT)*

While the statement above disclosed the value of traditional food and the satisfaction it brings, the purchase of such items could be hindered by a lack of financial means.

Some participants in my study reported that men rejected beans and requested meat as part of a main dish because it is seen as a sign of 'masculinity' in the African and Caribbean cultures.

*"I think most African men like meat. They won't eat beans, they like meat even when you tell them it has the same thing as beans, proteins. They like their meat. You lose your status if you serve an African man beans and not meat!" (She laughs). (Maria, Interview, Assistant Social Worker)*

This perception from a participant who used a 'Family Focused Approach' seemed to allude to the participant's view that meat consumption is considered a status food in Black African culture, which may increase familial self-esteem and is seen as part of masculine identity by African men. Since men's views are not represented in my study, it would be interesting to know whether African men still hold this view as strongly as the women in my study seemed to think (therefore leading them to provide meat in quantities that could compromise their own health). The implications of high meat consumption should be regarded as a concern, since red meat intake has been positively associated with various types of cancer, high blood pressure and metabolic syndrome (Cross et al 2007). The participant's statement shows a disconnection between diet and health relationships due to cultural factors within Black African and African Caribbean communities.

Moreover, it was interesting to note that some participants regarded food from their home country as a preferred choice because it was organic and therefore seen as providing a healthy diet:

*“I grew up in Trinidad & Tobago where we had vegetables around the home. We had fruit trees like bananas, oranges and avocado. We never bought any fruit or vegetables. You could just go outside and pick some cucumbers, tomatoes and pak chow. We reared our chicken. So there was a great sense of richness in the food I had then. So I tended to eat healthier.” (Danya, Interview, Unemployed)*

Another participant reported:

*“I go to the African or Indian food shops for most of my fruit and vegetables. Most of our food is organic and I like to continue with the African food. So we have some Indian shops that sell African food. It is expensive, but we can buy some African food there.” (Maria, Interview, Assistant Social Worker)*

These statements highlight the importance of health professionals having knowledge and awareness about how strongly black African and African Caribbean people are rooted in a particular food culture and not the foods *per se*:

*“I am vegetarian because I am a Seventh Day Adventist. We don’t eat meat. Where I grew up, in Jamaica we lived by the sea and had plenty fish for protein. I*

*don't eat meat. My family, we grew our own vegetables. We had plenty fruit trees, we never buy any, and we had our own.” (Vera, Interview, Retired Professional)*

Therefore, it can be seen that faith plays a crucial role in food choice for this participant. Cultural, religious and medical issues, for which treatment is sought by Black African and African Caribbean communities, are often interlinked. These issues may influence which foods are consumed and whether individuals contact health services. Therefore, if health professionals are to become more aware of cultural differences, they should start by asking patients how their needs can be met in an appropriate way during initial diagnosis assessments.

#### **4.2.4 Summary of Theme 2**

The theme 'Choice and lifestyle' acts as a reminder that the cost of food prevented some participants from following a healthy diet, particularly those with limited financial means. Another factor that influenced food choice and was reported by most participants was access to food in local neighbourhoods, which did not always stock fruit and vegetables. This meant that participants had to travel to supermarkets which involved transport costs. Moreover, culture was highlighted by all participants as the key influence on food choice, thereby answering my second research question. This was demonstrated by most participants as they bought African types of food and some were prepared to travel further out of town to buy food in African food outlets. Vegetarian participants reported a healthy diet and were more able to demonstrate that they had managed to control their T2DM by diet. Theme 2 also



helped to fulfil my first objective: to explore key factors that influence food choices and how they interact to inform decision-making.

### **4.3 THEME 3: Interface with health services**

Theme (3) draws together issues related to how the participants viewed the current National Health Service provision for T2DM care. Although participants revealed differences in the ways they expressed their dissatisfaction, there were obvious commonalities between the women which centred on overall dissatisfaction with the health service. People of Black African heritage, like other BME groups in general, are used to respecting their doctors as it is considered discourteous not to do so. However, this can affect the interaction between a physician and patient. For example, even though a patient might not agree with advice given by a doctor, they would simply remain silent. Instead, they would later avoid hospital appointments, not follow treatment, and take the opportunity to use home remedies or visit faith leaders for healing prayers. However, when a trust relationship is established, advice from a doctor becomes very persuasive, leading to a positive influence on healthcare behaviours (Helman 2004).

The theme of 'Interface with health services' is presented in four sub-themes: 'Self-management'; 'Collaborative pathways of care'; 'Raising awareness'; and 'Culturally appropriate service provision'. All participants expressed a common view that they needed support in coping with the diagnosis, culturally appropriate nutritional interventions, weight management and mental health advice, and service provision which offered them choice and control in their lives. This section responded to

objective 2 which was to identify challenges to dietary change and interventions to support people of Black African heritage with T2DM. The role played by healthcare professionals was perceived as central to dietary change. This included establishing sustainable T2DM awareness campaigns for individuals, their families and the Black African and African Caribbean communities generally. Participants highlighted areas of concern related to being treated with respect, feeling safe and supported, having their cultural identity acknowledged and the need for healthcare professionals to behave with cultural sensitivity.

#### **4.3.1 Self-management**

Participants were aware that lifestyle changes are part of the process of T2DM management. They acknowledged the role played by healthy eating and physical activity in order to effectively manage their weight, thereby halting the development of T2DM complications. Yet, the lack of physical activity among the women was apparent as six out of eight reported that they detested physical activity and preferred only nutritional intervention to manage T2DM.

Henshaw (2006) defined self-determination as a 'dynamic right' and an empowerment approach that seeks to increase autonomy in decision-making about health. The right to self-determination can be illustrated by the participants' decisions to choose a pathway through which to manage diabetes by nutrition. This was captured during the interviews, as demonstrated by two participants:

*“I am firmly of a belief that Type 2 can be controlled with care, diet and exercise. If these are the two criteria, then I would rather not enter the path of medication. You know you use food as part of the recovery process, so I decided to look into that. When I was diagnosed with high blood sugar levels, I needed to avoid having medication which became part of my healing.”*  
(Tamulah, Interview, Charity Worker P/T)

Another participant said:

*“Health is a priority but I think I know what I need to do to get what I want to be. I don’t need someone to tell me, because I know what I am supposed to be doing, so I didn’t carry on with that advice about medicine as an option.”* (Liz, Interview, Lecturer)

Moreover, another participant decided to resort to the traditional practices that she valued, based on knowledge from her home country, as demonstrated by the following excerpt:

*“My upbringing back in the West Indies, we rely on natural food to help and sort of cure ailments. So, when you are faced with a report that you are suffering from a sort of threat, like diabetes, you automatically resort to what you know.”*  
(Danya, Interview, Unemployed)

This demonstrated how a participant took proactive steps to manage her T2DM, by eating ‘natural’ foods. Black African and African Caribbean people may use

complementary medicine, traditional medicine or folk medicine but this needs to be recognised alongside a doctor's advice or from a biomedical perspective (Bird, 2004). For example, a diabetic patient might hope to be cured and might believe that traditional remedies will take care of metabolic control, leading them to ignore the importance of practising self-management.

However, not all participants were as confident in their self-management. Some expressed a lack of confidence which they attributed to not having sufficient competence in following a strict diet after diagnosis, for example:

*"I have done every possible diet you can think about. I have a strange relationship with food. At the moment I'm probably, a size 16. I can't put it into words right now." (Rita, Interview, Unemployed).*

Another participant reported that because she felt healthy, she had not attended a six-monthly appointment for blood glucose monitoring for the past two years. This was captured in the following comment:

*"I would go see my GP if I had a hypo, like some diabetics have a hypo, they faint. But I don't faint, I am ok and I still eat sweet things sometimes, because I don't faint I won't go until that happens." (Rita, Interview, Unemployed)*

This statement raised issues about the participant's ability to self-manage T2DM and the danger of minimising the risk posed by T2DM and its long-term effects. The participant was aware that she needed to have her blood glucose levels monitored at

six-monthly intervals but still chose to wait until she got ill before seeing her GP. There could have been various reasons for her reluctance to access health services. Rita voiced her dissatisfaction with the attitude of staff at the local diabetic clinic:

*“I was feeling a lot thirsty, drinking a lot of water and had blurred vision and I was going to the toilet a lot, urinating a lot. I became very ill over Christmas and went to see my GP. (The doctor) said I shouldn’t wait because they had the urine test and my blood sugar level was too high. The diabetic clinic staffs were very rude, they said it wasn’t an emergency and they were only handling emergencies because it was Christmas Eve and I wasn’t an emergency and didn’t need insulin, that my local GP could have handled this.” (Rita, Interview, Unemployed)*

The participant clearly described the usual symptoms of T2DM, and although it turned out that she may not have been as ill as her GP initially thought, her comments illustrate how insensitive professional attitudes can lead to dissatisfaction with NHS services. Previous experiences of being made to feel unwelcome may deter people from approaching services, thereby compromising compliance with treatment.

Healthcare staff may not always be aware of the barriers faced by their patients or may not know how to address them. One statement highlighted the problem of equity issues in local NHS diabetes service provision:

*“A universal service is about equal access only because there is a standard provision that all people have to accept, it does not take into account what*

*special needs people may have, and it is not flexible enough and therefore creates a particular kind of inequality - a kind of inequality that most Black people, like me have experienced when accessing health services.” (Danya, Interview, Unemployed)*

Self-management behaviours require environments that recognize that service users have different needs. Access to T2DM should also support autonomy and confidence to promote adherence to health regimes and positive health outcomes. It might be the case that self-management in this population group would remain ineffective if there is a lack of access to culturally appropriate nutritional interventions. Although some health professionals are sensitive to cultural needs, health services themselves also need to be designed to be culturally appropriate as far as is practical.

#### **4.3.2 Collaborative pathways**

The individualistic approach to care in Western countries might not necessarily support T2DM self-care for Black African and African Caribbean communities. Furthermore, cultural issues and how to address them are often obvious to people who possess a culture that is different from that of the health professionals. This may be problematic if they have a customary practice regarding care of the sick (Lawrence et al 2007). For example, a nurse in the UK shows respect for the patient’s culture by establishing rapport, and this requires that care is managed individually, confidentially and not collectively. By contrast, family members of patients from Black African and African Caribbean communities would expect to be

included in caring for the sick person. Despite the potential problems, the importance of social support has received much attention in T2DM care (Whittemore et al 2002, Gallant 2003). Patients' self-management behaviours appear to be susceptible to the attitudes of health professionals, whether these are principle-oriented or involve using their professional power, and this may lead to a positive or negative outcome.

