



EXAMINING POLICY IMPLEMENTATION
FOR TYPE 2 DIABETES: EXPLORING
BARRIERS AND ENABLERS ASSOCIATED
WITH UPTAKE OF STRUCTURED PATIENT
EDUCATION

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ABSTRACT

EXAMINING POLICY IMPLEMENTATION FOR TYPE 2 DIABETES:
EXPLORING BARRIERS AND ENABLERS ASSOCIATED WITH UPTAKE OF
STRUCTURED PATIENT EDUCATION

Background: Diabetes remains an incurable disease and as the search for a cure continues, the need to minimise complications and enhance the quality of life of patients is essential. A key UK policy initiative in the management of diabetes is empowerment through education. However, implementation of policy in the context of healthcare delivery in general may be challenging at times and the provision and uptake of diabetes education is not an exception.

Aims: This thesis aims to examine the barriers and enhancing factors that are associated with the uptake of structured patient education for patients newly diagnosed with type 2 diabetes.

Methods: The study used a sequential mixed methods approach. The data were collected using a focus group and face-to-face individual interviews of multi-professionals delivering the education, a questionnaire/survey of patients and individual face-to-face interviews of referring practitioners working in GP surgeries within a PCT.

Findings: Factors influencing non-attendance at diabetes education centres relate to barriers associated with the patients, practitioners and government regulations. The patients were affected by their healthcare beliefs and personal

circumstances such as work patterns, childcare problems, forgetfulness, bad weather and ill health. The practitioners' barriers were mainly around patient versus practitioner communication, inter-professional collaboration and administrative protocols. The barriers associated with the government directives relate to government regulations and funding issues. In contrast to barriers, the predictors of attendance are personal motivation, individual perceptions and beliefs coupled with the guidance given by the practitioners. Whilst it may be difficult to avoid non-attendance completely, positive steps to reduce non-attendance include enhanced communication, a positive pay-for-performance system and adequate support to develop a positive attitude towards diabetes education.

Conclusion: The results indicate that barriers to attendance are multifactorial and complex; therefore, response to improve uptake requires diverse interventions.

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DEDICATION

This work is dedicated to people living with a long-term condition.

'To raise new questions, new possibilities, to regard old problems from a new angle, require creative imagination and marks real advance in science.'

Albert Einstein (1879 – 1955)

'Few things are impossible to diligence and skill. Great works are performed not by strength, but perseverance.'

Samuel Johnson (1709 – 1784)

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OPERATIONAL DEFINITIONS

AADE – American Association of Diabetes Educators

ADA – American Diabetes Association

Asymptomatic – Patient that do not exhibit the symptoms of the disease

Attitude – The behaviour or response of a person to something

BBC – British Broadcasting Corporation

BHF – British Heart Foundation

Current research/study – This two words are used interchangeably in the thesis to refer to the research undertaken for this PhD programme of study.

CCG – Clinical Commissioning Group

CHRONIC DISEASE – Chronic disease refers to any long-term ill-health and the term long-term condition and chronic disease is used interchangeably in the thesis.

DAFNE – Dose Adjustment For Normal Eating

DEP – Diabetes Education Programme

DEC – Diabetes Education Centre

DESMOND – Diabetes education and self-management for on-going and newly diagnosed

DH – Department of Health

DM – Diabetes Mellitus

DNA – Did not attend

DSN – Diabetes Specialist Nurse

EUPH – European Union Public Health Information

FDH – Florida Department of Health

GP – A medical doctor working as a general practitioner (GP) in a GP surgery

GROUP EDUCATION - It is a diabetic education delivered to several patients at a time. It covers key areas, such as, blood glucose control, dietary management, and exercise.

HbA1c – It is referred to as glycosylated haemoglobin and it denotes the amount of glucose that is attached to the haemoglobin. It is used to measure the average blood glucose level for a period of 8-12 weeks

HBM – Health Belief Model

HCP – Healthcare practitioner

HEA – Higher Education Academy

IGT – Impaired glucose tolerance

IFG – Impaired fasting glycaemia

LTC – Long-term condition

MDE (Multi-Disciplinary Education) – Is a joint education session provided by different professionals – Diabetes Specialist Nurse, Podiatrist and a Dietician. It is a form of structured patient education that is delivered to a group of patients with diabetes

MRCEU – Medical Research Council Epidemiology Unit

NIDDM – Non-insulin dependent diabetes mellitus

NICE – National Institute for Health and Care Excellence

NHS – National Health Service

NMC – Nursing and Midwifery Council

NSF – National Service Framework

NCDCP – National Centres for Diabetes Control and Prevention

NDEP – National Diabetes Education Programme

NCDCP - National Centre for Disease Control and Prevention

OHE - Office of Health Economics

ONS - Office of National Statistics

PCDS- Primary Care Diabetes Society

PERCEPTION – The way an individual view an event

PHASE 1 – Phase one of the study (Focus group and individual interviews of diabetes educators)

PHASE 2 – Phase two of the study (Questionnaire survey of patients)

PHASE 3 – Phase three of the study (Individual interviews of referring practitioners)

PRACTITIONERS/PROFESSIONALS – The Diabetes specialist nurses, Podiatrist and Dietician delivering the structured group education to patients affected by diabetes. This also covers the Practice nurses and GPs who are involved in the referral process and commissioning of services.

PAHO - Pan American Health Organization

PHRU - Public Health Resource Unit

PSS – Personal Social Services

QOF - Quality and Outcomes Framework

RCN - Royal College of Nursing

Researcher – The term was used to refer to myself as the investigator for this current research

SBGM – Self blood glucose monitoring

SPE (Structured patient education) - It is a planned, flexible, and adaptable teaching covering all aspects of diabetes that is relevant to the patient needs. It is a diabetes education programmes delivered by a team of professionals.

RCT – Randomised Controlled Trial

T2DM – Type 2 diabetes mellitus

WHO - World Health Organization

CHAPTER 1

INTRODUCTION AND OVERVIEW OF THE THESIS

1.1. Introduction

The global challenges posed by a long-term condition in terms of cost and suffering cannot be underestimated (Furze et al 2008; Lorig 2007; World Health Organization (WHO) 2014). This introduction to the development of a research project aims to improve service delivery for a long-term condition by offering a brief background, aims and objectives, genesis of the study, and a justification for the study. In addition, it provides an overview of the research methods which are explored in chapter 3. Finally, later chapters outline the structure of the thesis.

Long-term conditions such as diabetes can be defined as a chronic or irreversible medical condition resulting in disability (Shaw 2007; WHO 2014) and it may cause physical, psychological and socio-economic problems (Department of Health (DH) 2004; Shaw 2007). Although long-term conditions cannot always be cured, they can be effectively managed, however it may require a long period of rehabilitation. There are several global and local policies and initiatives addressing the epidemic of long-term conditions. The National Service Framework (NSF) for Long-Term Conditions (DH 2005) focuses on the management of long-term conditions in general and this includes diabetes. In terms of specificity, the NSF for Diabetes sets out standards for twelve areas of

practice. The initiative proposed by this document emphasises diabetes service improvement (DH 2001). Despite availability of policies, preventing and managing long-term conditions remain a serious global issue.

1.2. Background of the study

Diabetes as one of the long-term conditions is a growing global concern and the epidemiology of diabetes is challenging. It represents one of the major health problems confronting the whole world, and in particular England (Bailey and Feher 2009; Gillibrand 2010a; WHO 2011). The rising prevalence of diabetes in the UK and its impact on patient wellbeing was echoed by the National Diabetes Inpatient Audit (2011). Diabetes is an insidious disease with many people with type 2 diabetes going undiagnosed for a long time (Bailey and Feher 2009; Brown 2012). Consequently, diabetes poses a serious health challenge, therefore, awareness and prevention are crucial to avoid a future health crisis.

The paradigm shift in management of diabetes from the basic disease model of the 1930s, which centred exclusively on treatment by healthcare professionals, to the recent integrated care approach involving the patients (Diabetes UK 2008a) stresses the importance of patient empowerment. Thus, the patient will require education, support and prevention of further disability from complications. According to Curzon (1990), learning offers the opportunity to alter a person's behaviour through various activities that may improve individual knowledge and skills. Uitewaal et al (2005) see diabetes education as the cornerstone of diabetic

management. In the same way, DH (2002) says that it is important to educate and empower the patient because a patient affected by diabetes spends an average of three hours a year with healthcare practitioners, and therefore, needs to manage themselves for the rest of the 8757 hours of the year.

As a result of the long-term nature of this non-communicable disease, the National Institute for Health and Care Excellence (NICE 2003; 2009a) guideline recommends structured patient education for every newly diagnosed patient with an annual update. Diabetes UK (2010) also sees diagnosis of diabetes as the beginning of a lifelong learning process and advocates that all patients who are affected by diabetes should receive relevant structured patient education such as Dose Adjustment for Normal Eating (DAFNE), Diabetes Education and Self-Management for On-going and Newly Diagnosed (DESMOND), Diabetes Education through Adult Learning (DEAL) or Expert Patient Programme (EPP). Similarly, Standard 3 of the NSF for Diabetes emphasises patient education and empowerment (DH 2001).

Several studies identify the beneficial effects of diabetes education in promoting self-care knowledge and care. Diabetes education programmes improve patients' knowledge of diabetes (Deakin et al 2006; Rygg et al 2012), reduce complications and hospital admissions (Cinar et al 2010; Karakurt and Kasiksci 2012), and promote healthy lifestyles (Davies et al 2008). Tang et al (2006) believe that diabetes self-management education has a positive health outcome

particularly in improving knowledge, blood glucose monitoring, attitude towards diet and exercise, glycaemic control, adherence to medication and coping abilities. Khunti et al (2012) conclude that diabetes education leads to improvements in some illness beliefs.

Despite the evidence supporting the benefits of structured patient education and the government directive, uptake of structured patient education still varies across the country. The statistics show that patients often fail to attend the structured patient education sessions for a range of reasons (Benoit et al 2004; Schafer et al 2013). Although it is accepted that not all the patients who are referred from the GP practice will engage with the education session, the rates of attendance could be improved. According to DH (2007b) documents on improving diabetes services, there is substantial evidence that not all patients with diabetes are aware of the need for structured patient education or access it. NICE (2009a) states that a significant number of people with long-term conditions do not fully comply with their treatment regimen leading to increased costs in healthcare due to deterioration of health. Also, DH (2005b) identified that most studies on diabetes focused on biomedical measurement. The document stated that there is a need for more studies on patient motivation, attitudes to monitoring and group dynamics.

In reality, the implementation of policy in the context of healthcare delivery may be challenging to the implementers at times and the delivery of structured patient

education to patients affected by diabetes is not an exception. One of the challenges of the government directive is the degree of non-attendance in structured patient education centres. NICE (2008) acknowledged that the majority of healthcare providers have difficulty implementing and resourcing structured patient education for patients with type 2 diabetes. Although non-attendance in hospital settings is a national problem, exploring ways to enhance attendance at Diabetes Education Centres within the South East of England is of great significance to the region and the whole country. This is important to reduce unnecessary hospital admissions, prevent avoidable complications, minimise waste of time and reduce healthcare costs (DH 2012b; Hasrold and Wootten 2011).

1.3. Aims of the study

The central aim of this thesis is to identify barriers and enabling factors associated with the uptake of structured patient education for people with type 2 diabetes. The rationale to focus on type 2 diabetes patient education is based on the incidence of the disease. According to the National Audit Office (2012), Nisal et al (2012) and WHO (2011), an overwhelming majority of patients with diabetes have type 2 diabetes.

In this study, my objective was to address the following research questions:

- What are the barriers associated with attendance from the perspective of patients and practitioners?

- What are the predictors of attendance at group education sessions designed to promote self-care management?
- What strategies might help improve the uptake of diabetes education?

1.4. Overview of the study

The discussions held with the practitioners and a critical review of relevant literature generated an impetus to investigate this phenomenon. A recent systematic review revealed limited documentation on the issue in the UK (Lawal 2014) and several other studies have identified the need for further studies in this area (Ngwenga et al 2009; Zailinawati et al 2006). Therefore, the choice of my current study emerged mainly from a practice gap. Consequently, the initial development of the study was influenced by practitioners to meet their clinical need. Thus, this study explores the problems associated with the implementation of a national directive, something which is crucial to them. To achieve the aims and objectives of the project, a sequential mixed method of study was utilised to investigate the phenomenon. The study was conducted in three phases and is referred to in the thesis as Phase 1, Phase 2 and Phase 3. Phase 1 was a focus group and individual interviews of diabetes educators, Phase 2 was a questionnaire survey of patients with type 2 diabetes (attendees and non-attenders) and Phase 3 was made up of individual interviews with referring practitioners working in GP surgeries.

Phases 1 and 3 looked at the phenomenon from the perspective of the practitioners while Phase 2 looked at the opinion of both non-attenders and attenders. This aspect of the study surveyed the opinion of attenders to gain an insight into what aided them to attend and what might have prevented them from attending the session while it enquired about the barriers to attendance from the non-attenders. The two-part survey allowed comparison between the views of the patients who attended the sessions and those who failed to attend. Phases 1 and 3 were both qualitative studies while Phase 2 has both quantitative and qualitative elements.

In total, the sample comprised 207 patients and 19 practitioners. Phase 1 used a sample of 10 practitioners (dietitians, podiatrists and diabetes specialist nurses) while Phase 3 used a sample of 9 practitioners (8 practice nurses and 1 GP). Phase 2 had a sample of 207 patients that were almost equally divided into two groups of attenders and non-attenders of diabetes education programmes. The researcher had initially undertaken a series of telephone interviews to capture the points of view of patients. However, the outcome was not useful because the quality of the data collected was too superficial. As a result, the researcher undertook this final version of the study, a new series of face-to-face interviews with the referring practitioners.

The questionnaire survey offered a statistical insight into the research questions. Realising the limitations of reducing all human experiences to a measurable

value (Polit and Beck 2009; Lincoln and Guba 2000; Fontana and Frey 2005; Parahoo 2006), face-to-face interviews were held; focus group and questionnaires with open-ended questions which provided complementary approaches to gain insight into the subjective experiences of the participants were used. This approach was guided by Kelly (2002) who suggested that exploration and adequate understanding of reasons for non-compliance with treatment may lead to solutions.

1.5. Thesis plan

Chapter 1 sets out the focus of the thesis by offering a brief introduction and background information. The chapter offers a brief discussion of the threat of non-attendance in clinical practice. In addition, it identifies that there are barriers associated with implementing the government directive of structured patient education and explored the need to enhance attendance. This chapter also states the purpose and origin of the study. Finally, it provides a brief introduction of the research approaches and concludes by giving an overview of the whole thesis.

The second chapter critically reviews and synthesises previous research studies on the phenomenon to identify the gap in current knowledge and research. This chapter explores the incidence of diabetes and models of care for long-term conditions as opposed to acute medical problems. It also gives an overview of diabetes mellitus and offers some understanding of the disease condition. It

provides the socio-political context of the study, cultural and social perspectives of diabetes, and explores the government's stance in relation to diabetes self-management education programmes. This chapter also covers structured patient education programmes for diabetes, the role of education in healthcare and highlights the key aspects covered in the education session. Furthermore, it discusses the Health Belief Model (Becker et al 1978) in relation to the promotion of health autonomy. These are important aspects that could illuminate the issue.

Chapter 3 presents the methodology for this research, including the philosophical underpinning, research design and methods adopted in each phase of the study. In this chapter, the research techniques used for the study will be discussed and justified. Thus, it covers the methodology for focus group interviews of practitioners, questionnaire surveys of patients and face-to-face interviews of practitioners.

The empirical findings for the study are presented in chapters 4 to 6. Chapter 4 provides the perceptions and beliefs of education providers regarding barriers related to non-attendance amongst patients that are affected by type 2 diabetes. Chapter 5 reveals the reasons for attrition in structured patient education centres from the perspectives of the patients. It examines the reasons contributing to attendance and non-attendance from both the perspectives of attenders and non-attenders who were surveyed. Chapter 6 focuses on the final set of data:

referring practitioners' views on barriers to attendance and reasons that could aid attendance were further explored through face-to-face individual interviews.

The discussion of the findings is presented within the theoretical context of the Health Belief Model (Becker et al 1978) in chapter 7. This chapter integrates all the three phases of the study, critically appraises the research findings and discusses the emerging themes. This contextualises the differences between the views of the practitioners and patients. The identified issues are further explored under five concepts: healthcare beliefs, patient-centred care, transcultural care management, communication and bureaucracy. These concepts captured the barriers and enhancing factors associated with attendance. It provides an exploratory framework for the contributory factors to non-attendance. The implications of these influences are also discussed.

Chapter 8 is a detailed illustration of strategies that could promote attendance in structured patient education centres. In addition to providing an insight into the barriers, this chapter offers some suggestions to mitigate the problems of non-attendance in diabetes education centres. This provides useful insights to improve the implementation of the policy and forms the bedrock for recommendations made in chapter 9.

Chapter 9 revisits the objectives of the study and draws conclusions in light of the strengths and limitations of this work. It highlights the clinical importance of the

study and makes recommendations for professional practice. This final chapter of the thesis draws conclusions from the analysis of the data and provides recommendations for practitioners and policy-makers who are involved in planning, developing and implementing the delivery of diabetes education programmes.

1.6. Summary

There is no clear answer to the long-standing problem of non-attendance in clinical practice, particularly in diabetes education centres. This introductory chapter has given a general overview of the research on this phenomenon and an outline of the chapters in this thesis. Specifically, it has given a brief background to the study, explored the issues surrounding non-attendance, the aims and objectives of the study, and offered an overview of the whole thesis. In addition, the focus of the research, scope and rationale are introduced to orientate the reader. Having provided an introduction to the study, subsequent chapters will explore the problem of non-attendance. To put the study within the international and local context, the next chapter presents a systematic review on the phenomenon and discusses the socio-political context.