My study showed that T2DM within Black African and African Caribbean communities was not picked up as early as it could be. This was a view commonly held by all participants, as illustrated by the following two excerpts:

*"I had been to see my GP and he said I was just working too hard. Then my sister in Africa rang me and told me she had just been diagnosed with type 2 diabetes. I asked for the symptoms and it was the same. So I went back to see my GP and asked for a blood sugar test. That is how I found out." (Maria, Interview, Assistant Social Worker)*

*"I was feeling really ill for some time and I thought I could be pregnant. I decided to go to the GP and they did lots of tests and thyroid test and they couldn't find anything. They were quite worried about my blood levels so they asked me to do a diabetes test, the fasting one. I think I waited for 2 weeks for the results." (Liz, Interview, Lecturer)*

These statements illustrate the late presentation of T2DM in the Black African and African Caribbean communities. This late presentation may be due to a number of

factors, including the attitudes of doctors and a lack of awareness of T2DM among people of Black African descent. Thus, healthcare professionals should strive to understand how they can work with these communities to promote better access to health services.

However, lack of access to services and support that can reach a significant proportion of people at risk of T2DM could also be another issue, as the following statements confirm:

*“There was no support whatsoever. Even when the blood tests results came back, you have to ring up and ask what it is, which means if you don’t call, you wouldn’t be able to know what happened.” (Liz, Interview, Lecturer)*

*“What is lacking is follow-up in terms of how this person is getting on three or six months later. A quick phone call or a letter or just probably send information to people will be helpful, people are afraid of knowing their results. I was afraid; there is also a fear of the health service among our people. I think contact will help to calm that fear of the health system.” (Danya, Interview, Unemployed)*

These statements show that participants were dissatisfied with the lack of follow-up support offered by healthcare staff which they viewed as an important component of T2DM care.

The perceived lack of support following blood test results which was highlighted by the participants seemed to have caused some of the participants to adopt negative



attitudes towards the healthcare system. This can cause isolation and creates fear and mistrust of the health service. It also reduces and delays engagement with health services and can result in increasing the 'burden of care' that families experience as a result of long periods of untreated illness, causing tremendous stress to the T2DM sufferer and their family, as expressed in the following statement:

*"Health is a priority but I don't have belief in the health system in a way, because I think they don't really ask." (Liz, Interview, Lecturer)*

By providing health information and psychological support, healthcare professionals play a vital role in comforting people during their first experiences of being diagnosed with a chronic disease. One of the most recent Diabetes UK recommendations is that all NHS Diabetes services should have a systematic recall system. This would ensure that people with T2DM receive an annual invitation for a check-up, which is an essential component of T2DM self-management (Diabetes UK 2013).

Support from health professionals for individuals living with T2DM is important for psychological well-being, as food can be used to modify temperament and mood. Emotional eating is the practice of consuming large quantities of food, usually 'comfort' or junk foods in response to feelings instead of hunger (Ouwens et al 2009, Strien et al 2010). In my study, half of the participants recognised that mood had a strong influence on their diet and weight management, which in turn caused them some stress:

*“I was bullied as a kid, mainly because kids pick on people who are overweight. Whenever I am upset I would eat, and eat more. I did lose it but I have put it on again. It is a constant struggle and it does get to you when you are down again.”*

*(Liz, Interview, Lecturer)*

Another participant stated:

*“I do feel that they could work with me as an individual, I would have been helped better. It puts a lot of stress, strain on me to make the choice. I have to be very clear and committed to do that, eh, which I feel I am.”* (Tamulah, Interview, Charity Worker P/T)

These examples show a need for a holistic approach to diabetic care and weight management. This means that individuals should have proper assessment, following on from diagnosis, to identify their needs. They are likely to need a range of practical and emotional support measures to equip them to live with the physical, social and practical aspects of T2DM, for example, weight management and counselling/psychological support should be part of the care package.

Moreover, a support group was seen as playing an important role in promoting a sense of relatedness: people are more likely to adopt values and behaviours promoted by those with whom they feel connected and in whom they trust:

*“I think in sharing with people who are or have a similar illness that sort of widens knowledge. For example last week, somebody who has diabetes in a big way was telling people what they can do.”* (Danya, Interview, Unemployed)

This showed how the participant valued support from someone facing challenges that she could relate to. The participant preferred this to come from someone who shared a similar ethnic and disease background, in order to raise awareness and foster a sense of empathy which could motivate other people to try to maintain a healthy lifestyle.

Another participant also revealed how she lived in isolation and fear because of her T2DM:

*“I am going to try... to change my diet. I know what happened to my Mum. When we were kids, I and my sister used to find my Mum on the floor in a diabetic coma. We would ring for an ambulance. I don't keep in contact with anybody. There is no support out there for me.” (Rita, Interview, Unemployed)*

This statement illustrates how the participant expressed her fear of T2DM and its complications, as well as highlighting that it is important that health professionals should not make assumptions about BME communities (for example, that ‘they all look after each other’). Although there is often support available within BME communities, there may be instances where this does not happen, especially with the growing number of single-person households. Therefore it is important that physical and social support from health professionals should be tailored towards individuals with T2DM and their families, including extended families. This approach is also effective in raising awareness, as I discuss in the next section.

### 4.3.3 Raising awareness

Part of raising awareness requires health professionals to focus on the individual with T2DM, but also to include family, extended families where they exist, and people from Black African and African Caribbean communities more widely. This helps to tackle the stigma of T2DM:

*“I think perhaps more Black women have diabetes but they never say. They don’t want people to know because of the stigma. You know most of our women are big and they don’t want to do exercise. I try and tell them how they should look after themselves and not end up like me, a diabetic.” (Maria, Interview, Assistant Social Worker)*

The above comment shows that while supporting privacy and confidentiality is important and should not be compromised, health professionals should also find acceptable ways to raise awareness of T2DM among Black African and African Caribbean communities.

One participant demonstrated limited knowledge of local support groups:

*“I would say there isn’t any support here. I don’t know where individual support there is for various ethnic groups here... I haven’t observed any, maybe a poster, or a flyer or helpline at the hospital giving information to Black people on diabetes awareness and diet.” (Resy, Interview, Professional P/T)*

Raising awareness of T2DM is also important because it offers health professionals the opportunity to explain more about the disease. The statement below demonstrated the need for health professionals to disseminate information and increase knowledge about some aspects of T2DM among Black African and African Caribbean communities.

*“When this was picked up, I was offered the chance to talk to my doctor and I discussed it with him and he said, well it was just bad luck, basically. I didn’t show the usual tell-tell signs, I was not fat. They measure your waist, as if that’s going to give them an idea about what’s going on inside your body, especially as the waist wasn’t measured in relation to a previous time, if my waist might have been measured then the differential will give them some indication of what was going on, but they just measure your waist.” (Tamulah, Interview, Charity Worker P/T)*

There may be a lack of knowledge of some aspect of T2DM diagnosis and care, for example, the reasons for taking waist measurement and Body Mass Index (BMI). People may need to know why it is necessary and how it may vary with ethnicity (See Appendix 13). It is therefore important to raise the level of awareness by routinely disseminating information about prevention and support services. This could be achieved by using diverse and targeted media in community languages and including radio and television channels specific to Black African and African Caribbean communities. This responded to objective 3 of my study which explored how health professionals could obtain information to develop culturally appropriate nutritional interventions.

However, raising awareness of T2DM requires health professionals to have a good understanding of Black African and African Caribbean communities and their cultural needs in relation to nutrition. All participants shared the view that professionals should develop a better understanding of building working partnerships and communication channels with Black African and African Caribbean communities with T2DM. This was viewed as an essential requirement to bridging the gap in awareness.

Participants aspired to have more choice and control in their lives and were positive about being involved in the design and delivery of the service they required:

*“It’s about tapping into organizations that are already engaging with BME communities that will have a greater presence in the communities.” (Danya, Interview, Unemployed)*

Another participant stated:

*“I would like to see a bottom-up approach ... (that) let people take the initiative themselves.” (Liz, Interview, Lecturer)*

The involvement of Black African and African Caribbean communities in planning and developing T2DM services is essential to ensure that the services respond to culturally specific needs. Interventions that target specific communities should involve them when developing the educational component of public health, in order to incorporate their cultural needs, such as culturally appropriate cooking classes:

*“I grew up eating cultural food like rice and chick peas, I miss that. So I try to cook a mixture of West Indian and English.” (Resy, Interview, Professional)*

Another participant reported:

*“I grew up in Tobago & Trinidad and coming to England is not the same sort of diet, so that sort of made a lot of difference in my diet.” (Danya, Interview, Unemployed)*

And another participant explained:

*“I go out to a local Caribbean kitchen club every Wednesday... I don't know how to cook Caribbean food like my mother used to. I need to stay in touch with my roots. They do green bananas, sweet potatoes, cassava and yam. I would go to a cooking class if someone can help with that.” (Rita, Interview, Unemployed)*

These statements showed how participants felt they could benefit from such culturally appropriate nutritional interventions, which could be a good starting point for the self-management of a changed lifestyle. This was also true of awareness campaigns and access to information and culturally appropriate literature and advice:

*“They have language support and translated diabetes information for Asian people but not so much for ... Black African people. I think most people think*

*Type 2 is common among White people, Asians and Indians. That's what the adverts show." (Maria, Interview, Assistant Social Worker)*

Another participant commented:

*"She (NHS Dietician) gave me a diet sheet, but did not ask me what type of food I eat. She just talked to me about different food that I shouldn't eat. Things I already knew like sugar and ripe banana but did not tell me what I should eat. I mean I needed to know what I should eat, you know." (Vera, Interview, Retired Professional)*

Working in partnership is key to bridging gaps in awareness and to helping people access and use services. This would suggest that organizations, individuals and communities should find ways of sharing awareness and expertise that complement each other to improve their understanding in addressing Black African and African Caribbean needs.

Two participants expressed their views of working in partnership:

*"Health professionals could start by working with the communities through their leaders. Most BME communities have leaders although not all have offices. So it might be a challenge but start with those who already know their communities and know how to meet them. I think leaflets in different languages should be left at community centres, mosque and BME charities where people can pick them." (Veronica, Interview, Care Worker)*



Another participant stated:

*“I think they should ask about faith. They need to know how to engage with members of our community and most faith groups run community projects and normally have large community membership. I help run groups in my church and I see a lot of black and minority people who come there on a regular basis.”*  
(Vera, Interview, Retired Professional)

These statements showed that effective ways of working across organizations and communities are needed to make access to services a reality for Black African and African Caribbean communities.

Another participant suggested innovative ways of reaching out to people such as effective use of technology and outreach work, as described below:

*“I would say internet Facebook will do a good job. Lots of people use Facebook and it’s a good place to discuss things for people. You could try food shops such as Global Fruits where I know a lot of local ethnic minority people go to get their ethnic food from. They could do outreach work.”* (Resy, Interview, Professional P/T)

Therefore, there are more ways of engaging with Black African and African Caribbean communities which are perceived to be appropriate to improve communication. This in turn could facilitate better self-management of T2DM for the

participants. Health professionals working with T2DM sufferers from Black African and African Caribbean communities could use these methods to improve communication channels. This could offer a better way to reach those who do not engage in either community events or church groups.

Moreover, there was a common perception among participants that focusing on good communication between health professionals and Black African and Caribbean communities may lead to effective self-management and help reduce the stigma of T2DM in these communities and the social pressure experienced at social events for those living with diabetes.