CHAPTER 2

LITERATURE REVIEW

2.1. Introduction

Although there is a general improvement in health outcomes of the British population, there remain areas of challenge, and the rising rates of diabetes and obesity is one of them (DH 2007b). Therefore, Britain would benefit from improved implementation of health policies pertaining to people affected by diabetes. This Chapter aims to review the literature that is pertinent to this research study and it will be divided into two broad sections. The first section presents a systematic review of studies that investigated the phenomenon. The second section will generally explore literature that is relevant to the research topic. This section presents an overview of diabetes by covering key areas such as its prevalence, aetiology, clinical manifestations, cultural implications and management options of diabetes. It discusses the socio-political context of the health problem; diabetes education programmes and explores the argument for and against group versus individual diabetes education programmes. The latter part of section two covers the theoretical models of health behaviour with emphasis on a particular Health Belief Model.

SECTION 1

2.2. SYSTEMATIC REVIEW OF STUDIES RELATING TO NON-ATTENDANCE IN DIABETES EDUCATION CENTRES

2.2. Introduction

The aim of this systematic review was to analyse the empirical evidence relating to barriers associated with non-attendance in Diabetes Education Centres. The first part of the review will illuminate how the search was conducted to retrieve relevant literature. Then, the selected literature will be critically appraised and the findings of relevant studies will be synthesised. Equally, the summaries of the studies will be presented on a table. The final part will draw a conclusion from the studies and discuss the implications of the findings to clinical practice. Therefore, the focus of this aspect of the thesis was to systematically review relevant literature in order to reveal what has already been known on this subject, identify the gaps in current knowledge and evidence with the view to identifying the key issues that require further exploration.

2.2.1. Objectives of the review

The aim of this review was to identify barriers associated with attendance in Diabetes Education Centres.

2.2.2. Methodology

A systematic literature search was undertaken to identify relevant articles that explored non-attendance in relation to diabetes education. The health related

databases searched were CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE, OVID, PUBMED, EMBASSE and the COCHRANE LIBRARY. The databases often used by nurses include MEDLINE and CINAHL (Barker 2010) and Parahoo (2006) argued in favour of combining Medline and CINAHL to search for health related studies. Thus, these databases are the most widely used by healthcare professionals as they provide international and comprehensive relevant peer-reviewed research articles on health related topics. In addition to using various electronic databases (Aveyard 2010), a hand search for references of key articles was also performed in line with Parahoo's (2006) recommendations (Table 2.1).

Table 2.1: Database sources

Data base	Cinahl	Medline	Ovid	Cochrane	Embase	PubMed	Web host	Supplementary search
Date covered	1984 - 2013	1948 – 2013	1946- 2013	2005 - 2013	1980 – 2013	Inception to 2013	Inception to 2013	Reference sources
Number of selected articles	1	2	1	0	2	0	4	4

The key words used were diabetes self-management education, attrition, drop-out, missed appointment, did not attend, barrier to attendance, non-attendance and diabetes education. Using a more refined criteria and key search terms often leads to more specific and useful results (Ogilvie et al 2005 and Hek and Moule 2006). The Boolean operator was used to filter the data collection by either decreasing or expanding the quantities of articles. The Boolean keywords combinations 'and' coupled with 'or' were used to join the key words such as

'diabetes' with 'self-care management', 'attrition' or 'missed appointment' to broaden the search while 'not' was used to narrow and exclude some resources. Due to the large amount of information available in the library and databases, some authors such as Levin (2009) and Aveyard (2010) advocated for the use of inclusion and exclusion criteria to identify the most recent and relevant research. Applying eligibility criteria enables the researcher to obtain relevant literature and exclude irrelevant sources through a careful evaluation of available literature.

The initial broad exploration of the topic identified hundreds of hits that were informative but were not appropriate for the review; therefore, a high proportion of papers were reduced through limiters. The selection of relevant quality papers included in the review was based on non-compliance in patients with diabetes, studies investigating barriers in educational settings, written in English language, world-wide research, peer review publications and primary research papers or systematic reviews (Table 2.2). Conversely, the exclusion criteria were studies written in other languages, research studies on non-attendance in relation to other disease conditions or settings and documents that were not peer-reviewed.

Table 2.2: Eligibility criteria

Inclusion criteria	Exclusion criteria
English language publications	Other languages
World-wide research	Documents that were not peer-reviewed
Publications from inceptions to July 2013	Non-attendance associated with other medical conditions
Systematic reviews	Studies related to non-educational settings
Primary research papers	Studies that were not research papers
Full text peer review articles	
Studies on non-attendance associated with diabetes education	

Although, the date of the search is another potential limiter, the results were not limited by date. Whilst Polit and Beck (2006) emphasised the importance of using research articles within the last five years, Bowling (2009) warns that this might lead to excluding some relevant papers. Although non-attendance in clinical practice is an old problem and service delivery continues to evolve, reasons for non-attendance have always been less variable, hence, time limit was not considered. The research papers within the last 5 years/recent studies may reflect current practice and knowledge, however, inclusion of old literature affords the opportunity to add all the relevant studies that could illuminate the phenomenon in question. Therefore, a comprehensive search of key words from the earliest possible date to July 2013 was conducted. The first apparent reason

for not meeting the inclusion criteria were studies that were not related to non-attendance in Diabetes Education Centres. In total, 14 research papers were suitable for inclusion and all the articles were research articles published in peer-reviewed journals.

2.2.3. Review of the articles

A literature review can provide essential information on patient care (Ellis 2010; Dawes et al 2005; Timmins and McCabe 2005) and carrying out a review provides reliable and valid literature to answer a particular question. Both Aveyard (2010) and Bowling (2009) emphasised the importance of evaluating the available evidence to inform practice. Polit and Beck (2006) stated that a research critique must evaluate the validity and credibility of relevant studies and highlight the weaknesses and Hill and Spittlehouse (2001) stressed the need for critical appraisal to explore the rigour of relevant studies. Therefore, the research papers will be critically appraised through systematic examination to judge their value and relevance in clinical practice (Aveyard 2010; Bowling 2009; Glasper and Rees 2013) by using the Critical Appraisal Skills Programme (CASP) tool as a framework. The key features of each piece of research that met the inclusion criteria are displayed in a table (Appendix 1).

Six of the 14 studies were conducted in Canada, five from the United States of America, one from Germany, one from Turkey and the only systematic review selected covered a wide geographical spread ranging from America to Europe. The geographical setting is a key issue in judging whether the findings can be

translated to another locality (Ellis 2010), thus, applying the findings to another country needs to be cautiously addressed. Generally, the authors have a wide academic and professional experience which adds to the credibility of the limited studies available on the phenomenon. Also, 13 (93%) of the selected articles are primary research except Gucciardi (2008) which was the only available systematic review relevant to the research question.

All the studies explored the reasons for non-attendance in Diabetes Education Centres, however, some of the research focused on the characteristics of the subjects as opposed to addressing the barriers in general. Only one American study surveyed the perspectives of practitioners through a mail survey of a diabetes educators association (Sprague et al 1999). In all, this review showed that studies on this phenomenon dated back to over two decades in America (Graber et al 1992) with no single specific study on this particular phenomenon in the UK. The systematic survey conducted by Gucciardi (2008) included non-attendance in diabetes clinics instead of solely focusing on attrition from Diabetes Education Centres. Similarly, Temple and Epp (2009) studied attrition from both diabetes and heart education programmes.

Although, the systematic review of 14 research papers conducted by Gucciardi in 2008 included four UK papers, these studies did not meet the inclusion criteria for this review. One of the studies was a letter to the editor (Lloyd et al 1990). Also, Scobie (1983) and Archibald (1992) retrospective studies coupled with Hammersley (1990) case control study focused on clinic attrition as opposed to Diabetes Education Centres. In addition, another retrospective study (Kellet

1988) from Ireland which was included studied non-attendance in the hospital clinic. Understandably, all these studies were conducted before the advent of key policy documents such as the National Service Framework for Diabetes (DH 2001) and NICE guidelines (NICE 2003; NICE 2009a) which recommended SPE in England.

Almost half of the studies did not discuss the ethical process adopted (Gucciardi et al 2012; Uitewaal, Hoes and Thomas 2005; Rhee et al 2005; Temple and Epp 2009; Sprague et al 1999, Graber et al 1992) and one study used verbal informed consent (Graziani et al 1999). However, two studies reported that they sought institutional approval (Gucciardi et al 2008; Gucciardi et al 2009). Three studies stated that ethics approval was granted by the board while the last study which is secondary research does not require any ethical approval. Ethics involved the process of protecting the subjects (GMC 2010; DH 2009). Arguably, it is possible that these countries have different ethical guidelines to the UK or the inability to discuss the ethical considerations of the studies in depth may be due to a limitation resulting from limited word count required by the journal.

With the exception of a systematic review which was included in this review, a total of 3,926 patients constituted the sample. The sample comprises 3,527 patients (89.8%) that attended the hospital, 256 non-attenders (6.5%) and 143 practitioners (3.6%) across various countries apart from the UK. The sample size varies widely and Rhee et al (2005) had the largest population of all the 14 studies while Uitewaal and Thomas (2003) had the lowest sample size of 45 patients. Rhee et al (2005) studied 605 sample populations of attenders using a

cross-sectional design. Again, the sampling technique of most of the studies is convenience sample. Unlike a quantitative study which uses sample size as the driver for statistical analysis with the intention to seek generalisations, qualitative study is not a research method dependent on sample size. Thus, a qualitative study tends to use non-probability sampling (Polit and Beck 2009; Procter et al 2010) as a way to collect information from key participants (Procter et al 2010; Tod and Joanne 2010).

The included studies were eight survey studies, three retrospective studies, and two controlled experimental study and one systematic review (Gucciardi 2008). Although Randomised Control Trial (RCT) is considered to be the most rigorous method often termed the 'gold standard' (Ellis 2010), it is not suitable for the research question of this systematic review. Qualitative study is a person-centred study focusing on understanding the feelings, opinions and actions of the participants (Holloway 2005; Offredy and Vickers 2010); therefore, it is an appropriate methodology to study this problem. The majority of the studies adopted a descriptive approach and used questionnaires and interviews to collect data.

2.2.4. Results

Half of the articles (7) indicated that low perception of the seriousness of the disease constituted a barrier to attendance. Almost half of the research articles (6) also found that low perception about the benefits of the session prevented the patients from attending the session. Six studies found transportation, distance

and travel expenses as a hindrance to attendance. Almost half (6) of the studies identified work-related problems as a factor contributing to attrition in diabetes education centre. Schafer et al (2013) reported negative feelings about group education whilst only Gucciardi (2008) identified inability to contact the clinic as a barrier. Also some smokers defaulted probably because the session encouraged smoking cessation (Graber et al 1992; Benoit et al 2004).

Rhee et al (2005) and Schafer (2013) both reported poor vision and hearing as a barrier to attendance. Two studies also stated that family problems (Gucciardi 2008; Schafer et al 2013), forgetting (Temple and Epp 2009; Gucciardi 2008) and seeing a family physician (Gucciardi 2008; Gucciardi et al 2008a) prevented some participants from attending the education session. Other barriers reported by a single study are previous exposure to diabetes education (Gucciardi et al 2008a), inconvenient time and location, insensitive interaction with the professionals and a long waiting list (Gucciardi et al 2012).

The results of four studies indicated different types of insurance cover or cited the financial implications of the education as a problem while another three studies identified lack of adequate publicity as a barrier. Two of the fourteen research articles reported preference for physicians to manage their medical condition while four studies found low level of education as a reason for non-attendance. Failure to attend the session due to ill-health or lack of interest was identified by four studies.

Finally, some characteristics such as male gender and smoking (Gucciardi et al 2009; Graber et al 1992; Benoit et al 2004), being aged over 65 years (Gucciardi et al 2007; Gucciardi et al 2008b; Rhee et al 2005), inability to adhere to weight loss (Gucciardi et al 2009), and having diabetes for over 5 years (Uitewaal, Hoes and Thomas 2005) were reported as contributory factors to attrition behaviour. These characteristics of non-attenders have been identified by other studies (Dyer et al 1998, Masding et al 2010 and Ngwenya et al 2009). Ajay and Rubin's (2003) systematic review of non-attendance in general practice revealed that although the epidemiology of non-attendance is well researched, there are limited studies on the reasons for non-attendance in primary care suggesting this is an area for study.

In all, findings related to personal problems and perceptions and attitudes to diabetes education cut across the majority of the studies for this review. Also, all the research articles have highlighted the importance of enhancing attendance and the need for further studies in this area. Thus, judging from this literature review, there is still no clear answer to the problem of non-attendance in Diabetes Education Centres.

2.2.5. Discussion of findings

This systematic review investigated barriers to attendance in Diabetes Education Centres and the articles produced a wide variety of evidence which will be synthesised and grouped into themes. The findings of the articles indicated

various barriers ranging from personal problems and beliefs to lack of motivation. Consequently, the findings were conceptualised under four broad areas: personal difficulties, perceptions and attitudes of patients, communication and motivation (Table 2.3).

Table 2.3: Emergent themes

Themes	Articles
Personal difficulties	Temple and Epp 2009; Graziani et al 1999; Gucciardi et al 2007; Gucciardi et al 2012; Schafer et al 2013; Rhee et al 2005; Gucciardi et al 2008a; Gucciardi et al 2008b and Sprague et al 1999; Benoit et al 2004; Graber et al 1992.
Perceptions and attitudes of patients	Temple and Epp 2009; Schafer et al 2013; Graziani et al 1999; Gucciardi et al 2008b; Gucciardi et al 2012; Sprague et al 1999; Gucciardi 2008; Uitewal, Hoes and Thomas 2005.
Communication	Temple and Epp 2009; Graziani et al 1999; Gucciardi et al 2007; Gucciardi 2008.
Motivation	Temple and Epp 2009; Graziani et al 1999; Gucciardi 2008; Gucciardi et al 2008b; Schafer et al 2013.

Emergent themes

Theme 1: Personal difficulties

The majority of the findings (Table 2.3) reported barriers related to the effect of personal circumstances on attendance. Almost all the studies identified personal difficulties such as work-related problems, family problems, illness, transportation, distance and travel expenses as a barrier. Other personal difficulties impacting on attendance identified by this study were poor vision and hearing coupled with inconvenient location and time. Several other authors have identified different personal difficulties as a barrier to attendance in clinical practice (Hamilton et al 2002; Stones et al 1999; Zailnawati et al 2006).

Three US based studies (Graziani et al 1999, Benoit et al 2004 and Sprague et al 1999) identified the insurance status of the patients as one of the difficulties encountered by the patients. In contrast, the NHS in the UK has a different funding system which depends largely on state funding and therefore healthcare is free at the point of delivery. Although, the NHS is largely funded by national taxation in the UK (Baggott 2010), non-attendance in Diabetes Education Centres has negative resource implications for Clinical Commissioning Groups and service providers. Lister (2005) and Baggott (2010) suggested that the NHS continues to face financial pressures and Saltman and Cahn (2013) argued that restructuring healthcare sectors in Europe is inevitable for the policymakers to reduce unsustainable cost.

Theme 2: Perceptions and attitudes of patients

Helman (2007) acknowledged the influence of perceptions and beliefs on people's choice of health intervention. In a similar way, perceptions and attitudes towards education were identified by some studies. Some patients failed to attend the session owing to their personal perceptions and beliefs such as their perceptions about the nature of diabetes and their perceptions about the benefits of the session. Several other studies have identified the impact of these negative perceptions on attendance for a long time (Glasgow et al 1997, Gucciardi et al 2008). Another perception and attitude that affected attendance is the perception that the physician needs to manage their diabetes with little or no personal input from them. Metcafe (2005) stated that this traditional paternalistic approach of the NHS towards patient care is outdated for patients with long-term conditions to prevent unnecessary admissions and improve their quality of life and independence. Rana and Upton (2009) also stated that empowerment entails involving patients in the management of their own care. However, the instigation to sustain a healthy behaviour is often due to individual social, psychological and environmental factors.

Theme 3: Communication

The review found that some patients did not attend the education session because of poor communication. These issues included patients' inability to speak or read English language very well, inability to contact the clinic, not being aware about the service and insensitive interactions with the professionals.

Similarly, patients are less likely to attend when there are long gaps between booking and the date of the sessions. The benefit of prompt and effective communication between the patients and care providers is well documented in the research literature (Collin 2009; Webb 2011). While barriers to attendance relating to communication may vary, the onus is on the healthcare professionals to enhance effective communication to aid attendance.

Theme 4: Motivation

The review illustrated the impact of individual motivation on attendance as some patients forgot the appointments; certain people were too busy to attend or were simply not interested in the education sessions. Others cited lack of time or lack of familiarity with the centre or the service as factors that prevented them from attending the sessions. A well-motivated learning experience may alter individual behaviour; however, DH (2001c) stated that research evidence and practical experience suggest that the patients are central to the concept of empowerment. Schafer et al (2013) emphasized the importance of motivation in diabetes education by stating that the success of the programme depends on the willingness of the patients to engage with the education. Self-care management requires the patients' own willpower to overcome some predicaments; therefore, motivation is crucial to this self-management intervention.

2.2.6. Limitations of the review

The methodological quality of the review was limited. There was a question about the level of evidence provided by these studies due to the low number of participants often studied by each research study. The limitation of the studies included lack of probability (non-probability) selection methods such as purposive and convenience sampling (Holloway 2005). A key methodological weakness was that the majority of the participants studied were patients that attended the hospital as opposed to predominantly surveying the opinion of non-attenders. This systematic review also showed that some studies described the characteristics of non-attenders and reasons for missed appointments whilst a few are retrospective medical chart reviews. Another major limitation was that most of the available studies were from other countries which had a different funding approach, mostly private health insurance, based on single practice and of short duration. Therefore, applying the findings to the UK setting has its limitations.

2.2.7. Implications of the review

This review revealed that various reasons such as miscommunication, bad time management, personal beliefs, individual circumstances and motivation are responsible for non-attendance and this might result from either the patients or practitioners. Ajay and Rubin (2003) argued that non-attendance could result from both the patients and providers such as the doctors and nurses. Although there are several international research studies on non-attendance in general, a

significant amount of the studies target attenders while some of the studies surveyed the views of non-attenders. Arguably, it is possible to explore the views of attenders to understand the reasons for missed appointment, nevertheless, the motivation for attendance in these two groups of patients may differ. The paucity of studies in this area might probably be due to the fact that these groups of patients that fail to attend hospital appointments are difficult to access. According to a systematic review carried out by Ajay and Rubin (2003), investigating reasons for non-attendance in primary care presents some obvious methodological problems because this group of patients might not be willing to participate in research and may see it as being confrontational if not handled with care.

In all, there is a continuous need for on-going education and support for patients affected by diabetes regardless of the challenges posed by non-attendance. This piece of secondary research has drawn upon a range of primary research papers and presented a wide ranging account of reasons for non-attendance in Diabetes Education Centres. Although there is a body of evidence on non-attendance in Diabetes Education Centres from America and Canada, there is limited documentation of this phenomenon in Britain; therefore, there is a strong reason to investigate this problem within the British context. Despite the existence of research studies outside the UK for over two decades, solving this problem remain a global challenge. Again, the methodological limitations such as findings based on retrospective data and focusing on attendees make it difficult to make firm conclusions.

SECTION 2

THE CONTEXT OF THE STUDY

2.3. An overview of diabetes

Diabetes mellitus (DM) can be simply defined as a long-term condition resulting from failure of the pancreas to produce adequate insulin or ineffective use of the insulin produced by the body. Poorly managed diabetes may lead to complications such as blindness and amputation (NICE 2011; WHO 2011). WHO (2011) classified DM into four main categories: type 1, type 2, gestational diabetes and impaired glucose tolerance (IGT)/impaired fasting glycaemia (IFG). Most patients suffer from type 2 diabetes (Levene 2003; Smeltzer and Bare 2004) and (WHO 2011; Waugh and Grant 2010) claim it accounts for almost 90% of diabetes. Furthermore, diabetes is an international medical problem and the incidence continues to rise worldwide (Diabetes UK 2012; WHO 2011; ADA 2008; DH 2006b).

Newman et al (2002) argued that the increased prevalence may be due to improved treatments which probably result in longer survival. Wild et al (2004) stated that a vital demographic change in terms of prevalence of diabetes across the globe appears to be due to the increase in the number of people over 65 years of age. Likewise, the American Diabetes Association (2008) attributed increased prevalence to improved diagnostic techniques, enhanced detection methods, decreasing mortality, increasing number of elderly people and increased prevalence of overweight and obese people. Shield (2012) also states

that there is interdependence between the prevalence of diabetes and obesity. Whatever the reason behind the epidemiology of diabetes, focusing on prevention seems logical in the face of increasing prevalence of diabetes. Therefore, this justifies the Government directives of empowering patients through structured patient education programmes.

The risk factors of diabetes includes increasing age, obesity, lack of exercise, family history, ethnicity, previous gestational diabetes and impaired fasting glycaemia or impaired glucose tolerance test (WHO 2011; Waugh and Grant 2010; Diabetes UK 2008b). The initial symptoms of type 1 diabetes are generally acute while the onset of type 2 diabetes is more insidious and may be detected incidentally during a routine medical check (Marie and Whitaker 2004). The symptoms of all types of diabetes mellitus include increased urinary output, increased thirst and increased appetite, fatigue, sudden visual changes, numbness in the feet or hands, recurrent infections and delayed wound healing (WHO 2011; Smeltzer and Bare 2004). Diabetes increases the mortality rate of the affected individual (Marie and Whitaker 2004).

The goal of diabetes management is to maintain the blood glucose level within the normal range of 4-8 mmols/l through a combination of pharmacological treatment and lifestyle modifications, which focus on a diet and exercise regimen (WHO 2011; Dixon and Salamonson 2006). The diabetes team has a significant role to play in caring for people affected by diabetes and a key aspect of their role is to provide adequate information to aid self-management skills. Therefore,

structured patient education should help the client and their family to understand how to manage diabetes by offering education about the disease, for example, importance of nutrition, monitoring, compliance with the management regimen and how to recognise signs of complications. This has led to the establishment of various Diabetes Education Centres which deliver structured patient education to the affected patients.

Globally, structured patient education is considered as a vital aspect of diabetes management. National Institute for Health and Care Excellence (NICE 2011) stated that type 2 diabetes has multiple risk factors and wide ranging complications. Therefore, NICE emphasised the importance of education for people affected by type 2 diabetes because of the required life changes involved, complexities of management and the side effects of medication. Regardless of the evidence supporting the benefits of diabetes education, non-attendance constitutes a problem. Graziani et al (1999), Temple and Epp (2009), Schafer et al (2013) and Gucciardi et al (2009) opined that the use of diabetes self-management education programmes is often challenged by non-attendance. To show the magnitude of the problem of non-attendance in clinical practice in England, it is still a common thing for healthcare practitioners to display the number of failed appointments on the walls at casualty, Diabetes Education Centres and in other clinics.

2.4. Non-attendance in clinical practice

Non-attendance in Diabetes Education Centres appears to be a recognised global problem as studies on this problem have been done in Germany, Turkey and in America and Canada (Benoit et al 2004; Gucciardi et al 2009; Schafer et al 2013; Uitewaal, Hoes and Thomas 2005). Although several interventions such as calling the patient closer to the appointment date and sending a letter of reminder has proved useful to some extent, nevertheless, non-attendance remains a problem with huge financial loss to the NHS. Ngwenya et al's (2009) research concluded that more studies are required on possible interventions to minimise non-attendance for patients affected by diabetes. Zailinawati et al (2006) study further recommended that studies involving patients and healthcare providers aimed at reducing the rate of non-attendance in patients with long-term condition is needed. Gillibrand (2010a) stated that further study is required to explore motivation and behaviour of people with type 2 diabetes to health education. Lawal's (2014) systematic review identified paucity of information on this phenomenon in the UK and recommended further primary research in this area of study.

The issue of improving attendance rates of patients' in general clinical practice is increasingly becoming an area of concern in self-care management. DH (2009b) states that 57,083 outpatient referrals were missed within the South East Coast Strategic Health Authority in the third quarter of 2008. The quarterly figures submitted by each NHS trust and PCT for January to March 2011 revealed that

375,443 first outpatient appointments were missed within this period and follow-up appointments resulted in an almost one million non-attendance rate. DH (2012) data on the number of patients who did not attend their outpatient appointment without an advance warning revealed that non-attendance remains a serious problem in general clinical practice. Although Did-not-attend (DNA) is relative to the number of total referrals, London had the highest number of DNA. The rate of non-attendance of 63,334 for follow-up booking in South West of England is also high in comparison to other areas such as the North East, South East Coast and South Central strategic health authorities.

Although missed hospital appointments for medical interventions is a recognised national problem in England (DH 2012b), a wasted hospital appointment resulting from non-attendance leads to inefficient use of precious NHS resources (DH 2012b; Car et al 2012; Hasrold and Wootten 2011; Hogan et al 2008; Bech 2005). Zailinawati et al (2006) affirmed that a missed appointment causes disruption to the clinic schedules and increases the workload of staff. Similarly, George and Rubin (2003) identified that non-attendance results in both time and financial loss. Beecham (1999) reported that a survey of 374 GP practices between July and August in the United Kingdom revealed that 5,520 GP appointments were missed per week costing an estimated sum of £150 million worth of appointment time. Non-attendance is an expensive problem and tackling it has been very difficult. In view of the financial implications and the

resultant pressure on health budget, non-attendance urgently needs to be further addressed.

2.5. The socio-political context of the study

Although the primary aim of health promotion is not cost saving, there is evidence to suggest that health promotion can save money by reducing healthcare costs (Cohen and Hale 2002). Health promotion is a process that offers an individual the ability to control and change their lifestyles in order to improve their health (Kozier et al 2008). Empowerment is a fundamental principle to health promotion and education is crucial to health promotion (Anderson and Funnel 2009; Weare 2002). The definitions of empowerment are many but they generally emphasise a patient taking greater control of their medical condition (Rana and Upton 2009, Adams 1996). Adams (1996); Rana and Upton (2009) agree that the element of empowerment entails involvement of the service users in the planning, delivery and evaluation of their care. Therefore, the shift in focus of diabetes care from dependence on healthcare staff to self-care management is not an exception.

The shift in emphasis from health provision to health promotion is a global phenomenon (Baggott 2004). The renewed global interest in primary care is further confirmed by the World Health Report 2008. The report focused on 'reinvigoration of primary healthcare' after 30 years of the initial Primary Healthcare (PHC) declaration at Alma Ata (now Almaty) (WHO 2008). However,

when the NHS was established in 1948, the founding principle was to improve health and prevent disease, not only to treat ill people (DH 2004b), and this vision of the NHS still continues. Since the establishment of the NHS in 1948 to date, patients have become more active, empowered and encouraged to take more control over their health (DH 2008); nevertheless more has to be done. According to the DH (2008) document published to mark the NHS 60th anniversary, prevention will continue to be high on the health agenda with the NHS promoting good health as opposed to treating ill health. This further justifies the policy of educating all patients with diabetes as a form of preventive measure.

The NHS is under severe budgetary pressure and the cost of healthcare services continues to grow fast. By 1991, the social security budget rose from £10million to over £2,000million and the Thatcher government embarked on several reforms when they came into power (Lewis and Glennerster 2000). The monetary view adopted by the Conservative government after 1979 included cutting of welfare costs to minimise an increase in direct taxation (Jones 2000). The introduction of general managers to the NHS in the 1980's as a measure to reduce public expenditure was an example (Malin et al 2002). The Labour government elected in May 1997 adopted the 'third way' in welfare. This approach emphasised greater involvement of service users in decision-making and professional power controlled through clinical governance and 'best value' policies (Jones 2000). The issue of reform was further re-echoed by the coalition government and more

changes were brought into effect with the Health and Social Care Act 2012 (DH 2011) in April 2013.

Baggott (2004) states that despite the different ideologies and political styles of each Government, the NHS remains largely funded by national taxation and healthcare sector continues to face financial pressures due to rising public expectations and financial pressures resulting from new technologies. Davies et al (2000) states that healthcare policy changes cross party lines with discernible differences. Butcher (2000) identified several characteristics that underpinned the traditional model of welfare delivery in Britain since 1945 as bureaucracy, professionalising, public accountability, equitable treatment and self-sufficiency. However, the former self-sufficient Department of Health Agencies is being replaced by an NHS operating on a new value system of high efficiency and value for money, competition and customer care (Butcher 2000) as opposed to a bureaucratic organisation. Consequently, wastage owing to non-attendance is seen as an unacceptable practice when attempting to cut down cost, ensure value for money and provide quality service to the entire population.

There is a body of literature alluding to the negative impact of bureaucracy in the healthcare service (DH 2010; Government Equality Office 2011; Malin et al 2002; Butcher 2000). Historically, the advent of industrial developments and increased complexity of organisations such as the National Forces and government establishments led to the growth of systems of social organisation and

bureaucracy with emphasis on routine procedures, control and specialisation (Hatch and Cunliff 2006). Huczynski and Buchanan (2001) states that bureaucracy corresponds to an organisational performance based on legal and rational type of authority. The structure of a bureaucratic organisation is characterised by specialised labour, hierarchy of authority and a formal set of rules and selection criteria. They argue that these characteristics could be a hindrance to organisational performance and therefore see it as a 'disease' (Table 2.4).

Table 2: 4 - Bureaucratic diseases and interventions		
Bureaucratic disease	Symptoms	Cures
Rigid functional boundaries	Conflict between sections, poor communication	Team building, job rotation, changes to the structure
Fixed hierarchies	Frustration, boredom, narrow specialist thinking	Training, job enrichment, career development
Information only flows down	Lack of innovation, minor problems escalate	Process consultation, management development
Routine jobs, tight control	Boredom, absenteeism, conflict for supervisors	Job enrichment, job rotation, supervisory training
<i>Source: Adapted from Huczynski & Buchanan (2001:489) Organisational Behaviour: An introductory text.</i>		

According to Hatch and Cunliff (2006), by conceptualising Weber's theory of bureaucracy (1924) which was originally published in Germany in his *book The theory of Social and Economic Organisation*, the structure of organisation can be classified into three main components namely: division of labour, hierarchy of authority and formalised rules and procedures. The first component relates to the

distribution of responsibilities and tasks among the workers whilst the second component refers to the levels of authority within the organisation. The formalised rules and procedures involve the degree to which explicit rules, regulations and policies govern the activities of the establishment.

In contrast to the old Strategic Health Authority, the National Health Service (NHS) Commissioning Board now addresses the NHS plan through the GP Commissioning Consortia as opposed to the previous Primary Care Trust and the care is implemented through the primary and secondary care agencies in line with the government directives. This organisational structure lends itself to the characteristics of an organisation described by Weber above. The new structure gave the authority to commission care which includes diabetes education from various healthcare providers including private establishments to aid competition, efficiency, provide better care, ensure rapid access, deliver more services in community setting, reduce health inequalities and contain escalating costs.

In the current system, the Quality and Outcome Framework (QOF) offers reward for giving high quality care by setting targets that are linked to General Practitioner rates of pay (Kenny 2009) and this currently includes referral to the education centres. Gadsby and Gadsby (2009) sees QOF as a method to encourage healthcare professionals to raise the standard of the diabetes service which includes prompt referral of newly diagnosed patient with diabetes to the education centre. However, Richard (2009) believes that linking General

Practitioners pay to the attainment of targets achieved by patients with long-term conditions is flawed. He argues that there is a tendency to manipulate figures to suit QOF purposes, for example, by excluding some patients that do not meet the criteria from the data. This demonstrates the impact of government targets and regulations on the delivery of services including the provision of diabetes education.

2.6. Diabetes education

Diabetes remains a growing international concern and healthcare practitioners are responsible for teaching the patients how to manage themselves and prevent complications. Group education involves interaction between three or more people (Guirdham 2002) while group dynamics refers to the process involved in group work regardless of the nature of the group (Quinn 2000). Small group teaching as a method of educational strategy is suggested by the government and therefore vital to diabetes education. The group size of most diabetes education programme ranges from 6-10 patients as this has been observed to encourage social support in adult health education classes.

Educating patients to empower them to engage with self-management is crucial to achieve the aim of the Governmental white papers such as *High Quality Care for All: Our Journey so Far* (DH 2009) and *Modernising Social Care* (DH 2007). Rickheim et al (2002) states that whatever the method of education, the aim is to empower the patient, by improving their knowledge, facilitating positive self-

management behaviour change and achieving clinical successes such as good glycaemic control. Anderson and Funnell (2009) saw the survival of this empowerment approach in America for the last two decades and its integration as a key aspect of global diabetes education as a testimony to its prospective success.

2.7. Individual versus Group education

The rising prevalence of type 2 diabetes with high economic implications and limited resources is part of the driving force for transition to group-based diabetes self-management education (Smaldone et al 2006; Rickheim et al 2002; Tang et al 2006). However, Zreibiec (2003) states that group teaching is a useful method to help diabetes patients as it stimulates learning by the sharing of their experiences through discussion. Several research studies have also compared individual and group diabetes education and found both to be equally effective (Rickheim et al 2002, Duke et al 2009, Norris et al 2002, Campbell et al 1996, Gatling 2003). Rickheim et al (2002) argues that group education may produce a more efficient and cost effective method in providing diabetes education. Nute (2004) states that group education may aid peer-support and promote active learning. Similarly, Tang et al (2006) states that group education can be cost effective, provide greater patient satisfaction and slightly higher positive behavioural modifications.

Regardless of the financial debate, there is no indication that group education offers any significant disadvantage in comparison to individual education session and several diabetes services in Britain and America now incorporate group education sessions as part of their comprehensive diabetes management programmes. The evidence to support the benefit of group education sessions for patients with type 2 diabetes is increasing and the British government is interested in pushing this agenda forward. Arguably, the patients should be given the options of whether they want to learn in group or individually. The recent NICE guideline (NICE 2009) suggested that patients should be offered group education as the preferred option but alternative individual standard education should be provided for people who are unable or unwilling to attend group education. However, this choice is not often available in clinical practice.

2.8. Diabetes Structured Patient Education in the UK

NICE (2009) recommended an evidence-based structured patient education for every diagnosed person with an annual reinforcement and review. The education should have a structured curriculum, learning objectives, and should support development of self-management attitudes, beliefs, knowledge and skills of the learner and their carers. Similarly, the education should encompass adult education, group learning, multi-disciplinary teaching, be locally accessible and embrace different approaches to promote active learning. NICE (2009) also emphasised that the educational programme should be quality assured and audited regularly by competent independent assessors.

There are several diabetes structured patient education (SPE) programmes such as Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) and the Diabetes Expert Programme (NICE 2003; DH 2005; Deakin 2006; Davies et al 2008) based on the theories of empowerment and discovery learning (Quinn 2000). Other educational programmes include DAFNE (Dose Adjustment for Normal Eating) for managing type 1 diabetes and DEAL (Diabetes Education and Awareness for Life) for type 2 patients (NICE 2003; DH 2005d). The expert patient model of care is an approach of care based on the philosophy of empowerment with a shift of power from the carer to the patient. The initiative proposes a method by which the patient takes responsibilities to actively participate in managing his or her care. The EPP (Expert Patients Programme) embraces the ability to develop to a level that the patients can manage themselves within the boundaries of a medical regime (Diabetes UK 2013; NHS Choices 2013).

Providing structured patient education for people with diabetes is a key policy goal (DH 2001; NICE 2009; NICE 2003) because there is substantial evidence to suggest that diabetes education has an overall benefit on the outcome of diabetes care. SPE for diabetes patients can simply be defined as a planned, flexible, and adaptable teaching programme covering all aspects of diabetes that is relevant to the patient needs (Hall 2006; NICE 2003). This involves delivery of education to an individual or a group of patients on key areas, such as, blood glucose control, dietary management, and exercise (Hall 2006).