All participants reported their experience of living with T2DM in the family. This is illustrated in the following excerpts:

*“My mother is also diabetic, type 2 and was diagnosed when she was 35 years old.” (Resy, Interview, Professional)*

And another participant said,

*“My mum was type 2 diabetes. Other members of her family have also had diabetes. So I was quite aware ...that, it’s in the family, and that I may have it you know.” (Vera, Interview, Retired Professional)*

Current attitudes among health professionals in their efforts to make self-management more effective have involved focusing on treating T2DM nutritional

interventions from the perspective of the individual. However, an approach that takes into account family history could be beneficial.

#### 4.3.4 Culturally appropriate service provision

The key issues identified by participants were a gap in public health nutritional interventions and a lack of cultural sensitivity in local T2DM service provision. One participant recalled the unsatisfactory service she received:

*“In terms of my illness I did not get any support. We need support from a District Nurse, but to actually get the GP to do the blood test was quite a challenge as well. So if people don’t push for services they could easily be ignored. There is no information and the family might end up doing quite a lot.”*

*(Liz, Interview, Lecturer)*

The key issues raised by participants to improve diabetes services in the future were early detection and support from health professionals following a diagnosis. The following excerpt illustrates this point:

*“They offered (medication) to me too quickly. As soon as I was diagnosed they offered me, metarformin. Basically my own feeling was that, there wasn’t any support. I don’t think they could see how else to support people like me who just don’t want to take medication and forget because medication causes complications too.”* (Tamulah, Interview, Charity Worker P/T)

This statement showed that there was a lack of engagement by GPs in terms of offering T2DM information and other forms of therapy rather than medication. The

patient preferred to have support to manage her T2DM by diet but this option was not offered by her GP. Yet much can be done if T2DM is detected early, and if people are given information and support tailored to their needs.

The attitude of several doctors with whom participants made the initial contact was viewed by some of them as unsatisfactory and in need of addressing. For example, they felt that GPs should provide further information:

*“BME people don’t have trust in the mainstream services. They either have a fear of the services or don’t know how to access them. When I go to my GP, I have always been able to make an informed decision about what I need to eat. So in terms of advice given, they just tell you what you already know and how does that help? I try and find out more.” (Liz, Interview, Lecturer)*

This statement also showed that the participant viewed the attitudes of health professionals as unhelpful, discouraging, and lacking in support. This could be viewed as a barrier to accessing mainstream health services which participants require to manage their T2DM successfully.

Fortunately some participants were assertive and able to communicate with their GP, and, in contrast, those participants who were assertive were eventually supported by their GPs, such as the two vegetarians who used a ‘Disease Focused Approach’. Both these participants also demonstrated successful self-management of T2DM by diet for over five years. This is illustrated in the following statements:

*“Fortunately my doctor is now very good. He does understand that I am willing to try, and he respects my decision. He rings me when my blood glucose test appointment is due and when he gets the results in. We discuss it but he understands that I am not prepared to take any medication.” (Tamulah, Interview, Charity Worker P/T)*

Another participant reported:

*“He said, because you found out early, then you don’t (need to use medication), I will just let you control it by diet, if that is your choice. That was ten years ago.” (Vera, Interview, Retired Professional)*

These statements from participants illustrate that treatment outcomes can turn out to be successful if GPs are prepared to be supportive. Communication with the individual to determine their preferred medical intervention seems to have been the key factor in developing a positive doctor-patient relationship.

However, physical activity at the recommended level was not well incorporated into their lifestyles by some participants. The following comments from participants illustrate that there was good understanding of the need for physical activity but that they held contrasting attitudes towards participation in physical activity:

*“I do a lot of work in my church, I walk, I run, I do gardening a lot.” (Vera, Interview, Retired Professional)*

By contrast, another participant commented:

*“I haven’t got ... motivation. I need to run with a group of friends or go onto a tread mill in a gym.” (Rita, Interview, Unemployed)*

Some women identified obstacles that made it difficult for BME females to fully access physical activity. These included cultural or religious sensitivity, and one participant raised a gender issue related to physical activity and body image:

*“It needs to be closed because some women don’t want men; they want a women-only environment. They don’t want to show their body parts.” (Resy, Interview, Professional)*

This seems to suggest that the situation cannot be changed without innovative approaches and a sustained effort in terms of community participation promoted by healthcare professionals.

In addition, unemployed women also found the cost of gym membership prohibitive:

*“It has to be free; most BME people do not want to pay, particularly if they are on benefits. They cannot afford it.” (Danya, Interview, Unemployed)*

One participant preferred group activities:

*“I think activities should be done in groups because I think groups are a really good way for people to do things together. So, either group walks, or organised*

*walks, or organised exercises, whether the women are doing karate or dancing.”*

*(Tamulah, Charity Worker P/T)*

While participants might prefer organised or group walks, only two participants seemed to meet the recommended guidelines for levels of physical activity. The rest had knowledge about the dangers of an inactive lifestyle and how it contributed to obesity which is a major risk factor for T2DM. However, physical exercise was regarded as difficult for some:

*“I couldn’t be bothered with exercise; it isn’t effective enough for my lifestyle I just eat less food.” (Resy, Interview, Professional P/T)*

Another participant concurred:

*“I don’t enjoy exercise, that side of being healthy than I prefer diet, I only did exercise when I was getting married because I wanted to lose a lot of weight. I feel that it’s quite a burden, my husband does the 8 mile with me on Saturday, so I don’t really, I would rather not if it was just me.” (Liz, Interview, Lecturer)*

These statements seem to show that physical activity was the least preferred means of self-management of T2DM metabolic control by the participants.

#### **4.3.5 Summary of Theme 3**

The key issues identified by participants with regard to the interface with health services were a gap in public health nutritional interventions and a lack of cultural

sensitivity in local T2DM service provision. My data revealed that participants preferred culturally appropriate nutritional interventions and would like less emphasis on exercise. Supportive environments that could promote weight management and appropriate information through targeted literature were also identified as important by participants. Participants recommended culturally appropriate support groups for sufferers and their families. Some participants reported that their GPs had failed to make a diagnosis and some individuals had to request a blood test for T2DM. Poor or delayed access to services may have implications for T2DM self-management and this could lead to complications and higher mortality risks in the long-term. My data also showed that participants who had improved communication with their GP reported positive health outcomes. Participants proposed several suggestions for diabetes service planning and development that could lead to improved future 'cultural sensitivity' among health professionals. The proposed approaches included effective engagement with individuals, families and BME community leaders. Cultural competence was also proposed, which involved health professionals attending cultural awareness training delivered in partnership with Black African and African Caribbean communities.

#### **4.4 Summary of Chapter Four**

In the context of the above findings my research questions have been addressed. The areas of highest importance include the similarities between participants' views on how culture informed their ultimate food choices. These findings also demonstrated that the African diet was the preferred option and physical activity was the least preferred option for self-managing T2DM. However, participants' opinions



differed in regard to how much they emphasized culture and the experience of how they self-managed T2DM by diet in the family and extended family context. Six participants adopted a 'Disease Focused Approach', while two participants adopted a 'Family Focused Approach'. This categorization impacts on themes 1 and 2 more than theme 3. My findings also revealed that communication channels between health professionals and Black African and African Caribbean communities affected by T2DM need to be improved in order to implement acceptable and culturally appropriate nutritional interventions. This would suggest a partnership approach to addressing public health nutritional interventions and T2DM in these communities.

## **Chapter Five: Discussion**

### **5.0 Introduction**

The purpose of this chapter is to draw together and discuss, in relation to the literature, the key findings from my study. I begin by comparing and contrasting the views of the participants from the two perspectives, namely the 'Disease Focused' and the 'Family Focused' approaches, used within the study to show their points of divergence and congruence.

### **5.1 Approaches to T2DM Management among Black African female participants**

There was a marked difference among the women participants in the way they managed their T2DM, with reference to the 'Disease Focused' and the 'Family Focused' approaches to disease self-management by diet. This formed the main contrast between the two groups of participants and answered the first research question: What are the main factors that influence food choice in women of Black African descent diagnosed with T2DM whose condition is managed by diet?

The experiences of the six women who did not have children living at home are consistent with the meaning they attributed to self-management of T2DM by diet. The key to understanding their experience is through the 'Disease Focused Approach'. My study showed that the women prioritised their T2DM and this helped them to successfully self-care for their condition. Amongst the six women, the two

vegetarian women who used a 'Disease Focused Approach' were the most successful at self-managing T2DM by diet, having done this for more than five years.

On the other hand, a 'Family Focused Approach' was adopted by two women participants who lived with their young children and husbands. These women prioritised family needs in T2DM self-management rather than their disease. The significance of family food shopping being done by women showed how important it is for public health professionals who emphasise individual needs within clinical care to recognise the daily coping strategies that individuals use in different situations, for example, at home with family.

The implication of this finding of the two groups of participants is that health professionals need to consider carefully the social context of their patients and clients – in particular, my study shows the importance of the household. On the face of it this would appear to be an issue which transcends culture.

However, there were some examples where the two groups of female participants showed similarities in their experiences of self-managing T2DM. The study showed an understanding of the key components of constructive self-management of T2DM, which are dietary knowledge and physical activity. However, most did not achieve the recommended levels of physical activity. Although this was a small sample, it is still an important finding.

### **Culturally appropriate diet**

A similarity across my findings was illustrated by the impact of migration which remained in the consciousness of the women as they demonstrated the importance of a culturally appropriate diet. The research question was designed to explore the main factors that influence food choice in the target group. My study showed the importance of culture, environment and knowledge as key influences, and suggested that culture is the most important factor.

All the female participants were born in either African or African Caribbean countries although two of them came to the UK at secondary school age. As mentioned previously in Chapter Two, the Black African diet referred to in my study consists of the type of food that is found in the Afro-Caribbean and most African countries and, although it is readily available in BME food outlets, this does not represent the whole spectrum of food from Africa. It includes food such as mangoes, water melons, pineapples, greens, yams, plantains, sweetcorn, okra, squash, sweet potatoes, etc. My study illustrated that the comprehensive base of their similarities in self-managing T2DM was grounded in a cultural identity. A common theme that emerged from the women was an attachment to their African heritage in terms of how they selected their food at local supermarkets and African/Caribbean food outlets. Moreover, they perceived their Black African heritage identity through food, particularly at family gatherings and social events. The participants recalled memories of a natural form of social support from their communities which meant that, although it had changed over time, they attempted to avoid social isolation through patterns of family organisation such as meals with their extended family and friends. A common theme mentioned by participants was the experience of sharing traditional food recipes.

They also talked about an informal system of self-help for the sick and the notion of mutual obligation; for example they mentioned their religious or spiritual gatherings which acted as informal community support systems.