2.8.1. Delivery of structured patient education within the PCT

The chosen Primary Care Trust (PCT) in South East of England (and in a National Health Service Commissioning Board for the Phase 3 of the study) was using DESMOND as a form of structured patient education (Table 2.5) and this education conformed to the standard of NICE guidelines. DESMOND is a structured patient education course designed to broaden the knowledge of patients and consequently help them to improve their self-management skills and quality of life (DESMOND Collaborative 2008). The practice nurses or occasionally the GP routinely referred all the newly diagnosed patients with diabetes to the education centre and the list of the patients are sent by the GP surgeries to the Diabetes Education Centres (DEC). As a follow-up, the staff in the Diabetes Education Centres are responsible for writing a letter to invite the patients to the education sessions that they have been booked to attend stating a particular education centre, date and time. However, some inconsistencies were observed in this process.

Table 2.5 – Characteristics of the education delivered by the PCT.

- It was 6 hours of structured group education designed for newly diagnosed patients with type 2 diabetes.
- It was offered as a 3 hour course on two separate days.
- It was delivered to a maximum group of 12 patients.
- The patient could attend alone or bring a friend or family member along.
- It has a written curriculum to ensure consistency.
- The course was delivered by trained multi-disciplinary healthcare practitioners that are certified as DESMOND educators mainly Diabetes Specialist Nurses (DSNs), Dieticians and Podiatrists.
- The educators were using defined resources and delivered a minimum of 5 courses annually to maintain their competency.

The team of practitioners delivering the education within the PCT consisted of Diabetes Specialist Nurses, Podiatrists, Dieticians and the secretary/administrator responsible for corresponding with the patients. The education was provided to an average of 8 to 12 patients by a team of Diabetes Specialist Nurse, Dieticians and a Podiatrist. The sessions were held on 2 Tuesday afternoons per month from 1.00 – 4.00 pm. The two sessions covered several topics (Table 2.6) and they were shown a video afterwards and they all had the opportunity to ask questions.

Table 2.6 – Contents of the session

- What is diabetes.
- Types of diabetes.
- Normal blood glucose levels and the implications of abnormal readings.
- Signs and symptoms of diabetes.
- How to treat diabetes.
- Complications of diabetes.
- Home blood glucose testing techniques.
- The role of diet, exercise, weight control, compliance to therapy in managing diabetes.
- The importance of foot care, eye screening, routine checks in preventing complications and enhancing quality of life.
- General issues such as driving, insurance, travel and sex related problems.

The Podiatrist used a PowerPoint and models of a diseased foot and emphasised foot care, glycaemic control, and complications such as neuropathy. The PowerPoint used by the Dietician emphasised the role of healthy eating in relation to diabetes. The Dietician also used a food chart with 5 portions representing each class of food and focused on fat, carbohydrate and high fibre diet. The DSN also gave a PowerPoint session and sign posted them to where to go in case of any problems and suggested that they should join Diabetes UK. In my opinion, the information given at one time was voluminous.

Anderson and Funnell (2009) and Nute (2004) state that a successful empowerment approach is suitable to help patients to make self-initiated changes concerning their diet, weight, exercise, and improve self-care ability of the patient. However, the patients need to take some degree of responsibility for their management and work in partnership with the healthcare practitioners to take greater control over their illness. This should equip them to reduce the severity of symptoms, improve their confidence and motivation to utilise their knowledge and skills to manage their illness effectively. Therefore, the key issue is how to motivate attendance in order to influence health behaviour regardless of the type of self-care management education involved.

2.9. Theoretical framework

The World Health Organization (1986) sees health as a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity. In order to deal with a patient holistically, there is a need to consider their health and illness beliefs (Naidoo and Willis 2000; Harvey and Lawson 2009). There are various beliefs influencing people's choice of healthcare, eating habits and lifestyle. Also, there are different cultural views about pharmacology and non-pharmacological approaches to treatment (Helman 2007; Upton 2010). In addition, there are spiritual and philosophical beliefs about illness and how different cultures deal with grief (Helman 2007). All these beliefs and perceptions are crucial to understanding the health behaviour of patients.

According to the most recent census, the population of England is culturally diverse (Office of National Statistics 2011) and this has implications for the delivery of care. Helman (2007) emphasised the impact of culture on health, illness and treatment; therefore, healthcare practitioners need to be aware of various socio-cultural beliefs. Type 2 diabetes is more common in older adults and in adults of Asian and African Caribbean ethnic origin (Newham et al 2002). Kulkarni's (2004) study showed that different ethnic groups have their culturally based food and eating habits. Also, cultural belief has implications for how each ethnic group will respond to self-management of diabetes. However, Fleming and Gillibrand (2009) stated that individuals interpret culture in a diverse way and suggested giving individualised culturally appropriate care to patients. Thus, better understanding of a patient's culture and beliefs may improve patient management and improve co-operation between the parties involved.

There are different theories that have tried to explain the role of various beliefs and perceptions on health related behaviour, for example, motivation theory (Maslow 1943), the Health Belief Model (Becker et al 1978) and the Stages of Change model (Prochaska and DiClemente 1984). Although there are limited studies regarding structured patient education in relation to health beliefs, several authors have adopted the theoretical perspectives of HBM in healthcare research and a Medline search from 1974 – 1994 conducted by Clark (2000) revealed that 64% of research studying health behaviours utilised HBM as their theoretical model. Thus, this section gives a brief overview of several models but it will

mainly focus on a theory of healthcare belief that is applicable to the study of barriers and motivating factors to attendance.

2.10. Health Belief Model

There are several models of health behaviour that are based on health beliefs e.g. Health Belief Model (Becker et al 1978) and the Theory of Planned Behaviour (Ajzen 1971; Lloyd, Hancock and Campbell 2007) but the HBM is widely used in healthcare practice. The Health Belief Model is a psychological model that attempts to use the attitudes and beliefs of an individual to predict and explain their health behaviours. It is based on the assumptions that a change in behaviour will be influenced by a perception that a negative outcome can be avoided.

The HBM was first developed by Rosenstock (1966) but further developed by Becker and colleagues with the intention to predict behavioural responses to both acute and long-term health problems (Ogden 2012). The HBM promulgated by Becker et al (1978) states that HBM enables understanding of individual health-related behaviours. According to this framework, the probability that a person will undertake a recommended health action depends on perceptions and beliefs which in turn are linked to compliance. Becker et al (1978) says that health behaviour is modified by three beliefs (Becker et al 1978). These beliefs are the threat of the disease which includes the susceptibility to the disease and the degree of severity of the consequences. The second belief is the potential

benefits of the health actions in reducing the threat of the disease. This also includes the physical, psychological, financial and other barriers related to initiating or continuing the recommended actions. The final assumption focused on preventive actions taken without symptoms and this relates to health motivation in order to predict compliance when an illness has not been diagnosed.

The belief about the threat of the illness relates to perceived susceptibility to the disease and its perceived severity. The susceptibility to the disease refers to the probability of acquiring diabetes complications which may be perceived to be low or high. The belief about the severity of the illness relates to the belief that diabetes is a serious medical condition. The second assumption of perceived benefits and barriers to compliant behaviour relate to the perceived benefits of the intervention and an individual's belief about their ability to take control of their health. This second belief is based on the perception to justify the physical, material and financial efforts involved in adherence. Although, behaviour is mostly motivated (Beard and Senior 1980, Green 2000), nevertheless, Maslow (1943), states that motivation theory is not the same as behaviour theory and motivation is just one of the determinants of behaviour. The third assumption of health motivation is an assumption which is guided by the perceptions and beliefs relating to the importance of ensuring and maintaining healthy living.

The Health Belief Model (HBM) is considered as one of the best models developed to predict the role of beliefs in health decision making processes (Upton 2010; Naidoo and Wills 2000) and several studies have used HBM as a theoretical framework to underpin their studies (Ogden 2012; Mirotznik et al 1998; Kagee and Marve 2006). Regardless of the popularity of HBM, it has also been widely criticized (Naidoo and Wills 2000; Upton 2010). Some of these criticisms relate to its focus on the conscious process of information, lack of clear relationship between the different assumptions and the role of intervening variables such as fear, denial and the unstatic nature of human opinion (Ogden 2012; Conner and Norman 2005). Thus, it is argued that the model laid little emphasis on psychological aspects of human being such as fear and denial and the question of whether behaviour is always rational.

Lloyd, Hancock and Campbell (2007) claimed that different beliefs do not have the same impact on health behaviour. Green (2013) opined that the HBM lacked predictive power for several behaviours because of limited scope to explain other predisposing factors such as emotion. Another weakness is that the HBM places emphasis on health protective behaviour and health promotion, therefore, difficulties may arise when the patients cannot return to their previous perfect state of health e.g. in diabetes or stroke. Green (2013) also argued that the HBM predominantly focused on the cognitive factors predisposing to a health behaviour with less emphasis on factors that are responsible for sustaining a behaviour, particularly when it involves lifestyle behaviours that need to be

maintained for a long time. Nevertheless, the HBM remains a valuable guide to practitioners (Ogden 2012; Kagee and Marve 2006; HSU and Gallinagh 2001).

The criticism has led to further development of other recent models such as the Theory of Reasoned Action (Ajzen and Fishbein 1975) and Theory of Planned Behaviour (Ajzen 1985; 1988). The theory of Reasoned Action (Fishbein 1967; Fishbein and Ajzen 1975) was further developed into the Theory of Planned Behaviour (Ajzen 1985, 1988). The Theory of Planned Behaviour (Ajzen 1985, 1988) is based on the premise that behaviours are determined by beliefs about outcomes and the evaluation of these outcomes (Upton 2010). Other assumptions are individual beliefs about others attitude and motivation to abide by it. The final assumption is internal and external control factors that may aid or hinder the performance of the behaviour. The social cognition model was later developed to include the social context of the behaviour in addition to the individual cognitions and attitudes (Upton 2010; Naidoo and Wills 2000; Upton and Thailaway 2010).

All these models share the basic assumption that behaviour can be predicted by beliefs and attitudes (Upton and Thailaway 2010) and the HBM (Becker et al 1978) is suitable to explain this study. All the above beliefs may either influence or hinder the performance of a behaviour. Funnell et al (2007) states that patients affected by diabetes vary in their attitudes and beliefs about diabetes and this may affect their perception about the value of self-management education.

Attitudes and beliefs are influenced by individual experiences such as family history of diabetes, media reports and advice from significant others. Therefore, Funnell et al (2007) argued that patients' beliefs about the benefit of education in dealing with their condition will either increase or decrease their motivation. The application of the HBM to the current research is further explored in relation to the data collected on pages 263 to 268 in Chapter seven.

Although, the HBM is influential in explaining the health related behaviours of people (HSU and Gallinagh 2001), nevertheless, the use of HBM and other models such as the Theory of Planned Behaviour (TPB) have their methodological problems. The studies do not often use randomised experimental design; therefore it is problematic to draw inferences about cause-effect (Conner and Norman 2005). Another criticism of similar studies using HBM is unrepresentativeness of the samples and participants' understanding of the variables construct (Clark 2000). Again, Mirotznik et al (1998) stated that several studies that have used HBM as a theoretical underpinning for their study have found conflicting results. In addition, although these models are designed to predict behaviours, these models have been found not to be successful in predicting behavioural actions because behavioural actions may be beyond the control of an individual (Conner and Norman 2005). Kagee and Marve (2006) also argued that variables such as intentions to comply with a medical intervention may be influenced by certain elements of social desirability.

Nevertheless, the assessment of health beliefs may lead to ways to improve beliefs and attitudes that are potentially detrimental to compliance (Gaber et al 1992). All the same, it has been observed that what people actually say they believe or do often contradicts their behaviour. As a result, the idea of integrating the models is seen as one of the ways to overcome the methodological limitations and in bridging the intention – behaviour gap (Conner and Norman 2005). Regardless of expansion and integration of models, it is thought that variance in human behaviour that may not be captured by models would always exist because several unexpected events may occur in the transition process (Ogden 2012).

2.11. SUMMARY

The shift in nature and pattern of disease that resulted from increased life span and lifestyle changes has consequently led to pressure on the NHS. The challenge to achieve good health for all has also led to patient empowerment as a paradigm shift from the traditional approach of long-term condition management. Although, empowering patients through education is an integral part of long-term disease management, yet, it has been problematic. This Chapter reviewed and synthesised previous research studies on non-attendance in Diabetes Education Centres to identify the gap in research. The systematic review revealed a lack of studies on this phenomenon in the UK and therefore identified the need for the current research.

This Chapter has also presented relevant topics that are related to the current research. It covered an overview of diabetes and its management in order to demonstrate areas that are necessary to be included in the structured patient education to promote self-care management. It also provided information about the socio-political context of the study and gives a snapshot of key issues pertaining to empowerment-based diabetes group education such as group/individual learning and specific diabetes education. Furthermore, the main theoretical constructs such as the Health Belief Model were explored to discern their relevance to the current research.

Although, it is acknowledged that the diabetes service in the UK is improving, there is a need for further improvement, particularly, in the area of promoting structured patient education geared to aid self-care management. A systematic review conducted on this phenomenon has established the need for further studies to promote attendance in Diabetes Education Centres; therefore, the topic is worth pursuing, particularly in the UK. In bridging the identified gap in research on this problem, subsequent Chapters will present how the phenomenon was investigated in this particular research project. Therefore, the next Chapter will discuss the methodological approaches used to gain data to investigate the barriers and enabling factors to attendance in Diabetes Education Centres.

CHAPTER 3

METHODOLOGY

3.1. Introduction

This Chapter examines a range of issues that are relevant to qualitative and quantitative methodologies used and seeks to justify the decisions made in terms of the research approach in this study which include a focus group, face-to-face interviews; and a questionnaire survey. The process of qualitative design and questionnaire survey development, such as the sampling techniques, data collection methods and analysis are also discussed. In addition, the process of developing the emergent themes for the qualitative data analysis are explored. This Chapter also addresses the ethical implications of the study, the concept of validity and reliability in relation to all aspects of the research and presents the constraints and problems encountered during the conduct of the research.

This Chapter discusses the methodology for this study in four sections. The first section provides an overview of the study design; the second section explores the qualitative components of the research which are the focus group and face-to-face interview techniques used in Phase 1 of the study. The third section discusses the questionnaire survey study (Phase 2). Finally, the fourth section discusses the approach utilised for third Phase of the study which was individual interviews of practitioners.

SECTION 1

3.2. Overview of the research design

This section outlines the methodological approaches that were utilised to explore the question and the study which was conducted in three Phases (Table 3.1). The choice of the research approach depends on the aim of the enquiry and the questions to be answered (Coates 2011a; Masters et al 2006). The Phase 1 of the study used a focus group approach, an interview with two participants and a one-to-one interview of practitioners to assess the barriers associated with non-attendance. It explored ways to improve uptake of group patient education designed to promote self-care habits of patients with type 2 diabetes. Phase 2 of the study was a questionnaire for two groups of patients: those that have attended the Education Programmes and those that had not. This Phase of the study used a self-report questionnaire to investigate the views of both identified groups (attenders and non-attenders) in four hospital sites in a Primary Care Trust (PCT) in the South East of England. The third and last Phase of the study was a qualitative study where practitioners provided their views about barriers and enablers that could aid attendance and the influence of changes since the demise of the PCTs and the advent of Clinical Commissioning Groups (CCGs) in the South East of England. The practitioners were engaged in a semi-structured interview and individual narratives were analysed by using a thematic approach. The strengths and weaknesses of each of the methods are discussed in the subsequent pages of this methodology Chapter. Table 3.1 provides a summary of the research design.

Table 3.1: The Research Design

Mixed Methods Design			
Process	Phase 1 study	Phase 2 study	Phase 3 study
Philosophical position	Interpretivist	Positivist + Interpretivist	Interpretivist
Methodology	Qualitative	Quantitative + Qualitative	Qualitative
Methods	Focus group + Individual face to face interviews	Survey (questionnaire) n=207	Face-to-face interviews
Focus in relation to the research questions	Identify the barriers and enabling factors to attendance from the perspectives of practitioners delivering the education	Identify the barriers and enabling factors to attendance from the perspectives of the patients that either attended the session or failed to attend	Identify the barriers and enabling factors to attendance from the perspectives of referring practitioners and further explore the previous findings and the influence of current NHS reform
Participants	Healthcare practitioners (Diabetes Specialist Nurses, Podiatrists and Dieticians)	Patients (attenders and non-attenders)	Healthcare Practitioners (8 Practice Nurses and 1GP)
Location	Hospital (headquarter site for the PCT in the South East of England).	All the 4 Diabetes Education Centres within the PCT	6 GP surgeries in the South East of England.
Sample sizes	10 practitioners (Diabetes educators)	207 patients (105 non-attenders and 102 attenders)	9 practitioners (Referring practitioners)
Data Analysis	Thematic analysis	Descriptive statistics/correlation / inferential statistics and thematic analysis	Thematic analysis

3.3. Philosophical perspectives

This section aimed to discuss the philosophical underpinning for this research and justify the methodological approaches of qualitative and quantitative approaches used for this study and explain the decision to use a mixed methods approach. Epistemology, ontology and methodology are interlinked and each influence the other and therefore each must be considered when deciding on a research approach (Denzin 1998; Hughes and Sharrock 1997). Every individual has a philosophy and my personal philosophy shaped my beliefs about how to generate knowledge of this phenomenon. Broadly, epistemology deals with the nature of knowledge while ontology refers to the nature of reality. One's ontological and epistemological position influences how knowledge is construed and therefore impacts on the choice of methodology. Whatever the research approach employed in a given study, the ways and procedures for obtaining the knowledge reflect the philosophy underlying the particular approach. Therefore, it was important to clarify my epistemological position on this topic of enquiry in order to understand what constitutes valid knowledge on this problem. To the researcher, knowledge of this phenomenon of enquiry can be gained from both practitioners and patients involved in Diabetes Education Programmes.