### **Knowledge of dietary issues**

Another similarity among the female participants was highlighted by their personal knowledge of a T2DM diet, which in medical terms is paramount in achieving the recommended blood glucose levels and also a healthy weight. All the women in my study revealed an increased knowledge about a healthy diet, including an understanding of various food groups that should be consumed in moderation. This indicated that a shift had occurred in what has been previously reported (for example DH 2004). However, participants reported that there was a gap in their knowledge about food substitution (in terms of African food instead of food found in Western countries e.g. apples, strawberries, pears, broccoli, cauliflower etc) because of the complicated nature of nutrition. They emphasised culturally appropriate knowledge to help them self-manage T2DM and suggested the development of an Eat-well Plate that could more accurately reflect the diet of people of Black African heritage. They also highlighted the need for the availability of nutritionists who possess a diverse knowledge of African food groups. Incorporating these needs into public health nutritional interventions would support the empowerment approach to T2DM self-management. However, Fredman et al (2004) argued that the link between self-management and outcome is complex and does not follow a linear pattern in regard to healthy eating. For example, giving people of Black African heritage translated information is not necessarily followed by healthy eating.

### **Unwillingness to engage in physical activity**

The participants reported their reluctance to participate in physical activity at the recommended level of at least 150 minutes per week for adults. This was observed across the participants in my study. The Department of Health's (2009a, 2009b, 2012) recommended guidelines for adults in the UK emphasised the importance of physical activity in maintaining a healthy weight. My study participants considered physical activity to be counter-cultural and preferred diet as an option with which to manage weight. It was also striking that even those who followed a 'Disease Focused Approach' did not meet the recommended guidelines for adult physical activity. Nevertheless, my study has revealed the nature of self-management of T2DM among women of Black African heritage which was previously not well known in public health nutritional intervention in the UK.

Previous research (Grace et al 2008) identified similar barriers for people of South Asian heritage in the UK. The only other study that showed a reluctance to participate in weight management activities by people of Black African heritage was conducted in the USA (Toumilheto et al 2001). The evidence from Health Survey England (DH, 2004) and Public Health England (2013) showed an increased prevalence of obesity in women of Black African heritage. While the cost of gym membership was raised as a contributory factor, the key issue identified was the lack of physical activity venues that were culturally sensitive, for example, the lack of women-only environments, particularly in the case of older women of Black African heritage who may be worried about their body image when using public places such

as gyms. Given that obesity is a major risk factor for T2DM (Charturvedi et al 2012), it would be beneficial for public health professionals involved in physical activity to understand how to work with women of Black African heritage in addressing their physical activity concerns. Perhaps public health practitioners could stress that the recommendation of 150 minutes a week is achievable, as it can be broken down into bouts of 10, 20 or 30 minutes to meet the needs of the individual. They could also emphasise that it may involve a variety of moderate activities that can be tailored to meet individual needs including gardening, walking and other activities, and does not necessarily mean going to a gym.

## **5.2 Culture and diet as an option for T2DM self-care**

The culture of the sick person can have an impact on their ability to meet their health needs. My study found that all the women participants had maintained their cultural background which was enshrined in their food practices, values and beliefs. Culture seemed to be the way in which participants valued African traditional food, good health and T2DM prevention. This has been supported by some studies, including that by Helman (2004), who found that culturally competent health service provision needed all health professionals to increasingly incorporate the culture of the target group into healthcare.

## **The individual and cultural identity**

What is already known from previous studies is that traditional medical models of T2DM care have relied heavily on individual compliance with prescribed medication which often led to poor diabetic control (Cheyne et al 2002, Guthrie & Guthrie 2002). The current practice is that GPs and specialist T2DM nurse facilitators use clinical judgment which places emphasis on successful self-care, associated with the recommended HbA1c levels (NICE 2001, Diabetes UK 2012). By contrast, my study participants emphasised the importance of a culturally meaningful T2DM diet.

My study identified how health professionals need to understand that T2DM can be managed by diet alone, as long as it is implemented properly. Previous research on nutritional interventions has been too closely associated with individual behaviour change, using individual psychological models such as the Health Belief Model and Trans-theoretical model. This view is further confirmed by Helman (2004), who argued that the role of the GP should be to understand the patient's culture and practices that inform diet. Central to empowerment is the idea that the behaviour of an individual is beyond the health professionals' control. Some authors (Paulweber et al 2010, Helman 2004) have argued that health professionals' attitudes have to change as they need to gain cultural competence skills. My findings demonstrated that participants felt that the decision about self-care still rested with GPs and healthcare professionals who recommended medication at diagnosis without patient consultation.

Health professionals' behaviour can be seen to be disempowering and it can fail because they have to rely heavily on what the sufferer discloses about how they deal



with T2DM in the real world, which could involve a variety of cognitive activities. This requires health professionals to have adequate knowledge of the cultural beliefs of individuals of Black African heritage.

My study also illustrated how participants' preference for nutritional interventions was not without problems. For example, adverse environmental issues affected the availability of fresh fruit and vegetables in local shops, as well as transport costs, and the non-availability of African and African Caribbean food at local supermarkets. Previous research (Blackwell 2009, Raphael 2003, Crespo et al 2000, Weinsier et al 2002) commented on the 'default dilemma', that food costs more in deprived areas. This was highlighted in my study by participants on low incomes who reported over consumption of energy-dense food such as carbohydrates and a lack of fresh fruit and vegetables in their neighbourhoods. This could perhaps be a contributory factor to the increased prevalence of obesity in deprived areas of the UK, as some of the participants in my study reported facing these challenges to weight-management (Blakewell 2009).

Some of the literature (De Fronzo et al 1992, Ferrannin & Camastra 1998, Butler et al 2003, William 2003, Hanley et al 2010) has demonstrated that T2DM is progressive and that individuals would have to rely on insulin. This medicalised model of self-care was challenged by the UK Prospective Diabetes Study (1998) which demonstrated that lifestyle issues would need to be incorporated in order to halt the progression of T2DM. Moreover, support for my study can be found in recent studies which have illustrated that diet alone can be successful in halting the

progression of complications (Lim, 2011) and more advanced studies in bariatric surgery (Taylor 2008, Camastra et al 2007).

My study's findings showed that the two vegetarian participants reported success in self-management of T2DM on diet alone for more than five years without taking any medication. While this finding is modest, it is significant in regard to our understanding of T2DM, culture and diet among people of Black African heritage living in the UK.

### **Culture and the family**

Another factor that could promote culturally appropriate public health nutritional interventions from a Black African heritage perspective is the nature of the kinship relationship that is sustained over time. McElroy and Jezewski (2000) argued that culture acts as a useful bridge, linking levels of health experience between the individual, family and community. Therefore, it is critical for public health to include this dimension when planning and thinking about how to achieve T2DM self-management for this target group.

My second research question explored the importance of culture, environment and knowledge as key influences on food choice among women of African descent who managed their T2DM by diet. What was known from previous research is that there are several influences on food choices among people of Black African heritage (Blakewell 2009, James 2004, Weinsier et al 2002, Raphael 2003). What has been

clearly evidenced by my study is that culture is the crucial influence on food choice among participants of Black African heritage.

Participants with children prioritised their children's preferences and accommodated family needs to self-manage T2DM. Although the concept of family has changed in Britain, my study demonstrated that participants preferred to buy African food when food shopping and also favoured serving traditional food at family gatherings. Turning to the family for support in T2DM presents the best opportunity for a T2DM sufferer to meet both individual goals and increase awareness because this disease is known among most people of Black African heritage families (Vaxillaire et al 2010, Chaturvedi et al 2012). The important role of the family among people of Black African origin has been highlighted in the literature by various authors (MacGolrick & Gerson 1985, D'Cruz 2004).

Meanwhile, the theme of culture and family roles for women with children living at home revealed generational differences (James 2004, Anderson & Cox 2000) in food preferences and added another source of vulnerability to T2DM self-care for the women. T2DM sufferers with young children experienced conflict between parents' and children's expectations. These expectations were embedded in differences in acculturation and life-course experience. For example, children had developed ties with the wider Western culture and preferred food like chips, burgers, strawberries and white bread, whilst the mothers preferred healthy but traditional food purchased at local African Caribbean outlets, such as greens, okra, plantains, mangoes, pineapples, papaya, water melons, oranges and sweet potatoes. The role of being a mother proved to be paramount for these participants, to the extent that they

prioritised family over disease, as they shopped for food that the children preferred; thus, a 'Family Focused Approach' hindered their self-management of T2DM.

### **Culture and gender**

Previous research (Scott 2001) demonstrated that most people of Black African descent perceived healthy eating recommendations as being asked to give up their cultural identity. My study confirmed culture as an important factor in food choices which interacts with ideals, identity and reciprocal roles in specific contexts to shape food choices in all the women participants. It can be argued that most people of Black African heritage would tend to seek a secure base as an important factor that promotes resilience and adherence to culture and provides a sense of stability and connectedness. Therefore, public health nutritional interventions that promote a cultural approach to T2DM care are one way of reducing T2DM complications among people of Black African heritage.

The women in my study also took on matriarchal and gender roles which were evident in food choices and interfered with nutritional care at family gatherings and at community festivals. In the case of matriarchal roles, these interactions were apparent among the vegetarian older participants whose children had left home as they took charge of family gatherings and imposed their vegetarian diet on others, which was generally well received. Their position as the person with the main food management role gave them the opportunity to take charge. This showed that participants in my study were not only dealing with T2DM, but they also played gender and identity roles, first as women and second as women of Black African

heritage, while at the same time performing these roles became the crucial element in preserving the integrity of the self. Collins (2000) argued that gendered roles and values are perpetuated through entrenched notions of patriarchal social structures. These structures have not challenged sexism or racism sufficiently and have continued to ignore women of Black African heritage who are exploited by both White men and Black men (Collins 2000). Progress in addressing gender equity issues could be achieved by acknowledging the role of men as care-givers in the family and community, and provide adequate support and guidance to enable male participation. However, the six women participants who used the 'Disease Focused Approach' overcame some of these barriers and were able to develop effective 'fighting back' strategies that promoted resilience in self-managing T2DM by diet. The ability to survive could only be achieved as they made efforts to meet the many demands placed on them, while having limited access to resources and supportive healthcare services. Gender identity and strategies to overcome barriers arose out of their religious values, knowledge and experience of cultural values and their interpretation of familial duties and the demands these placed on them.

### **Collective approach to self-care**

I have argued that medical models of self-care have failed to recognise the collective nature of self-management as an imperative component of successful T2DM self-care among people of Black African heritage. Here I argue that the collective approach does not deny the individual's crucial role in sustaining the process of lifestyle change required in T2DM self-management. For example, T2DM self-management extensively revolves around daily activities (such as food shopping and

cooking). Perhaps what the collective approach can do differently from individualistic approaches is to empower Black African heritage communities. Previous studies of public health nutritional interventions and national policy in T2DM self-care stressed the importance of self-management and focused on sustaining individual long-term behaviour by using behavioural and health promotion models (Stickland et al 2010, Gorczynski et al 2010). These behavioural interventions have had limited results among people of Black African heritage (Heisler 2006, Paulweber et al 2010). It is for this reason that I proposed the PEN-3 public health cultural model as being more effective because it advocates a collective approach that consists of the individual, the extended family and communities of the target group. Applying this knowledge has been shown to be effective in other areas of public health practice such as in HIV (Lawrence 2007) and T2DM in South Asians (Grace et al 2008). My study recognises that such an approach can be equally effective in the UK among people of Black African descent diagnosed with T2DM which they manage by diet.

### **5.3 Adherence to diet in T2DM self-care**

Previous research (Feldman & Hayes 2004; Diabetes UK 2006) has implied that many Black African and African Caribbean people diagnosed with T2DM fail to comply with recommended treatment. My study indicated that a doctor's approach to T2DM diagnosis and treatment options was important in generating positive responses from the participants, regardless of whether they followed professional advice or not. For example, the two vegetarian women who used a 'Disease Focused Approach' had successfully self-managed T2DM for more than five years. They attributed this success to their assertiveness which led to improved

communication and support from their GPs. Although some of the participants had attended six monthly hospital appointments to have their blood glucose levels monitored, which is a requirement for all T2DM sufferers, some participants reported that they had missed appointments. Poor adherence to treatment by BME people in the UK is a great concern which has been reported previously by Nazroo (2000), whose research highlighted barriers to accessing healthcare services.

This showed two important responses to T2DM by participants: firstly the role of appropriate T2DM treatment; and secondly the role of GPs in strengthening the participants' ability to respond positively to T2DM treatment. These findings illustrate that a doctor's approach to the patient's diagnosis and T2DM care is critical in generating positive responses to self-management of T2DM by individuals. My study also confirmed that GPs need to have an awareness of supporting public health interventions in addressing the social determinants of T2DM (for example, referring patients to lifestyle services) and should not just target disadvantaged groups for early detection of T2DM (Glanz et al 2005).

My study demonstrated that the role of health professionals was critical in giving the right information and explaining what was wrong. For example, some women expected health professionals to support their decision to manage T2DM on diet alone and to remind them about the six monthly blood glucose tests as part of the follow up by diabetic nurses, via a text message, letter or telephone call. When this did not happen, the women felt that this affected their confidence in terms of accessing diabetic services appropriately. When used appropriately by health professionals, the empowerment approach (Purnell 2002, Laverack 2008), could

inspire female T2DM suffers from Black African and African Caribbean communities with the confidence they need to attend blood glucose monitoring tests.

Bird (2004) argued that families may influence the T2DM sufferer not to disclose their T2DM status and encourage them to seek alternative therapies. My study showed 'negative' aspects which included health beliefs and actions that are harmful to health and needed to be changed. Previous studies showed that health professionals tended to focus on individuals when providing treatment and support in T2DM care. An individualistic approach has a tendency to make people feel judged and blamed for not following the health professionals' nutritional advice. This can add to the stigma of T2DM within communities, and foster conflict and tension between patients and health professionals, causing people to miss appointments, thereby risking the possibility of T2DM complications.

Some of the participants feared revealing their disease to members of their communities as this was perceived to be a barrier to carrying out T2DM self-management in public. For example, participants reported that, when they were at a friend's house, it was viewed as hospitable to insist on eating, but this could become a problem if the food was not appropriate for the diet of the individual with T2DM. Moreover, food is the major theme at many Black African and African Caribbean cultural festivals, religious and community gatherings, and most of the participants reported experiencing difficulties with self-control while attending such major events which revolve around eating.



However, Glanz et al (2005) argued that forces opposing healthy eating are found in health inequalities and deprived environments where disadvantaged people live. While focusing solely on the most disadvantaged groups will not reduce health inequalities sufficiently (Marmot 2010), it would help to contribute to the universal action and also demonstrate the scale and intensity that is proportionate to the level of disadvantage, which is referred to as 'proportionate universalism' (Marmot 2010). 'Proportionate universalism' also embraces social justice by promoting the idea that more support should be given to those with special needs, i.e. positive discrimination should be applied, which requires a strengthening of the primary level services such as ensuring they are staffed by sufficient personnel with adequate competence levels. This is what should be expected of the health service with the creation of the Clinical Commissioning Group (CCG). GPs are required to identify those patients who need the most healthcare, and those most at risk (Mathews et al 2012), for example making available public health interventions such as the health check for those aged 40 to 74 years that are conducted at GP surgeries. The latest SABRE study (2012) argued that the age of screening health checks should be lowered so that screening starts at age 24 for people of Black African heritage and South Asians, as an acknowledgement that early detection is necessary for those at higher risk of T2DM.

The role of GPs as the main providers in primary healthcare, introduced by the NHS in 2012, means they would be able to offer health checks and calculate a clinical risk score, for example identifying cardiovascular diseases (CVD) and making appropriate referrals (Mathews et al 2012). The NHS Public Health Trainer Service, based at most GP surgeries, provides one-to-one lifestyle interventions in deprived

neighbourhoods. This could be a potential entry point for promoting effective public health nutritional interventions and should be well-placed to reach people of Black African heritage. One way of achieving this is by working with BME charities and faith groups to recruit and train volunteers from the target communities to be T2DM community champions. Ultimately, the decision to seek prompt diagnosis and effective treatment may be influenced by whether the person of Black African heritage perceives the health services to be culturally sensitive or not. Delays in seeking treatment have been reported where health services have been perceived to be 'negative', as in the case of mental health (Bird 2004).

Enacting supportive and relevant public health nutritional interventions that would address the needs of people of Black African heritage could be achieved through the development of a partnership approach which was suggested by participants. Some studies (Lawrence et al 2007, Beaulieu et al 2002) have illustrated that the partnership approach has been considered and implemented for other chronic conditions affecting Black Africans, such as HIV, with great success. This would involve community leaders, faith leaders and healthcare professionals working together with people with T2DM to promote nutritional interventions to families and the wider community.

## **Chapter Six: Conclusion and Recommendations**

### **6.0 Introduction**

In moving towards a conclusion for this study, in this chapter I discuss the implications of the study for policy and for practice. I also examine the strengths and limitations of the study and consider areas for further research.

### **6.1 Contribution to knowledge**

The most important finding is the broadening of our understanding of the key influences on food choices among women of Black African heritage living with T2DM. Overall, I have demonstrated the need to develop culturally appropriate public health nutritional interventions that would help people of Black African heritage to self-manage their T2DM by diet alone. The role of culture was found to be paramount. Drawing on the PEN-3 public health cultural model, my study demonstrated how long-term food choices and decision-making can work towards dietary change that is acceptable to people of Black African heritage. This would help to prevent complications of T2DM among this target group.

#### **Family**

I used the PEN-3 framework to explore my findings about culture and diet (See Appendix 1). The PEN-3 public health cultural model for practice informed my study because it identified the need to consider both the nuclear and extended families whenever culture is considered to be the driving force, as the individual approach is

less effective. The first domain of the PEN-3 public health cultural model 'Cultural Identity' (Person, Extended family, Neighbourhood) was identified as being central to T2DM self-management. Recognition of this would help to make nutritional interventions more effective for people of Black African heritage. The individual or T2DM sufferer is the main actor who decides how to cope with the condition. This clearly demonstrated the importance of an individual's choice regarding how to manage T2DM. This model called for modes of adaptation that would enable public health and health professionals working in the field of T2DM nutritional interventions to adjust to the demands arising from the roles of women of Black African heritage, thus increasing their chances of successfully self-managing T2DM by diet.

The role of the family was demonstrated by participants with children. My study revealed that female participants of Black African heritage living with T2DM made their food choices either using a 'Disease Focused' or a 'Family Focused' approach. Having a young family at home seemed to compromise T2DM self-care, showing that people who live in a family setting, particularly those with young children, are more at risk of T2DM complications as they might prioritise the needs of the family over their own health.

Furthermore, T2DM was acknowledged as occurring in many people of Black African heritage. All participants reported that they had family members with T2DM. Therefore, working with families, and including extended families, would be an effective way to increase awareness and maximise prevention, while tackling inter-generational issues of obesity and physical inactivity, particularly by targeting children of Black African heritage. Effective T2DM self-management and the

subsequent prevention of complications are paramount in T2DM self-care which requires long-term commitment.

The second domain of the PEN-3 public health cultural model was identified as 'Relationships and Expectations' (Perceptions, Enablers and Nurturers). Of particular interest to my study is that this domain helped to analyse participants' knowledge, attitudes, and beliefs, as well as their accessibility to health services and structural factors that contribute to, or impede engagement in, particular health behaviour (see Appendix 1).

The third domain of the PEN-3 public health cultural model, 'Cultural Empowerment' (Positive, Existential, Negative) also informed my study because it includes values and relationships that promote the health behaviour of interest that could be incorporated into public health nutritional interventions. The 'existential' category of the 'Cultural Empowerment' domain demonstrated an understanding that illness-related decisions are important in the management of T2DM.

Participants identified positive decisions and practices related to treatment-seeking behaviours. Those who used a 'Disease Focused Approach' prioritised their own health needs but managed to integrate their culture by following their traditional African diet at the same time. They retained their Black African heritage and their individual identity as far as was possible.

The 'negative' category of the PEN-3 public health cultural model was also relevant in relation to considerations about the accessibility and lack of culturally appropriate

T2DM service provision, as expressed by participants. Consistent with previous studies (Marmot 2010, Nazaroo 2000) there was a common perception shared by participants that all people should have access to a high standard of culturally sensitive health services. Campinha-Bacote (2002) proposed a 'cultural skill' which relates to healthcare professionals' adeptness in collecting culturally relevant information for clients to carry out culturally based education and appropriate interventions. The role of outreach work could be crucial in reaching out to people of Black African heritage, who are part of the disadvantaged groups (Race Equality Act 2010). My study therefore highlighted the need for primary care health professionals, particularly GPs, to be aware of wider social issues that affect health decisions, as well as the clinical components that contribute to them, as part of their daily job. Doctors' surgeries are located at the heart of communities, and are therefore well placed to act as a focal point.

A common thread running through my study is that the participants require supportive T2DM health service provision. Health professionals may not recognise the importance of diet in T2DM self-care among people of Black African heritage, and fail to provide culturally sensitive support to individuals who are confronted by challenges within the context of everyday life. The PEN-3 public health cultural model identified cultural competence as having an effective impact on health education intervention. Cultural competence in the delivery of healthcare services should be a model that requires healthcare professionals to see themselves as becoming culturally competent rather than already having achieved competence.

### **Criticism and evaluation of PEN-3**

I now evaluate the PEN-3 public health practice model as a subsidiary part of my study. The PEN-3 public health cultural model is committed to informing public health practice for people of Black African descent using a bottom up approach. However, the uniqueness of the PEN-3 public health cultural model lies in the fact that not only does it establish culture as the core of nutritionally-related behaviour, but it also incorporates other theories used to explain health and public health human behaviour interventions into a single theory, which no other theory does (Airhihenbuwa 1995).