3.4. Positivism and post-positivism

A review of literature revealed a controversial paradigm debate (Guba and Lincoln 2005, Crossan 2003, Parahoo 2006), however, Crossan, (2003) claimed

that the two main paradigms in social and healthcare research are positivism and interpretivism. A paradigm can simply be defined as the world view about reality (Polit and Beck 2006) and the philosophical paradigm of positivism is the traditional scientific approach, often referred to as the gold standard (Denzin and Lincoln 2005; Polit and Beck 2006; Parahoo 2006). The old predominant belief in healthcare research originating from the positivist tradition believes in building scientific knowledge through objective, systematic observation, collection of quantitative information and lays emphasis on measurement (Hammersley 1995, Polit and Beck 2006).

The researcher has a different view and this has influenced the way the researcher has approached how to examine the phenomenon of non-attendance in Diabetes Education Centres. This view is also supported by some authors such as Alick (2002), who attributed the increased use of inductive approaches to the failure of deductive methodologies, and (Travers 2001, Crossan 2003, Travers 2001) who argued against rigid rules for enquiry methodology and one single approach to truth to explain phenomena involving human participants.

The research methodologies in qualitative and quantitative research are distinct. Dobson (2002) states that the choice of methodology is a reflection of the researcher's theoretical standpoint and argued that mixed methods research is not feasible because each methodology originates from a separate paradigm, and because qualitative and quantitative approaches have different epistemological assumptions. Guba (1985) argued that when mixed methods are used, each is used only superficially in a single paradigm. However, proponents

of pragmatism argue that qualitative and quantitative methods are compatible (Williamson 2005) with quantitative methods providing a sense of the main trends, and qualitative looking deeper at the experience of individuals. My own position reflects that combining both qualitative and quantitative methods is feasible to answer the same research question to understand both main trends and details of the experience of participants. Thus, the three phase research was designed with both qualitative and quantitative components which were relatively independent and self-contained but informed each other. The findings from both the qualitative and quantitative components were later combined together to answer the research question. The sequential nature of the design enabled the phases to build on each other as further explained below.

3.5. Mixed methodology

Hamdan and Anthony (2010) define mixed methodology as a mixture of both qualitative and quantitative research approaches. In simple terms, mixed methods research is an approach that embraces the use of a mixture of approaches that can best answer the research question in a single study. Guba and Lincoln (2005) suggested an interbreeding of paradigms, where two previously opposing theories are re-contextualised and inform each other. Barker (2010) argues in favour of multiple realities and states that while positivist paradigms yield quantifiable data, qualitative studies are concerned with non-quantifiable data in order to explore human experience and behaviour. In this

context, the importance of mixed methods in the current study comes from the researcher's view about different ways of apprehending reality, hence, the reason for using both quantitative and qualitative methods. To the researcher, what was important was the aim of the inquiry which was to identify the barriers and enabling factors to attendance, and the best methods to achieve this aim, with a concern for the validity and reliability of the process (Denzin and Lincoln 2005).

In a mixed methods approach, the three key considerations are sequencing, priority or dominance and integration (Descombe 2010; Simons and Lathlean 2010). Sequencing relates to whether the qualitative or quantitative elements of the study are conducted sequentially or concurrently. The sequencing reflects the researcher's belief about the best way to combine the methods in order to achieve the best result for identifying the barriers to attendance. This first consideration relates to the approach for collecting the data and the study may start with a quantitative study, followed by a qualitative study and vice versa; another consideration is whether to run in a sequential or concurrent order. In this study, the researcher conducted a sequential study which started with a qualitative component, followed by quantitative and qualitative components (Qual → Quant → Qual approach). The first phase collected and analysed qualitative data in order to inform and contextualise the statistical data collected in the second phase. The Phase 2 study was conducted with the aim of explaining the relationships and differences relating to certain barriers observed in phase 1

whilst Phase 3 further explored some of the findings from Phases 1 and 2 from the perspectives of practitioners.

One of the controversies surrounding the use of mixed methods is the dominance of one method over the other. The range of possibilities for dominance is qualitative – quantitative balance or imbalance of methods (Table 3.2). The dominance or priority refers to which method is given more emphasis in the research study. Although the researcher believes that it was better to use a mixed method approach to provide a holistic view of a complex phenomenon, both methods were considered to be of equal importance. Therefore, the researcher employed QUAN (Quantitative) → QUAL (Qualitative) balance sequential methods design.

Table 3.2: Sequence – Dominance Model

	Sequential methods	Simultaneous method
Sequence	Quant → Qual	Quant } Qual }
	Qual → Quant	
	Qual →Quant→ Qual	
Dominance	Equal status methods	Dominant versus less dominant methods
	QUANT→ QUAL	QUANT → Qual
	QUAL →QUANT	QUAL → Quant
Mixed methods research design possibilities adapted from Denscombe (2010)		

There was no priority or dominant method in this study design as both paradigms equally contributed to the understanding of the problem. The qualitative element of the research focused on in-depth exploration of factors influencing non-attendance from both the perspectives of healthcare practitioners and patients. It allowed the opportunity to examine the subjective realities of participants. Therefore, in the first phase of the study, qualitative data were collected using a focus group and individual interviews of practitioners that were diabetes educators. The goal of this phase of the study was to explore the practitioners' views and use the data derived to inform the second and third phases of the study. In the second phase of the study, quantitative data were collected using a questionnaire survey method to aid comparison of attenders and non-attenders.

The quantitative component of this phase of the study revealed the demographic characteristics of participants, health beliefs, structural barriers to attendance and allowed comparison between the views of the attenders and non-attenders on the phenomenon. Also, it allowed the opportunity to capture a large number of responses which would not be possible using qualitative methods in the time frame of a doctoral research programme. This phase of the study also has a qualitative element (using open-ended questions) focusing on the reasons of why they failed to attend and what can be done to aid their future attendance. Therefore, the survey provided a medium to solicit qualitative and quantitative data from a large sample of participants. The third and final phase of the current research used data from face-to-face interviews to further explore the barriers to attenders from the perspectives of referring practitioners.

The third consideration deals with integration of the studies and this can occur at any phase of the research such as data collection or analysis level. For the current research, each phase was informed by the findings of the previous phase and overall integration of the findings may be found in the final write up of the thesis in Chapters 7, 8, and 9. Thus, both qualitative and quantitative methods were integrated to inform subsequent phases and the results of the three phases were integrated during the discussion of the outcomes of the entire research programme (Creswell and Clark 2007).

The problem of non-attendance is complex; therefore, multiple sources of data were used to address this complexity (Table 3.1). A mixed methods approach was used to answer the research question from different angles and brought a range of views together to generate knowledge which offers the opportunity to better capture the social complexity involved in this study (Creswell and Clark 2007; Descombe 2010). The lesson of a multi-epistemological approach from Guba and Lincoln (2005) and Barker (2010) motivated the adoption of mixed methods (focus group, face-to-face individual interviews and questionnaire survey) which are discussed in Chapters 4, 5 and 6 of this thesis.

One of the advantages of combining the data collected from different methods in this study was to obtain different perspectives on the same topic, confirm and consolidate the previous findings and some statements were verified from a different group of people (Simons and Lathlean 2010; Williamson 2005). The data produced certain similar results, for example, diabetes educators, referring practitioners and patients verbalised that personal difficulties such as working

pattern was a barrier to attendance. Thus, the researcher combined the methods to serve the purpose of confirmation and completeness (Adami and Kiger 2005; Maggs-Rapport 2000) in this study.

In the current research, the survey was conducted using a questionnaire consisting of structured closed questions whilst the focus group and individual interviews were used to gather qualitative in-depth data. According to Offredy and Vickers (2010), qualitative research focuses on the behaviour and attitude of people. The rationale for this approach is that both approaches are valuable and were used to address different aspects of the topic and produced different forms of data that may complement each other in terms of developing knowledge about the phenomenon. Thus, the aim of using mixed methodology was to answer the research questions as opposed to reflecting the preferences of the researcher (Hamdan and Anthony 2010; Burnard and Hannigan 2000). Therefore, balancing the strengths and limitations of both approaches was a key reason for mixed methods in this study.

Whilst a questionnaire may answer the research question, the type of detailed discussion that took place during a focus group interview cannot be achieved and it will not produce the type of in-depth exploration obtained from the individual interviews. In contrast, face-to-face interview may produce in-depth information; nevertheless, it will be impossible to interview the sample size used for the questionnaire survey. Thus, the researcher was able to enhance the richness of the data collected, strengthening the research and in so doing enhance the

validity and relevance of the research. It is worth noting as indicated in the introduction that, in a previous iteration of this study, the researcher had interviewed patients by telephone but discarded these data as they were not a high quality.

3.6. Settings

The settings were four separate Diabetic Education Centres within a Primary Care Trust (PCT) in the South East of England. The PCT is responsible for delivering primary care services to a population of approximately 376,500 and it has four community sites. These settings were chosen because of the level of attrition from diabetic education sessions and also their demographic diversity. The population of the area is ethnically diverse and the demography of areas 1 and 2 is predominantly white whilst areas 3 and 4 comprise a multi-ethnic population. In the current structure, the PCT is broadly divided into East and West communities and comprises three Clinical Commissioning Groups (CCG) with 42 General Practice (GP) surgeries.

3.7. Sampling strategy

The sampling techniques used for the three phases of the research will be discussed under each section of the research. It will address the rationale for the choice of sampling procedures and sample sizes used for each phase of the research study. Out of the three phases of the research, two phases looked at the phenomenon from the perspectives of the practitioners, and another looked

at the opinion of both non-attenders and attenders. The profiles of the participants are practitioners that are involved in either referring patients to the Diabetes Education Centres or involved in the delivery of Diabetes Education and patients that have attended the Diabetes Education or who failed to attend the sessions.

3.8. Ethical implications

Generally, ethical considerations aimed to protect the patient and prevent abuse of participants (RCN 2011; GMC 2010; DH 2009) and the basic tenets underlying the guidelines are respect for individual rights and offering a free choice. For the purpose of the current research, a multi-phase ethics approval was obtained. The initial ethics application was submitted to the Faculty of Health and Human Sciences Research Ethics committee of Thames Valley University for approval (see appendix 2). The application was also sent to the relevant research ethics committee through the Central Office for Research Ethics Committees (COREC). Following presentation of the study to the committee, an approval was obtained from COREC (see appendix 3). An approval was also obtained from the PCT ethics committee (see appendix 5). Finally, ethical clearance was sought separately for the last phase of the study because of the time interval (see appendix 4). The RCN (2004) document on research ethics identified common research issues as ensuring consent, respect for the subjects, protecting confidentiality, autonomy and preventing harm. Similarly, Johnson and Long (2010) identified the key research issues as respect for participants, consent, confidentiality and balancing potential danger with the possible benefits to

patients. By comparison, the main ethical issues of significance for this research are informed consent, voluntary withdrawal and confidentiality.

3.8.1. Informed Consent

The Human Rights Act 1998 has implications for the principles of consent and medical law, particularly, Article 2 (protection of right to life), Article 5 (right to liberty and security) and Article 8 (right for private family life). A valid consent is a legal and ethical requirement in Britain and poor handling of consent may lead to complaints or litigation. Gaining consent is a legal and ethical requirements and Dimond (2011) stated that lack of informed consent could lead to litigation in the form of assault or trespass. Thus, ethical and legal issues relating to consent are linked and it requires ethical reasoning based on obligation to do the right thing (Dimond 2011).

The current research was conducted as per the Central Office for Research Ethics Committees (COREC) and institutional approval. Written consent was obtained for the focus group and face-to-face interviews while implied consent was construed from completion and return of the questionnaire survey. Recruitment of practitioners took place after they signified their intention to participate in the study. This was followed by signing a consent form after adequate information had been given to them through verbal conversation, presentation to the group and by giving explanatory information (see appendices 6 and 7 for the information sheet and consent form). The consent form and

information sheet clearly stated that participants were free to withdraw at any time. All the participants signed the attendance sheet as a further proof of consent. For the surveys, there was an implied consent, because the patient's willingness to complete the questionnaire suggests their voluntary participation. Thus, consent to participate in the survey questionnaire was inferred by the fact that participants returned their completed questionnaire.

3.8.2. Confidentiality

Confidentiality refers to using the patient's information for the intended purposes only and avoiding sharing it publicly (Dimond 2011). According to the Nursing and Midwifery Council (NMC 2008c), confidentiality is crucial to professional practice and it protects individual fundamental human rights. Equally, Polit and Beck (2012) stress the importance of protecting the privacy of study participants. Although it was impossible to guarantee anonymity for the focus group participants during the meeting (as they might have known each other), assurance of confidentiality in relation to how the data supplied would be used was given (Marks and Yardley 2004). Thus, the data protection guidelines relevant to healthcare research studies were complied to by using locked filing cabinet to keep both hard and electronic data; saving details on a password protected computer; and deleting data held on computer after use; and reporting and presenting the data anonymously.

In terms of balancing potential danger with the possible benefits to the research participants, the current research does not pose any significant danger. Regarding benefits, it has potential to influence practice and improve the uptake of diabetes education. Finally, as a matter of ethical value, the results of phases 1 and 2 were sent to the Diabetes Education Centres and made available to the participants during their clinical visit and were presented to local diabetes groups within the area.

SECTION 2

Phase 1: Focus group and individual face-to-face interviews

3.9. Introduction to section 2

This section discusses the focus group and face-to-face interviews used to collect data to address my research questions from the perspective of diabetes educators. Focus group study research is an empirical enquiry that investigates phenomena by using group interviews. By definition, a focus group is a type of interview with 8-12 people whose opinion is solicited simultaneously (Babbie and Mouton 2001) and Goodwin and Happell (2009) state that the use of focus groups in health research continues to grow. Focus groups may employ the use of unstructured/open-ended or structured format questions (Cormack 2000) and the methods of conducting a focus group depend largely on the purpose of the study and the skills required are similar to individual interview. Therefore, the researcher used focus group interviews to obtain in-depth or rich information about the phenomenon under study.

The various qualitative methods of data collection have both advantages and disadvantages (Serrant-Green 2007). Therefore, the choice of a focus group for this study was motivated by various reasons such as in-depth exploration of opinion and to capture the opinions of several busy professionals. Therefore, it was a realistic approach for this type of participants - busy professionals. David and Sutton (2004) stated that the focus group method is useful to explore the degree of consensus on a research topic. In this way, the group discussion offers

the opportunity to obtain rich data by exploring issues and promote discussions that are pertinent to the current research. Oppenheim (1992) stated that the aim of exploratory interviews is mainly to develop ideas and research hypotheses as opposed to gathering facts and statistics, thus, the data were used to inform the assumptions generated for Phase 2 of the study. Finally, a focus group is appropriate for one of the overall aims of this research which was to present the personal viewpoint of health educators on the barriers and enabling factors to non-attendance.

3.10 Sampling and recruitment of participants for Phase 1 (Focus group and individual interviews of Diabetes Educators)

The focus group technique and individual interviews used in Phase 1 of the current research utilised a convenience (opportunistic) sampling technique. The researcher identified the potential subjects and settings before selecting who and where to include in the study (Gillham 2000). The settings were selected because of the rate of attrition from the Diabetes Education Centres and the diverse nature of their demographic whilst the participants were judged to be the participants that can offer rich data relating to the research question (Procter et al 2010). The selection criteria were practitioners who might offer insight into the phenomenon in question and therefore all the practitioners involved in teaching newly diagnosed patients in the locality were eligible. In addition, they had to have a minimum of five years working experience and be currently working in the Diabetes Unit of the PCT.

Practitioners who are Diabetes Educators and who met the above criteria were identified through visits to the Diabetes Education Centres and they were approached in the Diabetes Education Centres. The sample population for Phase 1 of the research was drawn from healthcare practitioners delivering education who consented to taking part. Half of the target population were Diabetes Specialist Nurses (DSN), four Dieticians and three Podiatrists. The final sample of ten participants (71% participation rate) from a population of fourteen practitioners showed that they comprised of five DSN's, two Podiatrists and three Dieticians with a minimum of five years' experience which has a positive implication for the outcome of the study in terms of their clinical experience. Importantly, practitioners delivering education in all the four localities within the PCT were represented in the final sample.

3.11. Data collection procedure

Initially, the aims and methods of the study were presented to the group in the diabetes education team meeting at the Primary Care Trust (PCT). After this, the entire group of 14 practitioners delivering structured patient education in the PCT were further contacted through electronic mail and 10 of them were finally recruited for Phase 1 of the study. Participant information sheets (appendix 6) and consent forms (appendix 7) were also supplied for signature and all the participants signed the attendance sheet at the beginning. The seven participants who took part in the focus group research were gathered in a private seminar room in one of the hospitals within the PCT in South East of England and the

focus group discussion took seventy five minutes. The three consenting participants who could not attend the focus group took part in face-to-face interviews on different days. It is worth mentioning that the level of discussion generated in the focus group cannot be achieved in these individual interviews, however, the researcher used the additional interviews to supplement the data previously collected and the participants are reported as participant's eight to ten in the report.

The participants were arranged in a round table sitting arrangement in order to aid effective communication and eye contact (Oppenheim 1992) and the conversation was recorded on a tape. A senior colleague who is an experienced researcher acted as a facilitator and recorded participant responses on a flip chart (Miller et al 1996). The use of another person to act as a facilitator has proved beneficial in various focus group studies (Tod and Joanne 2010, Rubin 2005, Curtis 2001); the researcher took field notes while the facilitator was recording the key points on a flip chart and assisting with facilitation of the group discussion. Beyea and Nicoll (2000) argued that using a facilitator helps to minimise group disruption; however, being a group of professionals, there was a high level of orderliness.

Seven open-ended questions were used as a guide to collect data for the study (Appendix 8). The open-ended questions gave the participants the opportunity to express their thoughts and feelings and allowed for probing and clarifying of data

(Ashby et al 2005, Berg 2007; Mansell 2004). Questions were generated based on the NHS Institute for Innovation and Improvement (2008) guidance in improving attendance in practice and other literature such as Sprague et al (1999) questionnaire survey of 143 Diabetes Educators on potential barriers to diabetes education. The question template (see appendix 8) was pre-tested to ensure its appropriateness by piloting it with a group of practitioners from another PCT and resulted in amendments to the question guide. This was to ensure that the questions would achieve the aim of the focus group which was to obtain in-depth information that led to some understanding of the perceptions (Travers 2001) and behaviours of patients towards motivating and demotivating characteristics to group learning designed to aid self-management skills.

Regardless of these benefits, researchers operating in the qualitative paradigm are faced with some issues about factors that may affect the authenticity and trustworthiness of responses. Some of these factors are the influence of the researcher, the group dynamics, non-participation, and the interpretation of the findings (Fontana and Fray 2005, Babbie and Mouton 2001). Oppenheim (1992) states, leading research focus group discussions requires skills and experience. Thus, focus group interviewing requires a lot of facilitative skills to coordinate the activities of the group in an organised way to minimise the various disadvantages of this method. The researcher has formerly facilitated several group activities as part of his role such as moderating group learning activities (enquiry based learning), selection interviews and has participated in a series of focus group

interviews. The data were collected by effectively coordinating the group during discussion and by recording the conversation electronically and keeping field notes. The group was facilitated to develop discussion and further questions were asked as a follow-up to clarify some answers and all their responses were later transcribed and analysed. As they are professionals willing to talk and share their views openly in a group, the level of participation was good through the effective coordination of the group. The separate interviews were also conducted in an office within the hospital premise of the PCT and both field notes and tape recording of the conversation were also undertaken.

3.12. Data analysis approach for Phase 1

Qualitative data analysis is the process of organising and interpreting the numerous data collected from the inquiry in order to make sense out of it, and a way of reducing large amounts of data into a manageable amount and identifying patterns and give meaning to it (Huberman and Miles 2002). However, Walliman (2005) emphasises the difficulty of analysing open-ended questions. There are frameworks to analyse qualitative interview data and as Coates (2011b) states, qualitative data can be analysed manually or by using electronic software such as Nvivo or ATLAS Ti. For this research, a manual procedure which is described below was employed to draw conclusions by collating the themes from the focus group and interview data to find out the aims of the study.

3.12.1. The process of analysis

According to Marks and Yardley (2004), thematic analysis is similar to content analysis but more exploratory, looking for themes rather than the frequency of occurrence within the data. In a similar way, Aronson (1994) sees thematic analysis as a way to identify themes and pattern of data by paraphrasing common ideas or directly quoting the information collected from the subjects. Holliday (2002) also believes there are different ways to process raw data in thematic analysis. These can either be by totally arranging the responses under themes or by simply organising the data into the questions used for data collection. Therefore, for this study, the researcher organised and analysed the data under themes by adapting Holliday's (2002) process of thematic analysis as a guide. Thus, the researcher identified data that addressed the research questions, classified them into a pattern, and combined them together under a heading relevant to the research questions and finally developed them to themes (Holliday 2002, Marks and Yardley 2004; Aronson 1994).

3.12.2. The coding process

All the data were transcribed as accurately as possible and the initial coding was undertaken as discussed below. Based on the above framework, the whole data were analysed to identify the themes using the following four steps:

- (1) The first step of the coding process used the participant's verbatim transcriptions of the raw data to establish the first code (appendix 9).

- (2) Then, all the key statements in the data were tabulated into a column; a second column indicating the initial code and the last column recording the researcher's comments (appendix 10).
- (3) The third step initiated the reduction process by clustering the codes from the raw data into sub-themes (appendix 11).
- (4) The final step developed the sub-themes into five major themes (appendix 12) which were used for interpretation and discussion of the Phase 1 of the study.

The themes resulting from Phase 1 were: (1) Perceptions and attitudes of practitioners to diabetes education (2) Patients perceptions and attitudes towards diabetes education (3) Personal circumstances (4) Official protocol and self-management education resources and (5) Strategies to improve attendance. The detailed report of the results will be presented in Chapter Four and the discussion of findings will be presented in Chapters' Seven and Eight.

3.13. Rigour in qualitative research

There is an argument related to the issue of how to demonstrate methodological rigour in qualitative research (Marks and Yardley 2004, Gillham 2000, Corbean 1999), nevertheless, assessing quality in qualitative research is important to examine the overall claim made by the researcher (Mays and Pope 2000). According to Coates (2011b) lack of structure in qualitative research should not be considered as lack of rigour. The common measures that could be used to

assess how rigour was attained and maintained in a qualitative study are: authenticity, auditability, credibility, transferability and trustworthiness (Ryan-Nicholls and Will 2009; Mays and Pope 2000; Lincoln and Guba 1985). Although there is some degree of overlap in some of these measures, the researcher ensured authenticity by recording the interviews and accurately transcribing the data. Also, during the interviews, the researcher avoided guessing what the participants meant, and sought to ensure that what I had understood them to say was what they actually meant.

The measure of auditability was ensured by providing a detailed description to aid audit trail of the study by explaining the data collection methods, recruitment and showing the coding and making linkages with the interpretation (Clark 2001). The process of collecting and analysing the data in a systematic way with accurate presentation may aid open evaluation and replication (Ryan-Nicholls and Will 2009). The criterion of transferability was addressed by providing a detailed report for the readers as this can help with judgments of transferability for those who may wish to assess the relevance of the findings beyond the setting (Ellis 2010). This was ensured by providing information about the participants and settings, showing the link between the data, findings and interpretation of the data to provide a form of audit trail as shown by the coding process.

Lincoln and Guba (1985) stressed the importance of cross checking the findings of qualitative study with the participants to aid credibility. Mays and Pope (2000) argue that there is no easy way to reduce the chance of errors in qualitative study, however, its validity can be improved through various methods, through the researcher stating his own position (see section on epistemology); and justifying his decisions. Therefore, to verify the authenticity of the data interpretation, the participants were sent the collated statements and findings from the focus group interview for validation and to add their comments (Gillham 2000). Three participants confirmed that they agreed that the statements and interpretations reflected their views and the researcher assumed that those who did not respond also agreed with it. Thus, the participant reaction to the analyses was incorporated into the study as a way to further reduce error (Mays and Pope 2000).

Marshall and Rossman (1999) state that analysis of qualitative data can be effectively managed when data collection and analysis go hand-in-hand to develop a logical interpretation of the data. The use of a field diary can improve the reliability of qualitative research (Clarke 2009) as this was compared with the electronic recording and the flip chart. Tape recordings were transcribed verbatim and verified with the flip charts data recorded by the facilitator. The role of the facilitator further offered the researcher the opportunity to control the conversation and the additional source of data gathering could promote the credibility of the data. A detailed account of the data collection process, coding

and analysis was given to show that the interpretation was well supported by the data (May and Pope 2000). In addition, attention was given to negative or contradictory statements as shown in the findings of the study.

According to Gough (2003), reflexivity within qualitative research offers the researcher the opportunity to demonstrate the trustworthiness of the outcome of the study. Hand (2003) emphasised the importance of reflexivity in semi-structured interviews and Marks and Yardley (2004) and Walliman (2005) also identified the potential influence of the researcher on the result. In this case, my role and activities with the participants was as a researcher but not a contributor and all the responses were recorded as accurately as possible and the interpretation of the data was coherent with the raw data by following the steps previously discussed above.

SECTION 3

Phase 2: Questionnaire survey

3.14. Overview of the questionnaire survey study

This section discusses the questionnaire survey used for the Phase 2 study of the research. It will cover the development of the questionnaire, method of administration, key issues relating to reliability and validity, data analysis and constraints to the methodology. Polgar and Thomas (2007) state that surveys are commonly used in healthcare research for purposes, which include utilisation of certain healthcare; therefore, both mailed and face-to-face questionnaire techniques were used to obtain information from selected patients that met the inclusion criteria. The broad aim of the study was to examine the factors affecting attendance at diabetes education programmes amongst certain patients to address the research questions from the perspective of patients.

A questionnaire survey of two distinct groups of patient was undertaken. The first group of patients had attended the education programme and the aim was to find out why they were motivated to attend the education session. It also examined what could have prevented them from attending the session. The second survey group of patients were those that failed to attend the sessions with the intention to investigate the reasons for non-attendance and find out ways to improve attendance. The benefits of using the questionnaire survey method include capturing the opinion of a larger number of participants. Also, the questionnaire for both the attenders and non-attenders was the same with the exception of the

two qualitative questions; therefore, it allowed some comparison between the two groups of patients.

3.15. Questionnaire survey design

The format of a questionnaire can contain either open or closed questions or a combination of both in order to interrogate the research questions of interest. Structured closed questionnaires allow the questions to be focused and uniform, easy to answer and analyse (Polit and Beck 2012, Burns and Grove 2005) while open-ended questions allows the participants to talk freely (Goom 2004, Depoy and Gitlin 2005). This survey consisted of a questionnaire that included questions of both closed and open-ended format administered at four different hospital sites in the selected Primary Care Trust. The close-ended questions limited participant responses using both dichotomous questions and a Likert-type scale whilst the open-ended items gave participants the opportunity to express their beliefs, opinion, feelings and preferences in more depth.

Some of the key factors that were considered by the researcher in designing the questionnaire were the study objectives, type of data to be collected and the target population in terms of age, language and accessibility (Depoy and Gitlin 2005, Polit and Beck 2012), therefore, questions were generated to construct a short questionnaire that will be easy to answer. The resulting survey questionnaire for the Phase 2 study of the research included socio-demographic

characteristics, attitudes to self-care, motivational factors, barriers to attendance and perceived benefits of group education on their diabetes self-management.

3.15.1 Aims of the survey

Following data analysis from the Phase 1 study, a survey questionnaire was developed with the intention of gathering data from patients. The focus of the study at this phase was to examine:

- (1) The barriers and motivating factors that are associated with attendance
- (2) Any differences that exist in demographic characteristics between the two groups
- (3) Whether differences exist in certain health beliefs between the attenders and non-attenders.

3.15.2 Assumptions

The assumptions for this study were drawn from the theoretical arguments of Graziani et al (1999) and the results of Phase 1 study. Broadly, the researcher hypothesized that the factors associated with non-attendance and subsequent attrition would be identified in addition to the health beliefs that were identified by Graziani et al (1999), the Phase 1 study results and the guidance provided by NHS Institute for Innovation and Improvement (2008) because it is a recognised NHS toolkit for examining the causes of non-attendance at the hospital. Thus it was hypothesized in the present study that there would be a positive relationship between perceived benefits of the session and attendance. This perspective

stems from research by Graziani et al (1999) which found low perceived benefits of the education as a barrier. The findings from the focus group research in the Phase 1 study of the current research revealed that perception about the importance of the education does affect attendance as shown in this excerpt *“Because they do not have a perception that it is important”* (Chapter 4, page 114). The last hypothesis was that perceived seriousness of the disease would be associated with attendance. Graziani et al (1999) indicated that this perception impacted on attendance in Diabetes Education Programmes. The Phase 1 Focus Group study results identified perceptions relating to the seriousness of diabetes as a barrier to attendance *“A lot of patients don’t recognise diabetes as a serious condition”* (Chapter 4, page 124).

3.15.3 Item selection

Several studies have identified the association between health beliefs and utilisation of healthcare services (Becker et al 1978; Cockburn, Fahey & Sanson-Fisher 1987; Mirotznik et al 1998). In particular, the findings of the study conducted by Graziani et al (1999) reflected aspects of the Health Beliefs Model (HBM) (Becker et al 1978) and the two key beliefs identified as barriers to attendance were low perceived seriousness of diabetes and no perceived benefits of the education session. Thematic analysis of the data in Phase 1 of the current research also revealed the impact of these health beliefs on attendance. In order to examine whether there is any difference in the health beliefs held between the two groups of patients, the Health Beliefs Model (Becker et al 1978)

was applied to illustrate the findings. The original HBM (Becker et al 1978) includes three broad assumptions: health motivation, perception of the threat and perception of the effectiveness of an action to reduce the threat. Therefore, questions were generated for this study to examine the influence of these beliefs on attendance. Thus, this study has used the HBM to explain or interpret the study and a detailed explanation of the application of HBM in making health choices in relation to this study is presented in Chapter 7 (pages 263 to 268 refer).

The variables within the HBM are psychological constructs; therefore, they cannot be directly observed but inferred. The inference is often carried out by assessing the behavioural predictors previously discussed (pages 53 – 59 refer). Although the main focus of the study was not to construct a questionnaire purely to measure HBM, however, the possible influence of some beliefs was examined. Items were based on the research conducted by Graziani et al (1999) and the questions were in line with the model that they proposed. The pool of items relating to the HBM assumptions consists of questions which assess their motivation. Question 1: *“I believe that taking responsibility to care for myself is an important aspect of my healthcare”*. The belief relating to their perceptions about the threat level of diabetes was examined by question 4: *“I believe that my diabetes is well controlled and do not need to attend the teaching session”*. The final assumption of the HBM on perceptions about the benefits of the session was covered by questions 2 and 3: *“Attending planned sessions on diabetes at*

an education centre is important to develop the ability to care for myself” and “Using the internet and talking to other patient to find out about my medical condition is sufficient to offer adequate information”. The questionnaire was constructed so that participants responded to each item on a five –point Likert scale anchored at the extremes by 1 (strongly disagree) and 5 (strongly agree).

In order to examine the contributions of the HBM drawn from Becker et al (1978), some items which are dichotomous questions (i.e. answered either Yes or No) also reflected each of the three theoretical dimensions of the original HBM (Becker et al 1978). Question 7: *“Group education is a good way to learn about diabetes”* and question 8: *“I like to share my experience and gain support about diabetes care through group education”* examined their motivation to engage with self-management and the education programme. As shown by the results of the focus group in Chapter 4, practitioners verbalised that patients failed to attend the sessions due to various reasons such as unwillingness to take responsibility for their care and using the internet as a source of information on diabetes management.

The health beliefs are not the only factor that influenced the health decisions of patients to attend hospital appointments (Graziani et al 1999, NHS Institute for Innovation and Improvement 2008). Therefore, focusing solely on the influence of health beliefs may lead to exclusive emphasis on a set of few influencing factors to attendance (Stephoe and Polland 1995). Consequently, it is important to

explore the role of other key influences on educational uptake as a whole. Lack of awareness of the programme and misperceptions about what the education involved was reported by Graziani et al (1999). Also, the researcher asked the participants whether they were encouraged by the healthcare practitioners. These findings were addressed by questions 5: *“The Doctor or Practice Nurse told me what to expect during the teaching session”*, question 6: *“There is opportunity to contact the education centre or GP clinic to clarify”* and question 9: *“The letter of invitation is clear”* respectively. In the same way, analysis of the data from the phase 1 study revealed poor referral systems and inadequate information given to the patients: *‘The GPs and the practice nurses who are at the point of diagnosis are obviously not giving them (the patients) the information that they should and need to be having’* (Chapter 4, page 120).

Graziani et al (1999) surveyed the participant’s age, gender, race, education, employment and marital status. For the present study, demographical characteristics including age range, gender, living arrangements, level of communication in English language and ethnicity were collected in the final section due to their perceived influence on attendance (Gucciardi et al 2007; Gucciardi et al 2008a; Rhee et al 2005). The researcher used the ethnic group classification for use in a survey recommended by the Office of National Statistics (ONS 2010) because of the difference in the geographical location of the study. Other demographical data such as years of diabetes, method of controlling diabetes and cardiac risk factors (Graziani et al 1999) were not

included in the survey questionnaire because the target populations are newly diagnosed patients with diabetes.

Graziani et al (1999) identified some structural barriers such as transportation, time, awareness of the existence of the session, insurance status and trouble with reading. Some of these barriers were also identified by the Phase 1 of the current study, therefore, questions 5 – 11 in part 1 and questions 7 and 8 in part 2 of the questionnaire were based on these identified barriers. However, the researcher did not include any question on insurance cover because the UK has a different healthcare funding system. Lastly, there were two qualitative questions which were in line with Graziani et al (1999) study and the overall aim of the current study. The qualitative question asked the participants to state the reasons why they have either attended the session or not.

The resulting 21 item questionnaire, included two open-ended questions, short, reliable and easy to administer (O'Neil et al 2012, Polit and Beck 2012, Goom 2004). Section 'A' Part 1 addressed questions relating to the Theory of Health Belief Model (Becker et al 1978). This first section of the questionnaire contained four items relating to the patient experience with responses measured on a five point Likert scale with 1=strongly disagree and 5=strongly agree. The questionnaire was partly developed by extracting the salient beliefs which could illuminate the topic by using the beliefs identified by Becker et al (1978). Section 'B' Part 1 of the questionnaire contained nine items about the reasons that either

encouraged or discouraged participants to attend the session. The last part of this section contained two qualitative questions that further explored their barriers and motivators to attendance. Part 2 enquired about demographic information that are deemed to be relevant to the study. Finally, the survey included the common barriers identified in the literature as opposed to an exhaustive list of barriers (Rhee et al 2005) and mostly designed to measure different constructs in an attempt to avoid a lengthy questionnaire.

3.15.4 Validity and Reliability procedures

Validity is the ability of the instrument to measure what it is designed to measure whilst reliability refers to the capability of an instrument to measure the variables of interest repeatedly (DeVellis 2012, Polit and Beck 2012). The validation processes used by the researcher were content and face validity, reliability testing using a split- half reliability test and Cronbach's alpha to ascertain that the tool has measured what it was supposed to measure and ascertain its reliability in order to ensure that participant's responses were stable.

The first step of the survey development covered identification and generation of items to be included in the questionnaire and assessment of its readability. Thus, content validity was considered in order to assess whether the content of the survey questionnaire was appropriate and relevant to the purpose of the study (Parsian and Dunning 2009, Pallant 2007). Content validity is often undertaken by several experts in the field (Polit and Beck 2012); therefore, the researcher

sought the expert views of 14 practitioners with a range of 6 to 17 years' experience within the field of diabetes care and two supervisors who are also from a nursing background to review the draft of the questionnaire. These practitioners who are familiar with the context of the research reviewed the items and suggested contents to be deleted or added to the pool of items (DeVillie 2012). In addition, the item development included a focus group interview and three individual interviews to identify the key issues and language they used to describe the barriers. Therefore, the content reflects what is relevant to the research question, based on the research literature and data from the Focus Group and interviews run in Phase 1 study of the current research.