However, the PEN-3 public health cultural model does have its limitations. There is a lack of clarity regarding the meaning of culture which makes it difficult for the model to be fully operationalised. This probably explains why it fails to address or explain some of the differences between participants in my study concerning influences on food choice in terms of adhering to a traditional African diet. All the participants believed that they could manage T2DM by diet alone. While the six participants who used a 'Disease Focused Approach' were able to prioritise T2DM, the two other participants who used a 'Family Focused Approach' yielded to challenges from family members, which seemed to prevent them from prioritising their own T2DM. My study revealed that cultural adherence is not an inherent characteristic. If culture is fixed and diet is perceived as an important expression of culture, all the women in the study would have behaved in the same way. This would help to explain dietary adherence as a learned phenomenon, whereas my study demonstrated that if

culture responds to a new context, then the women who used a 'Disease Focused Approach' are making more of a cultural shift. The PEN-3 cultural model portrays culture as static but it is actually more complicated and fluid than that. My study revealed that culture can shift, as demonstrated by the participants who showed differences in their adherence to diet for managing T2DM when they clearly all preferred a traditional Black African heritage diet.

An additional limitation of the PEN-3 public health cultural model is that it does not consider the fact that, although many Black African populations embrace collectivism, some do not. There were some participants in my study who demonstrated the needs of single-person households. There is a potential danger that the needs of people who may not belong to groups or have less contact with families or social networks and do not fit into the notion of 'collective culture' suggested by the PEN-3 public health cultural model will be overlooked by health professionals. Moreover, although collectivism is important and desirable for people of Black African heritage, it is not specifically exclusive of other ethnicities. Moreover, not all people of Black African heritage with T2DM in the diaspora have extended families to support them.

## **6.2 Recommendations for practice**

### **Support in nutritional interventions**

My study has conducted an in-depth exploration, from the participants' perspective, of issues around T2DM self-care and service provision, which has facilitated an



understanding of gaps that need to be bridged. This will enhance the existing knowledge base and provide valuable input for service provision and practice, and education and policies for T2DM care among people of Black African heritage.

My study recommends the adoption of a partnership approach between public health professionals in T2DM management, individuals, extended families, and community and faith leaders in the Black African and African Caribbean communities. This also means intervening in areas such as providing linguistic support, advocacy, outreach workers and public health volunteer/community champions. In Chapter One, it was noted that previous research on T2DM self-care in the UK has been conducted mainly on Caucasians and South Asians (Grace et al 2008). My study has focused on women of Black African heritage living in a Western society. It has highlighted the need for support enhanced by cultural competence among healthcare professionals, especially in an area where dietary change is needed.

I am arguing that cultural knowledge and skills would make a significant difference to the quality of support that is offered to people of Black African heritage who self-manage T2DM by diet.

### **6.3 Recommendations for policy**

Policies such as Equality and Diversity are designed to educate healthcare staff to deliver improved T2DM care for people of Black African heritage. They also have the capacity to educate healthcare staff to deliver culturally sensitive T2DM self-

management. However, a culturally competent service provision can only offer effective support if it is properly adhered to by all staff through cultural competency training (Campinha-Bacote 2002). Cultural competence is a process that occurs over time, in which the healthcare providers must be constantly reassessing and changing their practice to integrate suggestions and recommendations such as cultural awareness, knowledge, skills and encounters. For example, statutory health care providers deliver online cultural competency courses for staff such as Equality and Diversity which are ineffective. This could be achieved by face to face contact which would allow staff to explore cultural issues they encounter in service delivery. Consequently, learning about culture is a never-ending process which develops primarily through cultural encounters.

Therefore, implications for educational programmes are that they need to include cultural perceptions because of the individual's vulnerability in the context of culture. A programme of training is required to help develop cultural knowledge and to capitalise on the existing strength that families possess.

### **Political considerations**

The idea of a community public health nutritional intervention in T2DM self-management was also highlighted in my study. Black African and African Caribbean communities' lack of political weight means that their needs are often overlooked in the commissioning processes. This is the case despite the equality duty (Equality Act 2010) which stated that eliminating discrimination and advancing equality meant recognising and taking steps to meet different needs and acting to remove

disadvantage. In practice this would be taken to mean that resources may need to be diverted and this may involve treating some people more favourably than others. However, my study demonstrated that services do not necessarily have to be provided on the same basis or scale for different communities, given that resources are limited. Rather, my study recommends that additional practical guidance on the provision of women-only services could be effective in promoting physical activity.

### **Policy recommendations**

An implication of my study for policy is the development of a culturally competent service provision which is needed to inform the nutritional needs of T2DM sufferers from the Black African heritage population. This also means that all health professionals involved in T2DM care should be trained in cultural competence as they would be required to demonstrate culturally appropriate nutritional interventions. They would also be expected to have an understanding of traditional African and African Caribbean T2DM diets. My study also recommends that health professionals should work with Black African and African Caribbean community and faith leaders to develop and facilitate outreach work and the recruitment of T2DM community champions.

A further implication of my study is that public health nutritional campaigns should carefully consider the family context. Health professionals' nutritional interventions may benefit from the recommendations of this study, as it focuses more on the lived experience of food choice for new and second generation Black African and African Caribbean participants. This would help health professionals to encourage retention

of the healthy aspects of diet in the face of challenges related to changing food environments.

These implications for both practice and education also have policy implications both for people of Black African heritage and health professionals. This is the case since any diversion of resources would involve reviewing current policies in terms of resource allocation, distribution, and making services available at the primary care level using outreach workers, T2DM community champions and health trainers. However, it has to be acknowledged that the NSF (DH 2002, 2003, 2007) has yet to be fully implemented and there is still a disproportionate increase in the incidence of T2DM among people of Black African heritage in the UK. It has not been outlined how specific strategies for early detection for those at risk, such as the NHS Health Check programme, should target people of Black African heritage.

My study identified an over-standardised local T2DM service provision. Standardisation is inflexible because it does not take into consideration Black African and African Caribbean communities' specific T2DM needs. In an equitable service provision, variability is permissible to guarantee fair access to appropriate care to enable effective follow-up treatment or intervention after T2DM diagnosis. This would avoid misunderstandings and perceptions of discrimination by people of Black African heritage.

#### **6.4 Further research**

Further research in the area of food choice among people of Black African heritage could prompt a study designed to investigate the link between immigration and

acculturation, and fully explore these areas in relation to public health nutritional interventions. Moreover, research has also shown that Black African and African Caribbean migrants are disproportionately poorer than the general population (Marmot 2010, Nazroo 2000), thus making poverty a potential confounder in any relationship between health and diet. For example, my study illustrated that some of the participants on low incomes were greatly affected by the food environment in their neighbourhoods. This led to poorer nutritional choices, contributing to fluctuations in food choice which were ultimately associated with weight gain. Research is now needed that explicitly addresses the assumed increase in consumption of high-calorie, low nutrient-dense foods that may be associated with immigration to the UK (Weinsier et al 2002). In this way, my study highlights the complexity of food choice, and the ways in which low incomes interact with and affect dietary change as food environments change. Further quantitative research is needed in this area to specify the interactions of these factors more precisely.

## **6.5 Limitations of the study**

My study has explored factors influencing food choice in women of Black African heritage diagnosed with T2DM which they manage by diet alone. However, there are potentially limitations to generalising information gleaned from this small sample in rural counties of the UK to the Black African and African Caribbean population as a whole. Difficulties in recruiting participants from the target communities led to the numbers being limited to these geographical local areas. However, from a methodological perspective, the number of participants was sufficient to answer the research questions.

The term Black African, confines all these women into a single group and to some extent the lack of acknowledgement of heterogeneity is problematic. While Public health nutritional interventions require targeting and also limited resources may make this grouping essential to address the issues raised in my thesis, it remains the case that 'Black African' and 'African Caribbean' are different ethnic groups which each merit investigation separately to provide more nuanced findings and recommendations.

The lack of men in my study was another study limitation. Gender and ethnicity studies showed that, in general, most Black African and African Caribbean women are involved in food shopping and cooking activities. Nevertheless, my study would have benefited from men's involvement because of changing gender relations in the home, which could have provided a deeper understanding of the key factors involved in food choice and T2DM self-care for women.

Another limitation was that my study did not recruit women with limited English language skills. Issues of English interpretation and translation were not paramount for this group of participants. This could be an area worthy of further research to explore whether culture is mediated through language, and whether perhaps being able to speak English is empowering women to choose to manage their T2DM by diet only and reject medicine. It could also be possible to investigate whether this finding can be applied to non-English speaking Black African and African Caribbean women.

A final limitation is that my presence as a member of the health profession may have influenced the extent to which participants could express their critical views about the NHS openly. Nevertheless, these women have certainly contributed significantly to T2DM nutritional intervention management for the Black African and African Caribbean communities.

## **6.6 Conclusion**

The study aimed to explore the key influences on food choice and implications for dietary change among women of Black African heritage who self-manage T2DM by diet only. The women most preferred diet and least preferred medical therapy and physical activity as an option for managing T2DM self-care. What makes current public health healthy eating models inappropriate for people of Black African heritage is their lack of cultural sensitivity. The PEN-3 public health cultural model provided a conceptual framework for T2DM self-management which linked the influential factors that play a role in food choices. This provided an enhanced understanding of T2DM self-care for the target group.

My study demonstrated that successful metabolic control was believed to be achieved by six participants who used a 'Disease Focused Approach' for T2DM self-care, particularly the two vegetarians who had been managing T2DM for more than five years. This also demonstrates that it is possible to achieve good metabolic control by diet and to halt the progression of the disease with improved doctor and patient communication. A minority of the participants used a 'Family Focused

Approach' and had greater difficulty in achieving good metabolic control and this highlights the particular needs of people with T2DM in households with children.

A number of factors that influenced the food choices of the participants were highlighted. Culture was recognised as the significant driving force behind food choice among the participants. Participants' knowledge of cultural values became essential in maintaining their cultural identity. Within the context of the Black African heritage family "tradition", gender roles are passed on through observation and oral "tradition", and in my study this was enacted through the subjective interpretation of the female T2DM sufferers' understanding of cultural connectedness. Fundamental to the women's actions was the aim of achieving a way to self-manage T2DM by a traditional African diet, to halt the disease's progression. This led the women to experience a wholeness and connectedness to their gender and Black African heritage identities. Public health nutritional interventions and healthcare professionals in T2DM should therefore adopt a stance that reflects these values to enable them to work in a culturally respectful and competent way. These values are embedded within the PEN-3 public health cultural model.

My study showed that culturally specific public health nutritional interventions for people of Black African heritage are required to address the needs of T2DM self-management by diet alone. While participants acknowledged the crucial role they played as individuals in T2DM self-management, they also emphasised that health professionals could consider a collective approach which involves working with their families, including extended families and the wider Black African and African Caribbean communities. This renders it crucial to develop culturally competent T2DM



service provision that is accessible to Black African and African Caribbean communities. This therefore reinforces the need for health professionals to facilitate empowerment approaches that take into account the patient's culture. The significance of culture can be acknowledged by working with individuals, their families, and communities of people of Black African heritage in the UK.

Finally, the economic burden and the long-term health consequences of T2DM make it worthwhile for public health nutritional interventions and service provision to invest in the implications and recommendations of my study.