To determine the face validity of the questionnaire, an evaluation of the wording was undertaken, the potential that the target patient would be able to understand the question to minimise the danger of the items been prone to a wide range of interpretations was therefore ascertained (Parsian and Dunning 2009, Bryman and Cramer 2001). In particular, the healthcare practitioners commented on the suitability of the questionnaire including layout and style and amendments were made to make sure that it is easy to read and comprehend. The need to avoid professional jargon and abbreviations were addressed to produce comprehensible questions. The length of the questionnaire was suggested to be questions that could be completed in less than 10 minutes as a lengthy questionnaire that takes a longer time to complete may be counterproductive, particularly, in this group of patients. This approach concur with that of Graziani

et al (1999) whose study used a questionnaire survey that could be completed in between 10 – 15 minutes.

Ten patients in a diabetic unit were also selected to complete the questionnaire as a pilot study to further clarify the wording of items, gauge the administration time and test the open-ended questions (Graziani et al 1999). The patients were asked to comment on the questions and there was no negative feedback received. The instrument was found not to be ambiguous because the patients completed it within ten minutes and agreed that they understood the content and it was easy to read it. Following piloting and analysis of the pilot responses (Appendix 13), minor corrections were made on the final copy to reflect the feedback obtained from the practitioners and during the administration of the pilot questionnaire. A descriptive analysis of the pilot data was undertaken by looking at the observed frequencies, summaries of the distribution of the data and its graphical representation to assess the responses for content and face validity. This helped to assess that the questions were suitable and relevant to the subject of enquiry that is being assessed and ascertain if the tool can gain the needed information. The final versions of the questionnaire can be found in Appendices 14 and 15.

For reliability testing, Cronbach's alpha was run for the Likert scale items of the questionnaire. The items of the survey questionnaire that were developed as a scale are Q1 – Q4 and because the survey instrument was new, a key aspect of

the analysis was to test its reliability (DeVellis 2012, Pallant 2007) to measure its internal consistency, to assess how the items of the questionnaire hang together (Pallant 2007, Tavakol and Dennick 2011). Although, there are various measure of internal consistency, calculating Cronbach's alpha is the most commonly used objective measure of reliability in medical education research (Tavakol and Dennick 2011), therefore, it was used for the current analysis. A review of the research literature revealed a controversy regarding the acceptable level for Cronbach's alpha calculation in order for a scale to be judged reliable (Tavakol and Dennick 2011, Hinton et al 2004). An ideal alpha ranges from 0.70 – 0.95 (Tavakol and Dennick 2011), a Cronbach alpha coefficient value of 0.7 or above is the most ideal (Pallant 2007), below 0.50 is low, 0.50 – 0.70 shows moderate reliability, 0.70 – 0.90 shows high reliability and 0.90 and above can be considered as excellent reliability (Hinton et al 2004). Two of the four Likert questions in Section 'B' required to be reverse scored. For this study, internal reliability of the four Likert –type scale questions was measured to assess whether the items that comprise the scale are consistent. The mean and standard deviation used to test the four items of the scale on 'Attitudes to Diabetes Education' was (M = 13.99, SD 3.67) with a Cronbach's alpha (α = 0.73). Although a low alpha reliabilities are not uncommon with a small number of items on a questionnaire (Kagee and Merve 2006), this denote a moderately reliable instrument.

Lastly, all the questions in the final version of the questionnaire were examined for its reliability to see if it consistently measures what it is supposed to measure. Test-retest is an estimate of correlation between two scores given at two points and it is common to check reliability by re-testing or repeating questionnaire administration multiple times and the scores from Time 1 and Time 2 can then be analysed in order to evaluate the consistency of the repeated responses. However, it was not appropriate for this type of hard to engage patient to fill the questionnaire more than once over a period of time to avoid further fuelling non-attendance. The key estimation of reliability used was the split-half reliability test. A split-half reliability applied to a reliability check done on a single pool of items that are divided into two (DeVellis 2012). For a split-half test, a reliability test score of $r = 0.8$ or above is preferable (Bryman and Cramer 2001). Thus, SPSS was used to generate a correlation coefficient for the two halves of the items in the questionnaire. For this research, the split-half test result has a high split-half score of $r = 0.937$ and this further demonstrated the reliability of the items.

3.16. Sampling and recruitment of participants for Phase 2 (Questionnaire survey of patients with type 2 diabetes – attendees and non- attenders)

The access to the patients for the sample for the Phase 2 study (questionnaire survey) was gained through the General Practitioners' register in the Primary Care Trust (PCT). The criterion for selecting eligible patients was all the recently diagnosed patients who had been referred to Diabetes Education Centres for a structured patient education programme within the last twelve months. The

survey participants were drawn from newly diagnosed patients referred by the GP to the four Diabetes Education Centres within the PCT and two sets of patients were surveyed.

It is possible to determine the minimum sample required for statistical analysis by using a power calculation software such as the G* power 3 programme to determine the sample size for the study (Faul et al 2007; Barker 2010). Therefore, the researcher performed a power calculation to determine the required sample size for the Questionnaire study using the G* power 3 programme. The calculation was based on Cohen's (1988) effect size guide (correlations: small = 0.1; medium = 0.3; large = 0.5). It was calculated that a total number of 176 participants (n=88 in each group) would be needed to generate a moderate effect size of 0.3 at a power rate of 0.95 which is sufficient for this study.

Having determined the minimum sample required for statistical analysis, a convenience sample of patients irrespective of their sex, social status, occupation, religion or educational background was used to recruit from attenders of diabetes education sessions. For the 'Attenders' group of the Phase 2 study, a sample size of 102 participants was recruited. An average of 23 to 28 participants (Table 3.3) were chosen from each of the four locations by randomly selecting and approaching three to five participants in each session.

For the 'Non-Attenders' group, a convenience (opportunistic) sample size of 105 non-attenders was targeted from a population of 394 patients that failed to attend

the sessions within a year. This sample size was derived by sending questionnaires to the entire population of non-attending patients over a period of one year. A key issue is that the non-attenders in the Phase 2 study are recognised as 'hard to reach' participants; therefore, a random selection technique was inappropriate to collect the data from them. However, due to sampling problems involved in accessing non-attenders, the sampling technique has taken non-response rate and representativeness of the population into account by using a census sampling approach. Therefore, all the non-attenders between January and December 2008 were sent a mailed questionnaire. Apart from the people that did not return their questionnaire, n=17 (4.3%) questionnaires were returned to me by the Royal Mail company which suggests that the addresses on the envelopes may have been incorrect. Consequently, the total sample successfully recruited for the study (n=105) exceeded the minimum sample size required for the input parameters identified in the power calculation of the sample size.

3.17. Procedure of Questionnaire administration

The researcher and the practitioners approached each eligible individual in the Diabetes Education Centres at the four locations for the attenders group. With the help of practitioners, the questionnaires were administered following adequate information being given and consent of the client being received (Johnson and Long 2010). In addition to the instruction, a note soliciting for the participant's support and assurance of confidentiality was included on the

questionnaire. The questionnaires for Attenders were distributed to patients during the education sessions whilst the Non-Attenders were surveyed by posting the questionnaire to them. Each questionnaire was assigned a code number to identify the participant and the area and to facilitate return a postage paid self-addressed envelope was provided. In total, 733 questionnaires were sent to an identified sample of 394 Non-Attenders between March and November 2009.

3.18. Response rates of questionnaire

Hamilton et al (2002) suggest that sending a second cycle of questionnaires might increase the response rate; this approach was used in the current study to attempt to increase the response rate of non-attenders without any significant achievement. On the whole, a total of 207 participants completed the survey, however, every person did not complete all the questions and this occasional missing data will be reflected in the sample of each question. The samples comprise 102 participants that attended the session and 105 non-attenders. Table 3.3 shows the total number of responses per geographical locations. The total response per geographical locations ranged from 22% – 29% of the overall numbers.

Table 3.3 - Response rates of questionnaires by geographical location.

Geographical locations	Attenders		Non-attenders		Total number of response per each location
	Number of returned questionnaires	Percentage response (%)	Number of returned questionnaires	Percentage response (%)	
Area 1	n=28	27%	n = 33	31%	n=61 (29%)
Area 2	n=26	25%	n = 29	28%	n=55 (27%)
Area 3	n=23	23%	n = 22	21%	n=45 (22%)
Area 4	n=25	25%	n = 21	20%	n=46 (22%)
Total number	102	100%	105	100%	n=207 (100%)

3.19. Data analysis

In addition to reliability analysis using Cronbach’s alpha and the split-half test, the organization, analysis and interpretation of findings of the questionnaire data was done in three stages to give meaning to the data collected (Polit and Beck 2006). For the Phase 2 survey study, SPSS software (Version 22) was employed to analyse the quantitative data and the results are presented in Chapter 5. These results are reported in three distinct stages; each of these stages leads to the next and also provides justification for the stage that follows. Firstly, analysis of the descriptive statistics using percentages and Chi Square test to describe the characteristics of the participants. Secondly, a t-test was run to show statistical difference between the two groups and finally Logistic Regression to produce a model that predicts which variables might lead to non-attendance.

The first stage of analysis involved descriptive statistics such as frequency distribution, simple percentage, cross tabulations and graphical presentations (bar charts) which provides the opportunity to illustrate the distribution of the data and sum up the data (Baker 2010; Depoy and Gitlin 2005). Although, cross tabulation helps the researcher to determine whether there is an association between certain variables, Pearson correlation was performed to indicate the strengths and direction of the relationships of the variables of interest.

In addition to Pearson correlations, Chi-square is a method of analysis suitable for categorical data (Barker 2010). Chi-square is a test of association that can be used with ordinal and nominal variables and Chi-square is one of the most commonly used tests of association for this purpose. The researcher used Chi-square to estimate the probability that the association between the variables result from random chance by comparing the observed (actual) distribution of responses with the expected distribution of responses (Bryman and Cramer 2001). To report the expected and observed frequencies using the Chi-square statistic, American Psychological Association (APA) style of reporting (American Psychological Association 2001) will be used. Therefore, the Chi-square statistics will be reported with degrees of freedom and sample size in parentheses, the Pearson Chi-square value will be rounded to two decimal places and followed by the significance level. As the exact p-value will be reported in the text, the alpha level used as a significance criterion for all the statistical tests is $p \leq .05$.

Whilst Chi-square operates on the basis of a contingency table by using crosstabs procedure, the t-test is a test of difference based on differences in means value. The researcher computed a new variable (Attitude toward diabetes education) from the four item Likert scale questionnaire section to compare mean scores between the two identified groups (Attendees and Non-Attendees). An (independent samples t-test) was used to compare the means computed and investigate any difference in the attitude of participants in both groups towards diabetes education.

However, some indicators of barriers to attendance may not be obvious by simply comparing the views of attendees and non-attendees (Rhee 2005). Whilst, correlation attempts to consider symmetrical association between two variables, regression introduces the notion of prediction; therefore, additional analysis was performed by using logistic regression analysis. The purpose of undertaking the logistic regression test was to determine the influence of certain variables upon attendance behaviour because it is a more stringent test to analyse predictive relationships between variables. Logistic regression was performed on socio-demographic variables of interest because they were dichotomous and not on a continuous scale, therefore Multiple Linear Regression was not suitable (Field, 2009). At this phase, the aim of the researcher was to observe whether attendance behaviour can be predicted based on ethnicity, family history of diabetes, living arrangements and flexibility of working pattern/environment.

Both Cox & Snell R-square and Nagelkerke R square values may be computed to explain the variation in the sample of the regression model but the latter is a modification of the former, therefore, it is often used to report the variation. Due to the importance of reporting the variance of the calculation, the researcher will use the Nagelkerke R square to explain any variation in the result. The researcher will also report the effectiveness of the predicted calculation as this is essential to show whether cases can be correctly predicted from the independent variables. Logistic regression classifies an event as occurring if the probability of an event occurring is greater than or equal to half chance. The researcher will report the variables in the equation to show the contribution of each independent variable to the model and its statistical significance. Lastly, the odds ratios will be reported as these show the odds of an event occurring and this will give depth to the explanation of the regression model produced.

Finally, the qualitative aspect of the questionnaire collated the data and arranged it into themes as previously discussed in the qualitative section of this Chapter on pages 83 - 85.

3.20. Constraints to the quantitative approach

A key constraint could be considered to be the use of a new non-validated questionnaire as opposed to an existing one. However as previously discussed, it was felt that a bespoke short measure with several dichotomous questions and limited number of items would have greater participant appeal to examine the

contribution of certain beliefs on attendance given the recognised lack of engagement of some of the sample. Also, due to categorical data being collected and the lack of several items which measured the same construct necessitated by the nature of the participants limited the use of certain statistical analysis. The non-experimental approach used in this study does not allow definite conclusions regarding the causal relationships between the identified variables and attendance. Also, the use of convenience sampling technique and small sample size may restrict the generalisability of the findings (Polit and Beck 2012, Parahoo 2006). However, given the 'hard to reach' nature of the targeted sample, it was deemed more important to have ecological validity in terms of participant appeal in order to gather as much data as possible.

The application of the theoretical model of Health Belief Model (Becker et al 1978) used in this study was not intended to test the full range of assumptions responsible for predicting behaviours of patient's attendance. Whilst the short number of questions on the questionnaire could be a source of limitation, this type of a short and a concise questionnaire that patients will respond to and would not find complex or hamper the response rate, was deemed the most appropriate. Although personal belief is one of the reasons responsible for non-attendance in clinical practice, the key objective of the study was not to measure the beliefs of patients but to explore the entire range of reasons that could contribute to non-attendance, hence, an existing validated questionnaire on HBM was not used as these tend to focus mainly upon beliefs. In addition, the primary focus for developing the questionnaire was not as a scale to measure HBM,

instead the researcher wanted questions that can be answered easily, consistently and will be of use to practitioners afterwards. However, the researcher intended to explore the reasons for non-attendance and correlate the opinions of attenders and non-attenders, therefore, the survey method using a new questionnaire was an appropriate approach. By using the survey method, the researcher was able to further explore ways to influence policy and practice as opposed to mainly providing support for a theory. As we will see in Chapter 5, the data generated at this phase of the study supported the substantive assumptions generated from the onset and also the data collected in Phases 1 and 3 of the current research.

SECTION 4

Phase 3 - Face-to face interviews

3.21: Introduction to section 4

This section discusses the methodology regarding the last phase of the study which used face-to-face interview questioning technique to establish the perspective from referring healthcare practitioners to address my research questions from the perspective of practitioners. The use of face-to-face interview in healthcare research is a useful tool (Walliman 2005). This phase used this interview technique in order to further explore findings from Phase 1 and Phase 2 study (see appendix 16 for the question guide) and the data was transcribed as accurately as possible. Interviews can be described as structured, semi-structured or unstructured (Polit and Beck 2009). For the purpose of this study, a semi-structured interview technique was used to collect in-depth information that led to a better description of complex human behaviour. The benefits of a face-to-face interview includes in-depth conversations with a small sample size, the opportunity to experience the tone of the participants' voice and to clarify understanding. It also helped to further explore issues raised in the previous two studies.

The Phase 3 used a similar approach to the Phase 1 study; therefore, this section will report specific information relating to Phase 3 only. The epistemological assumptions of interpretivism go beyond description and arrived at meaning through a blend of those articulated by the participants and expert

knowledge of the researcher. The reasons that may aid non-attendance were generated through in-depth conversations with participants and the interpretation of the findings based on their views on non-attendance interpreted through the filter of the researcher's own knowledge on this topic, including as a result of the literature review on this topic.

3.22. Sampling and recruitment of participants for Phase 3 (Individual interviews of referring practitioners)

In order to present a balanced view of the practitioners, Phase 3 of the study had drawn a sample of the healthcare practitioners that are responsible for referring patients to the Diabetes Education Centres. Although, there were changes to the organisational structure of diabetes education management in the country with effect from 1st of April 2013 due to a service restructuring brought about by the latest coalition government health policy - Health and Social Act 2012, the GPs and Practice Nurses are still responsible for making referrals to other Health and Social Care Institutions which includes Diabetes Education Centres.

However, the restructuring process has replaced the PCTs with CCGs and the four geographical locations used for Phase 1 and Phase 2 of the study now fall under two distinct communities (East and West) with three clinical commissioning groups (CCGs). Therefore, the researcher decided to take similar number of participants from each new CCG within the two communities. The eligibility criteria included all practitioners that are involved in referring patients with diabetes to the Diabetes Education Centres, who are working full-time and have a minimum of 5 years working experience. These selection criteria ensured that

potential participants were engaging with patients affected by diabetes and had five years' experience in order to provide adequate insight to the question of enquiry. Finally, they needed to be familiar with both systems of operation over the period before the recent changes in the NHS.

Based on the above criteria, all eligible healthcare practitioners who are responsible for referring the patients to the Diabetes Education Centres were contacted to participate in Phase 3 of the study. As a measure to collect additional data from the referring practitioners, visits were made to 42 GP surgeries within the geographical location of the study to distribute information sheets and consent forms. All the GP sites were requested to contact the researcher if they wished to participate in the study. Also, follow-up telephone contact was made to solicit practitioners' participation in the study.

Similar to Phase 1 of the study, this Phase used an opportunistic sample to collect additional information as a follow-up to further explore the barriers and enabling factors to attendance. This led to individual interviews of nine referring practitioners from six General Practice surgeries across the four geographical locations within the three CCGs. Thus, the focus of both Phase 1 and Phase 3 of the study was to gather the perceptions of educators (Phase 1) and referring practitioners (Phase 3) about non-attendance.

3.23. Data Collection method for Phase 3

The question guide was developed based on data generated from Phases 1 and 2 and the current context of healthcare delivery in the NHS. The researcher conducted the one-to-one interviews through face-to-face techniques in the participant's office within the GP surgery and each interview lasted for a minimum of 30 minutes and a maximum 53 minutes with the exception of one interview which lasted for 15 minutes. The researcher took field notes and recorded the interviews.