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## APPENDICES

### Appendix 1: Application of the PEN-3 Cultural Model

The Domains	Positive	Existential	Negative
<b>Persons</b>	<p>Enjoy eating cultural food with family</p> <p>Family support is good and reduces isolation</p>	<p>Religion is good for health and well-being</p>	<p>Prioritising family needs over disease</p> <p>Feeling negative about the disease</p> <p>Eating chicken with the skin taste better</p> <p>Sedentary lifestyle</p> <p>women with children shouldn't worry about putting on weight</p> <p>healthy eating is giving up heritage food</p> <p>we cannot eat raw vegetables</p> <p>healthy food taste disgusting</p>
<b>Extended Family</b>	<p>Strong family support system</p> <p>Help with food preparation</p> <p>Children motivating parent to exercise</p>		<p>All people of Black African heritage like meat</p> <p>Meat is an integral part of a meal</p> <p>Preference of unhealthy traditional meals e.g. salty fish, deep fried chicken ,high intake of energy dense meals</p>
<b>Neighbourhoods</b>	<p>Most people in the Black African and African Caribbean communities have been affected by disease</p> <p>Value church support groups</p> <p>Need for strong social links</p>	<p>Advocating for awareness of T2DM</p> <p>Participating in target community health events</p>	<p>Belief that its God's Will and nothing can be done about it</p> <p>People live in fear of diabetes complications</p> <p>Low working knowledge of the disease</p>
<b>Perceptions</b>	<p>Ability to self-manage T2DM</p> <p>Comfortable contact with GP</p> <p>Fluency in English</p> <p>Confident about choosing T2DM diet when eating out</p> <p>Know where to look for more information</p>	<p>Use of home/herbal remedies</p> <p>Use of alternative therapy is considered a better option</p>	<p>Stigma of having T2DM leading to poor access of T2DM health services</p> <p>English information literature is the primary source of information in UK</p> <p>Belief that T2DM is inevitable in the African/African Caribbean communities</p> <p>Lack of adequate financial resources</p> <p>Poor access to proper T2DM care</p> <p>Reluctance to engage with health care services</p>
<b>Enablers</b>	<p>Development of cultural appropriate nutritional information and food guidelines</p> <p>Increased outreach work by healthcare professionals is needed</p> <p>Identification of relevant language support for those who need it</p>	<p>Caring for sick individuals by giving them T2DM food e.g. low salt, sugar and fat diet</p> <p>Access to African vegetables and fruit diet</p>	<p>Fear of going to the doctors</p> <p>Late presentation of disease</p> <p>Cost of health food is expensive</p> <p>Perception that health system are not supportive</p> <p>Inability to self-manage T2DM</p> <p>Due to pressure from family and social networks</p>



	Culture specific nutritional education would be a great benefit Availability of affordable cultural specific food locally		
<b>Nurtures</b>	Want health professionals to engage with target communities  Culture encourage helping others  Accompanying/reminding individual about T2DM hospital blood glucose tests	Family learning/ searching for T2DM information  Family support with physical activity	Eating deep fried convenience food  Eating out at restaurants/takeaway regularly  Healthy food taste disgusting  Too busy to cook or prepare healthy meals  dislike raw food i.e. salads

## Appendix 2: Outline of the Literature Review Search Strategy

The following databases were searched from April 2000:

### 1a. Search for peer reviewed, published literature

- PUBMED
  - EMBASE
  - CAB Abstracts (including nutritional abstracts and reviews)
  - The Cochrane Library
  - CINAHL
  - MEDLINE
  - Proquest Nursing Journals
  - Science Direct Elsevier Journals
  - Journal of Diabetes
  - Journal of Advanced Nursing
  - Nursing and the Diabetic Educator
  - Wise and Willey
  - SIGLE (System for Information on Grey Literature)
  - Other relevant databases and cross referencing the articles retrieved.
- Referencing enabled search of different media such as books, articles and electronic resource search entries by author, subject, type or keyword export.

Search Tools included:

### 1b. Free text terms:

- \* Such as (diet\* OR food habit\*) AND (vegetable\* OR fruit\*);
- \* MeSH terms used included diet\*, food habit\*, fruit\*, vegetables\* (not exploded to exclude nuts and seeds); with health behaviour, health promotion,

Key word search:

Such as black African, Black Caribbean, diet, dietary intake, nutrition, food, eating habits, food consumption, nutrition, food purchasing, weight, physical activity, exercise, obesity, food choice, food shopping, consumer choice, food aversion, food tolerance, food context and ethnic minorities, food and income, deprivation, health,

type 2 diabetes, blood glucose, access to health and minorities, social eating, eating patterns, meal structure, cooking skills, healthy eating, social class and health, socioeconomic status and health, culture and health, knowledge and diabetes, health of minorities, minorities and primary care, inequalities in health.

Other sources of information used are as follows:

1c. To deepen my understanding further, I carried out a search for unpublished literature / grey literature / studies in progress. I included much of the relevant research mainly classified as 'grey' literature e.g. NHS PCTs websites, University and relevant organisation websites.

#### 1d. Government and statutory sector

The topics on Nutrition used by NHS and the Department of Health and other statutory sector bodies e.g. National Institute for Health and Clinical Excellence (NICE) Guidelines (2001, 2011, 2014) were used as key sources of information and data.

The main statistical data on populations used in this study is that produced by the 2001 census.

## 2. The Voluntary Sector

\* Voluntary sector organisations provided a wide range of data and information. These sources provided comprehensive link directories and information hubs for more information relevant to the UK context.

- \* Diabetes UK
- \* Advisory Service e.g. Insulin pump services
- \* BME charities in Norfolk and Suffolk
- \* Community Based Organisations in Norfolk and Suffolk

## 3. Academia

The key academic databases used were obtained by accessing the catalogues of specialised libraries e.g. King's Fund

## 4. Process for selecting included studies

- \* Inclusion criteria

- \* Human beings

English language articles were identified (2000-present). Articles were rejected on initial screening only if I could determine from the title and abstract that the article was not a report of a fruit and vegetable intervention study or promotion programme. Also studies involving T2DM, policy, health inequalities, health, social eating, empowerment, education, management of chronic conditions, low income and food, disadvantaged neighbourhoods and obesity, vulnerable and contained minority ethnic communities, were reviewed because they often provided appropriate information and also signposted me to other relevant information for the study topics.

- \* Exclusion criteria

The studies that did not address fruit and vegetable intake, the intervention was not humans, the report was on critically ill or mental ill individuals.

-identified literature directly relevant to the research phenomenon and excluded literature that was of only peripheral interest or of no interest.

5. The Department of Health (DH) website was an important source of information which was consulted to build up introductory materials. It was also consulted because of its reliability in providing accurate information and useful signposts for pursuing research. Government departments and other statutory sector bodies (Health Survey for England, 2004, NHS Public Health Reports) were used as key sources of information and data about topics on Inequalities in health and to a lesser extent, BME and T2DM.

6. The main statistical data on diseases and populations used in this study is that produced by the:

- \* DoH National Statistic website: [www.statistics.gov.uk](http://www.statistics.gov.uk)

- \* Diabetes UK: [www.diabetes.org.uk](http://www.diabetes.org.uk)

- \* Health Survey England (HSE)

- \* NHS database: [www.nhs.uk](http://www.nhs.uk)

- \* National Observatory : [www.apho.org.uk](http://www.apho.org.uk)

- \* National Obesity Observatory: [www.noo.org.uk](http://www.noo.org.uk)

These sources provided comprehensive link directories and information hubs for more information relevant to the UK context.

## Appendix 3: Think Aloud Training (Product Choice Reasoning Task) Procedure

Version 1 14/10/2011

### Think Aloud Training (Product Choice Reasoning Task) Procedure

As I have already mentioned-----in this task I would like you to think aloud while you are doing your usual shopping. What I mean by thinking out loud is to say everything you are thinking while you are shopping. This will be what you are looking at, reasons why you are choosing to buy it, or reasons why you are not buying it

Please say everything you are thinking of mentally about the product as well as anything you are doing. The idea is that you continue talking as much as possible.

We will have a few practice examples so that you get used to the idea of thinking aloud.

I will start now as an example to help you understand what I am asking you to do.

“I am looking at a bag of bananas. It costs £1, 09. There are 8 bananas in the bag and they look nice and cheap and within my budget. We are 4 in the family so will get 2 bananas each this week. I can see other bags of bananas over there, they are organic and cost £2, 09 for 6. I won't buy them because they are too expensive. So, I think I will choose this one.”

Could you now do the same as though you wanted to buy a bag of bananas and you were choosing between these two?

## **Appendix 4: Accompanied Shopping Instructions**

### Accompanied Shopping Instructions

-Carry out your shopping in your usual way. Do not rush on my account. It may feel strange to have me following you around.

-Think aloud at all times

-I will prompt you if you fall silent for more than 10 seconds - I will probably say 'keep thinking aloud; or 'what are you thinking' or 'what are you looking at?'

-I will not start a conversation with you.

-I may make some notes during the shop. Don't worry about this

-I am not here to judge what you buy

-Has participant consented to providing till receipt? Yes/ No

If yes explain that we will photocopy the relevant sections and return the original to them.

### **Any more questions before we start?**

Set up recording equipment, microphone clipped to collar throughout the shop

Start recording and say Code ID number

### After shopping

That's the end of our shopping task. I will turn the recorder off before we reach the tills. Do you have any questions?

Can I have your till receipt now?

Thank participant and confirm next meeting time and location.

Version 1 14/10/2011

## Appendix 5: Participant Training and Accompanied Shopping Task Procedure

Version 1      14/10/2011

**Participant Code No:** □□□□

**Date and time:**

**Location:**

**Till receipt:** **Yes/No**

\* Thank you for your completed consent form. Are you happy that you have read and understood the information sheet and that your questions have been answered satisfactorily? □

\* Summary of today's task: □

-Think aloud training (10 minutes)

-Shopping-remind them it is their shopping and they are paying

3. How long do you think your shopping will take today? -----

Do you need to leave by a particular time? -----

4. Check interview session. □

Time of interview -----

Date of interview -----

Location -----



## **Appendix 6: Invitation letter for patient to participate in a research study**

Version 1    Date 14/10/2011

### **Address of Diabetes Centre added by nurse facilitator**

**Title: What are the determinants of food choice and implications for dietary change among women of Black African and Caribbean descent with type 2 diabetes?**

Dear xxxxxxxx,

#### Invitation letter for patient to participate in a research study

We are helping ----- a postgraduate student at the University of Essex who is undertaking a Doctorate in Public Health. She is conducting a research study as part of the requirement of the degree. We would like to invite you to participate as we have identified you as having Type 2 Diabetes.

If you decide to participate, you will be required to take part in an accompanied shop task at your local shop, where you will undertake a think aloud task (Product Choice Reasoning Task) which requires you to say what you are thinking as you choose your food for your normal food shopping. You will also be asked to meet the researcher for an interview to talk about factors that makes you decide to choose the food you eat.

If you are interested, please take time to read the enclosed participant information sheet which gives more details about the study. If you would like to take part, or have questions about the study, please contact .....using the contact details below:

Thank you for your consideration

Contact details:

E-mail address:

Telephone:

With regards

Signature

## **Appendix 7: Study Information Sheet for Participants**

Version 1 14/10/2011

**What are the determinants of food choice and implications of dietary change among women of Black African and Caribbean descent with type 2 diabetes?**

### **Information Sheet for Participants**

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and why it would involve you. We will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 60 minutes. Talk to others about the study if you wish.

#### What is the purpose of the study?

My name is ----- and I am a postgraduate student for the Faculty of Science and Health at The University of Essex. As part of my studies, I am undertaking a research project for my thesis. The aim of the study is to explore the key influences of food choice for women of Black African descent with type 2 diabetes.

#### Why have I been invited?

We are seeking 10-12 people. You are eligible to participate in the study if you are aged 18 years and over, have been diagnosed by your GP as type 2 diabetes mellitus and you are a woman of Black African or Caribbean descent.

#### Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

#### What will happen if I take part?

The study will involve participating in an accompanied shop task. You will be accompanied by the researcher to your local shop or supermarket and you will be observed as you carry out your usual food shopping. We will ask you to 'think aloud' as you pick up each food item and put it either in their basket or back on the shelf. We will not engage in any conversation while the food shopping is taking place. We will ask you to wear a tape recorder on your collar to record yourself as you 'think aloud'. We will provide you with a short training of the 'think aloud' technique before the food shopping commences.

We will also ask you to take part in an interview lasting approximately 1 hour. The location and time of the interview will be organised to fit in with your convenience. This interview will be taped recorded and a copy of the transcript will be made available to you.

#### What are the possible risks?

We are not aware of any risks associated with the study, however given the subject matter the details of the local Counselling services are at the back of this information sheet. This confidential Counselling service is free to all participants should you wish to use it.

#### What are the possible benefits?

There may be no benefits from taking part in the study. It offers the potential for you to make more healthy choices in the food they eat. It is also hoped that the findings of the project will be useful in developing good local based community interventions and good practice guidelines in relation to type 2 diabetes sufferers.

#### Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be kept confidential. Your name will be replaced with a code number or a pseudonym, and it will not be possible for you to be identified in any reporting of the data gathered. Any data gathered will be kept in a secure place to which only I will have access. This will be kept for a year for the examination purpose and later stored securely for 5 years (Data Protection Act 2003) then destroyed. The results will be published in a journal or presented at a conference. Your identity will remain

confidential. Your name will not be published and will not be disclosed to anyone outside the study group.

Disclosure of neglect, abuse or criminal activity must be reported. Such disclosure would no longer allow the researcher to keep that information confidential.

#### What if there is a problem?

Ethical approval for this study has been granted by The University of Essex and -----  
-----.

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If there is a problem you can contact me or my supervisor. The contact details are given at the back of this information sheet.

If your complaint cannot be resolved, the normal NHS complaints procedure is available for you.

#### What to do next.

Thank you for reading the information sheet. If you are interested in taking part after reading this information sheet, or have any questions, please contact myself using the contact information below.

### **Contact Details**

Researcher Supervisor:

### **Counselling Services**

## Appendix 8: New food labelling Scheme

The new consistent label will include the below information presented consistently per portion of food:

\* The amount of energy - presented in kilocalories and kilojoules - fat, saturated fat, salt and sugar. This will be presented as Reference Intakes (RI) - formerly known as Guideline Daily Amounts (GDA) - and will show how much of the maximum daily intake a portion accounts for

\* a consistently determined red, amber or green colour-coding system (note the basis of this is per 100g not per portion except where the amount in a portion exceeds 30% of the RI)

Cost benefit studies have demonstrated that front of pack labelling could be both an effective and cost saving intervention against obesity. Evidence tells us that a combined scheme of colour-coding and nutritional information is preferred by consumers and is the labelling system that consumers can most easily use to choose healthier foods.

Source: Food Standard agency 2012

## Appendix 9: Participant Consent Form

Version 1 14/10/2011

**Title of Project:** Exploring the determinants of food choice and implications of dietary change among women of Black African and Caribbean descent with Type 2 diabetes

**Name of Researcher:** -----

Please initial  
box

1. I confirm that I have read and understand the information sheet dated..... (Version.....) of the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	
2. I understand that my participation is voluntary and that I am free to withdraw at any time	
3. I understand that relevant data collected during the study, may be looked at by individuals from the University of Essex, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I understand interviews will be audio-recorded. I understand that anonymous quotes may be used in any report, but I will not be able to be identified in these reports.	
5. I understand that the researcher will accompany me on a shop task and that a tape-recorder will be attached to my collar to record as I say aloud everything I am thinking while shopping. I give my permission to take part in this activity.	
6. I understand that confidentiality will be broken if any disclosure of neglect, abuse and criminality activity is made.	
7. I agree to take part in the above study.	

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person taking Consent                      Date                      Signature

When completed: 1 for participants; 1 for researcher site file

## Appendix 10: Interview Question Schedule

Version 1 14/10/2011

### Interview Question Schedule: (The interview should last about an hour)

Q1. Present products from the food 'basket'.

Following on from the shopping task, I am going to show you e.g. 4 food items you picked and will ask you whether or not you would eat each one with regard to your type 2 diabetes.

(There is no right or wrong answer, I am simply interested in your explanations about how you make decisions regarding type 2 diabetes.)

\* What was your experience about the Think Aloud Task?

(Probe-if not why? If you are not sure, try telling me why you are not sure.

-to assess concept of what makes a food healthy or unhealthy, are they interested in eating a healthy diet? Which foods will be the most difficult to change? Do these foods have any special meaning to you?)

Q2. Tell me about your background and interests

(Probe- why? What do you consider to be the key factors for your decision in food choice? What about when you eat out? )

Q3. Tell me what you like to eat?

(Probe-why?)

Q4. Why do you eat the food you mentioned?

(Probe- Where should we start?)

Q5. Tell me about any local activities you attend?

(Probe-why? Where? Do you get any support?)

Is there anything else you would like to add that you feel I have not covered in the interview?

### At the end of the interview

Thank you very much for giving up your time today for this interview. Do you have any questions about this interview?

I am now able to hand you a fruit and vegetable voucher as compensation for your time.



## Appendix 11: Research Ethical Approval



### Health Research Authority

NRES Committee London - City & East

South West REC Centre

Whitefriars

Level 3, Block B

Lewins Mead

Bristol

BS1 2NT

Telephone: 01173421386

Facsimile: 01173420445

21 January 2012

Mrs Margareth Rungarara-Keenan  
Doctorate student  
University of Essex  
Wivenhoe Park  
Colchester  
Essex  
CO4 3SQ

Dear Mrs Rungarara-Keenan,

**Study title:** What are the determinants of food choice and implications for dietary change among women of black African and African-Caribbean descent with type 2 diabetes?  
**REC reference:** 12/LO/0121

The Proportionate Review Sub-committee of the NRES Committee London - City & East reviewed the above application on 13 January 2012.

#### Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

## Appendix 12: Framework Analysis - Associative Central Chart

**Age:** 28, 42, 44, 46, 47, 54, 63, 68.

**Gender:** All Female

**Ethnic Origin:** Jamaica x 2, Trinidad & Tobago, Kenya, Tanzania, Uganda, born in UK x 2

**Current Employment History:** 2 educated unemployed on benefits, 1 assistant social worker, 1 lecturer (Further Education), 1 charity worker, 1 retired nurse, 1 Pastor's wife, 1 carer.

**Family status:** 3 single status, 1 widow with 2 teenage children, 2 married with children at home and 2 married with children left home.

### **Summary of factors influencing food choice:**

- Biological e.g. taste of healthy food, likes, dislikes
- Economic-cost, income, availability, affordability, value for money
- Physical e.g. education, access, cooking skills, time, convenience
- Knowledge about food, reading food labels, eat-well plate
- Social determinants e.g. culture, family, meal patterns
- Psychological e.g. emotions attached to food
- Attitude e.g. positive, negative,
- Beliefs e.g. religion, alternative paths, healing power of nature

### **Coping strategies for weight management and role of nutrition:**

- Varied with individuals e.g. controllable, struggle, stabilise,
- Older participants preferred gardening and church activities
- Food was a challenge for younger participants
- Diabetes was not a priority for all when eating out
- Having to prepare separate meals for family and events
- Shopping for family was a challenge

### **Summary of factors regarding physical activity:**

- Attitude to outdoor activities perceived as a threat
- Reluctance because of self-esteem and body image
- Did not see the benefits
- Avoidance
- Lack of motivation
- Preferred group activities
- Time is a factor

### **Summary of factors regarding health services:**

- How people found out about diagnosis
- Lack of follow up
- Contact with health professionals
- Relationship with GP
- Professional advice
- Professional attitude

### **Proposed interventions:**

- Supportive relationship from professionals
- Cultural relevant material
- More options about diabetes management e.g. how to control disease by diet only
- GP not engaging
- Lack of trust e.g. health professionals not monitoring progress, or giving information
- Access and sensitivity remains an issue

### **Attitude towards lifestyle changes:**

- Trying to restructure life
- Meaning behind diabetes for individuals and community
- Integrating advice rather than compliancy

## Appendix 13: Classification of obesity/overweight

### Classification of healthy and unhealthy weight in adults

BMI (kg/m <sup>2</sup> )	Classification	Risk of Obesity related co-morbidities
<b>Less than 18.5</b>	Underweight	Low
<b>18.5 to 24.9</b>	Desirable Weight	Average
<b>25.0 to 29.9</b>	Overweight	Increased
<b>30.0 to 34.9</b>	Obesity I	Moderate
<b>35.0 to 39.9</b>	Obesity II	Severe
<b>40.0 or more</b>	Obesity III (Morbidly obese)	Very severe

Source: WHO (2015)

### Waist-hip-ratio (WHR) or Waist Circumference

Waist circumference measurement is used to assess a patient's abdominal fat content or 'central' fat distribution (sometimes referred to as central or abdominal adiposity). Central obesity (fat) is linked to a range of diseases and/or complications such as higher risk of type2 diabetes, coronary heart disease, hypertension, etc. NICE recommends the use of BMI in conjunction with waist circumference to measure weight status and determine health risks for those with a BMI less than 35. For adults with a BMI of 35 or over, health risks are assumed to be very high with any waist circumference. The currently recognised waist circumference thresholds used to assess health risks in the general population are shown in the Table below:

### Waist circumference thresholds and risk categories for adults

	Male	<94cm	94 – 102cm	>102cm
	Female	<80cm	80 - 88cm	>88cm
<b>Healthy Weight 18.5 – 24.99</b>		No increased risk	No increased risk	Increased risk
<b>Overweight 25.0 – 29.99</b>		No increased risk	Increased risk	High risk
<b>Obese I 30.0 – 34.99</b>		Increased risk	High risk	Very high risk

Source: NICE (2006)