3.24. Data analysis for Phase 3

The analysis of the individual face-to-face interviews used the same thematic analytic approach, which was used for the Phase 1 study analysis with the following stages (Table 3.4) below:

Table 3.4 - Stages of face-to-face interview data analysis
<ul style="list-style-type: none">● Reading the text several times● Initial coding by using participants statements● Second degree coding with remarks● Clustering of codes into sub-themes● Developing sub-themes to major themes● Interpretation● Argument development

The process of analysis and interpretation covers transcription of the data and initial coding (appendix 17), identification of categories (appendix 18), sub-themes (appendix 19) and themes (appendix 20) which was used to build a descriptive theory of the phenomenon (Polit and Beck 2010). Based on the analysis, the themes of the face-to-face interviews are discussed in Chapter six.

3.25. Rigour considerations

The same considerations in relation to trustworthiness in qualitative research discussed on pages 78 -81 were applied to enhance the rigour of this phase of the study. In a similar way, the authenticity, auditability, transferability, and credibility of the study was ensured by presenting the findings for the individual interviews to the participants who agreed that the findings were reasonable account of their responses. A note of the field note in all the interviews was kept (Clarke 2009) and a quick transcription of the discussion was undertaken to aid recall of the events that took place during the study. Again, the researcher explained the methods, data management procedure and described the setting to aid the readers' judgment of the relevance of the study to their clinical environment. In this study, the researcher avoided the influence of personal bias on the study and there were no personal relationships with all the participants (Mays and Pope 2000).

3.26. SUMMARY OF CHAPTER 3

This Chapter has explored the philosophy that guided the research design and explained the methodological approaches utilised to gather the data. All the three Phases of the research study were connected and merged together to investigate the research question and to provide a broader understanding of the problem. Phase 1 used a focus group and individual interviews of three participants to identify the barriers and enablers to attendance from the perspective of healthcare practitioners providing the education. The sampling techniques, ethical considerations and the underlying issues relating to the rigour of qualitative methodology in terms of credibility, auditability and transferability were considered in this Chapter. The qualitative data were analysed by using thematic analysis to arrive at key themes.

The second phase built upon the qualitative Phase 1 results to develop a questionnaire to survey the opinions of two patient groups. In order to address the overall research aim and allow statistical comparison between the two groups of attending and non-attending patients, a questionnaire comprising mostly closed items based on a previous study was used to survey the opinion of patients. Items for the questionnaire were also developed through a series of discussions and consensus among the practitioners. It examined barriers and enablers to attendance and included the influence of beliefs as one of the determinants of attendance. The quantitative data analysis was done in three sequential phases. Firstly, the descriptive statistics were conducted, then

associational statistics and finally inferential statistics were computed. The final aspect dealt with the constraints pertaining to the survey, its implications and justified the benefits of the survey in achieving the overall aims of the study. Both content and face validity of the questionnaire instrument were examined and a split-test reliability and Cronbach alpha was used to demonstrate the reliability of the tool.

The third and final Phase took an exploratory qualitative approach using face-to-face individual interviews to explore the phenomenon from the perspective of practitioners referring patients within the Clinical Commissioning Groups. This phase offered the benefit to explore the implementation of diabetes education policy over time and new data and data that confirmed the previous findings were generated. The next Chapter will report the findings of Phase 1 study, which are a focus group interview and individual face-to-face interviews of healthcare practitioners.

CHAPTER 4

BELIEFS AND ATTITUDES OF TYPE 2 DIABETES PATIENTS' TOWARDS EDUCATION FOR SELF-CARE: PERCEPTIONS OF EDUCATION PROVIDERS

4.1. Introduction

Although there is a national diabetes education policy for all newly diagnosed patients with diabetes, non-attendance in Diabetes Education Centres remains a challenge. Owing to the known non-compliance of patients with diabetes education for self-care management, and a question of whether operational policy can be adequately translated into practice in this area, this part of the study seeks to meet the study objective of obtaining the views of healthcare practitioners on why patients that were referred failed to attend the education session. A qualitative approach was adopted using a focus group interview and semi-structured interviews with practitioners in a PCT in the South East of England as previously explained in the methodology chapter. It involved Diabetes Specialist Nurses, Podiatrists and Dieticians. Thematic analysis was used to analyse the data. Therefore, this Chapter will report the findings of the first phase of the study which used a focus group technique, a paired face to face interview and one individual interview to explore factors influencing non-attendance from the perspectives of healthcare professionals. Thereafter, the discussion of findings will be presented.

4.2. Results/Findings

Following the thematic analysis approach discussed in Chapter three (section 3.12), the initial coding was grouped into sub-themes and this was later categorised into the following major and sub themes shown in Table 4.1 below:

Table 4.1 – Themes and sub-themes

Major Themes	Sub-Themes
(1) Perceptions and attitudes of practitioners to diabetes education.	<ul style="list-style-type: none"> - Attitude of Practitioners - Meeting targets - Introducing sanctions /penalties
(2) Patients' perceptions and attitude towards diabetes education.	<ul style="list-style-type: none"> - Perceptions and beliefs of patients about their health and the benefits of education - Preference for group learning - Patients' socio-cultural background
(3) Personal circumstances.	<ul style="list-style-type: none"> - Employment/education - Holiday -Language problem
(4) Official protocol and Self- management education resources.	<ul style="list-style-type: none"> - Referral and appointment systems - Resources
(5) Strategies to improve attendance.	<ul style="list-style-type: none"> - Flexible delivery - Use of health activist - Government incentives -Adaptive official protocol

4.2.1. Overall attitude of education practitioners

The discussion began by trying to establish whether having a compulsory structured education for patients is a good idea to equip patients with self-care knowledge and skills. When asked whether the policy itself is good, all the participants in the focus group interview agreed that offering education to all newly diagnosed patients with diabetes is good. Two of the participants in the focus group verbally substantiated their own agreement thus:

Yes, because it is an ongoing progressive disease, so they need the education initially and then they need education as they go along (Participant 1, Area D, Diabetes Specialist Nurse (DSN) and

The practice nurses don't have time for one to one, I went to a practice with a new patient and they have 20 minutes which is not long enough to tell somebody lifestyle changes (Participant 4, Area A, DSN).

Another participant verbalised the same opinion during the one to one interview thus:

I think it is a good idea that people are offered the education, but not necessarily they would attend it and we have a longer time to deliver it while the GP have shorter time to spend with the patient (Participant 9, Area B, Podiatrist).

When asked whether the government policy of education for all newly diagnosed patients is beneficial to the patients, the same positive view was expressed by another person during a separate interview:

It is a good idea to be offered the opportunity to have more time to deliver the education (Participant 8, Area D, Dietician).

4.3. Perceptions and attitudes of practitioners

There was a view among the practitioners that the perceptions and attitudes of healthcare practitioners to the session could either hinder or aid patients' attendance. Similarly, the need to meet targets set by the government was seen as an issue that could shape the attitude of doctors towards the education service. A final point on this theme is their view about using a form of sanctions/penalties to motivate patients.

4.3.1. Communication with patients

The participants felt that the attitudes of practitioners may affect the way they raise the level of awareness of the education among the diabetes patients. There were some issues relating to inter-professional relationships with one group of professionals trying to push the blame to other professional colleagues. To some participants, some general practitioners and patients have a negative perception about the importance of diabetes education:

Because they do not have a perception that it is important and the GPs don't always have a perception that diabetes education is important (Participant 1, Area D, DSN).

The same participant also believed that the general practitioners do not emphasise the importance of attendance:

In my personal view, I think some GPs don't emphasize the importance of attending the session (Participant 1, Area D, DSN).

In the same way, another participant thought that the general practitioners are too vague in their approach which invariably does not make the reason for attendance so clear to the patient:

They (GPs) are quite vague in referring patients to the education centre (Participant 7, Area C, DSN).

Although, the patients are routinely referred, some participants thought that the general practitioners and practice nurses need to give more information as to why they need to attend the sessions. They stated several instances where the patients did not know the reason for attendance when they came for the session.

Participants three and seven said:

The GPs and the practice nurses who are at the point of diagnosis are obviously not giving them (the patients) the information that they should and need to be having (Participant 3, Area A, Podiatrist) and

The patients don't know why they are coming to the centre (Participant 7, Area C, DSN).

Two participants felt that the use of appropriate terminology to explain the condition may be another reason for non-attendance. She suggested that practitioners need to talk to patients at appropriate levels to avoid misunderstandings:

It is about understanding as well, do they (the patients) understand the terminology I'm going to have a problem with my eyes, so what if I have the problem; but if I say you may go blind, they may understand (Participant 4, Area A, DSN).

Participant six corroborated this view by saying that the use of technical terms by practitioners may lead to misconception:

I think there's terminology as well because people are used to being sent an appointment to attend a clinic and when they see the word education they may not attach so much importance to it. Or again, whatever wording you use in the letter, patients often come with the misconception about why they are actually here. (Participant 6, Area C, DSN).

Some of these views about attributing the attitude of practitioners that are in first contact with the patients non-attendance suggested some issues with inter-professional partnership. A participant attributed this inter-professional issue to a poor link between the education centre and the GP practices:

To a degree, because we can only go into practices who invite us in, it is not easy to build relationships with the surgeries. We haven't got any directive from the PCT to go into a practice and demand to see their patient; it's only by building up a rapport and relationship. We can't say we've come in and I'm a diabetes nurse, I've come to look at your diabetes clinic or paperwork (Participant 1, Area D, DSN).

Some participants viewed that the responsibilities to make education for all diabetes patients a success, rest with all practitioners involved in diabetes care. As a result, one of the participants offered a broader view on this issue. She thought that stressing the importance of SPE should not be attributed to the general practitioners alone; instead, all professionals that are in contact with diabetes patients need to be pro-active:

The frightening thing is that sometimes patients aren't even aware that they have diabetes. Another thing is how important it is to attend the actual structured education. I think it is not emphasised enough by all the staff either, whether it is the nurse practitioners or whether it is the general practitioners themselves (Participant 4, Area A, DSN).

This view was corroborated by another participant who said:

The practice staff needs to emphasise the importance of the session (Participant 7, Area C, DSN).

In addition to problems of communication, government targets are also seen as one of the drivers for the attitudes of general practitioners towards SPE.

4.3.2. Importance of meeting targets

Although, there seemed to be a general view about the negative attitude of the general practitioners during referral, some participants viewed that SPE was not a key priority for the GP because GPs are driven by targets but not patient care, such as diabetes education. Having a separate benchmark for several professionals working to achieve a common goal may in fact create some tension in the delivery of service such as patient education. Two participants expressed this view:

Because I think the practices are driven by all the targets, they are not driven by patient care. Diabetes is so driven by the targets, we've actually forgotten about the rest of itit is all about target (Participant 1, Area D, DSN).

In the same way, another participant stated that government targets for the GP do not reward provision of diabetes education. She expressed it thus:

Moving on from that as well, you've got to look at the wider scale. I mean what the general practitioners are actually being targeted against and providing type 2 education is not high on the agenda at the moment whereas a quick fix to get the HbA1c levels down is going to be much higher on their priority list. So it may not even be the general practitioners, the government needs to promote how important this is and attach some value to it. They don't get any remuneration for it (patient education for diabetes) at

the moment, that's my understanding (Participant 7, Area C, DSN).

The issue of competition for funding was also mentioned by participant 7:

It becomes a competition between different disease areas and what the priority is in that local area as to how the money is spent (Participant 7, Area C, DSN).

Another participant introduced the concept of offering an incentive such as awarding points to the GP for SPE:

I think if they have an incentive, that might make them to do more, you know the points given... take for example, a lower HbA1c attracts an incentive (Participant 4, Area A, DSN).

This sub-theme identified in the data points to the possible role of government targets as a determinant factor for the level of attention giving to SPE by the GP.

4.3.3. Introducing sanctions/penalties

On a different note, some participants believed that patients with diabetes need to take more responsibility for their health or be subjected to sanctions. In this way, patients should be striving to improve their health. A participant said:

I think that people should make more of an effort for their health. I think we are doing too much for the patients in our care with the way we work at the moment. I think people need to make a conscious effort themselves to change their health. (Participant 2, Area D, Dietician).

On the issue of patients taking responsibility for themselves, another participant has a slightly different opinion even though she believes that the patients need to take more responsibility for their health:

But if they do not know the importance, then that's still our role to do it. As they say, you can take a horse to water but you can't make it drink but we do have a responsibility; are they DNA because they don't understand or they don't think it is important. Do we just strike them off after one time? (Participant 1, Area D, DSN).

Some healthcare practitioners felt that introducing payments may motivate patients to attend. Judging from this statement, the patients are seen as unmotivated and being tough or imposing a penalty may help. The tone of her voice at this particular time was high suggesting her passion for imposing a penalty:

If patients have to pay for their health, maybe they would take more effort to look after themselves. (Participant 2, Area D, Dietician).

On the issue of becoming stricter with the patients, for example by discharging them if they fail to attend, this participant went on to say:

I think we need to learn from the doctors or dentists, if they don't turn up, then that's it. I think we are too caring sometimes. (Participant 2, Area D, Dietician).

A similar view was expressed by another participant who shared the views that becoming stricter with the patient may help. She felt that a penalty should be applied to non-attenders:

But people do go to the doctor for their medicines and what have you, the doctor may need to pull them in and say you haven't been to the education centre and you should go, and if they don't attend maybe the doctor should penalise them. (Participant 3, Area A, Podiatrist).

In contrast, some participants felt that a penalty such as payment may demotivate some patients. This participant felt that a sanction is not the way forward. Her response showed a negative facial expression followed by a short statement:

No, having seen countries where patients have neglected their health even more due to healthcare cost. (Participant 1, Area D, DSN).

A participant echoed the negative effects of penalty by offering a short statement thus:

Sometimes, it can have the opposite effect (Participant 1, Area D, DSN).

Another participant also disagreed by citing an example from one African country. The participant described a situation by which similar action has led to increase in dropout rates of attendance:

I was just thinking about Kenya where we have to pay for our services, there was a lot of people who did not want to access the service because they had to pay, they could not afford it, those are the patients who probably get more complications and end up in a hospital. (Participant 4, Area A, DSN).

In the same way, introducing sanctions, such as payment or discharging them if they fail to come to the education centre, was seen as a grey area by another participant who was unsure whether this could lead to a negative or positive health outcome:

Introducing a fine is still another area, like the Dentist, if a patient fails to come, there is a sanction. I don't know but if that is the way the NHS is going to move forward, that could be an option in the future --- I don't really know. (Participant 10, Area B, DSN).

This participant later clarified her views by saying:

I believe it is better to give an incentive to attend than to be worse off if you don't attend. I think I am not for or against it and we have to see how it works in practice (laughing) – I think it may make things worse. (Participant 10, Area B, DSN).

On the issue of opposing the idea of sanctions, another participant supported the initial view of finding ways to motivate patients to attend the sessions:

It may be better to offer an incentive to motivate them, but not sure. (Participant 8, Area D, Dietician).

A participant felt strongly about the issue of imposing a sanction. Her body language showed disagreement to the statement. Then she went further to introduce another angle to it by suggesting the possibility of displaying a frightening picture of diabetes to the patients. The participant said:

I mean sometimes we are a bit too soft because they say people only make changes to their lives when they get a diagnosis of cancer or something, perhaps we should be putting pictures of three deaths per minute or this or that might happen. .. (Participant 2, Area D, Dietician).

This particular participant was passionate about it and added further:

I think it stems down to the general public as a whole. If there were shocking pictures and posters of complications related to diabetes, if they know relatives or friends who had an amputation or suffered a devastating condition, then they would relate it to themselves. At the moment, I feel our society is too soft. (Participant 2, Area D, Dietician).

Although, painting frightening pictures of diabetes to emphasise its seriousness was also seen as part of the solution by some participants. Another participant

disagreed by stressing that individual differences should be considered. She actually said that:

I mean it's like any disease, look at the smokers they've been told its going to kill you, it will give you cancer, but I'm still smoking away my life. (Participant 4, Area A, DSN).

Then, a participant further introduced a softer approach to the issue:

Should we just tell them what we learnt this week, for example, three deaths per minute from diabetes related complications. (Participant 6, Area C, DSN).

This section suggests that the following factors may influence attendance – communication; targets; financial and behavioural factors. Similarly, the findings have suggested some problems relating to inter-professional collaboration. Another key concept in this theme is the possible influence of the desire to meet government targets in shaping the attitudes of GPs. Their statements above also showed some agreements and few disagreements in their perceptions and attitude towards the approach of using sanctions to engage patients in the education service. The second theme relates to patients understanding and attitude towards diabetes education.

4.4. Patients perceptions and attitude towards diabetes education

Although, the practitioners' attitude was identified as a hindrance to attendance in the previous section, patients' attitudes were also expressed several times as a

possible reason that contributed to why patients do not attend the education session.

4.4.1. Perception and beliefs of patients about their health and the benefits of diabetes education

The concepts under this heading relate to the effects of patients understanding on attendance, possibility of having genuine reasons for non-attendance and individual preference for group or one to one education. Finally, different cultural background with different expectations is also suggested as a hindrance to attendance:

I think as long as people have the opportunity to telephone to make some form of contact if they are not able to attend (Participant 2, Area D, Dietician).

Another practitioner stated that some patients just choose to ignore the letter and some may not get the letter:

And that still doesn't really address why you may get those motivated enough to make the appointment but what about those who ignore the letter or how do we even know they've even got the letter (Participant 2, Area D, Dietician).

One of the participants felt that a poor understanding of the nature and care of diabetes among the patients is an issue:

I think there is also a perception that diabetes is very much around eating a healthy diet and keeping active and people probably feel quite defensive and may think that they are actually doing those things already and don't want to come and perhaps feel that they are being told off (Participant 5, Area D, Dietician).

Another participant felt that some patients think diabetes is a mild condition and may not take the education very seriously. This statement corroborates what has been said before:

I think that a lot of patients don't recognise diabetes as a serious condition and I think that their actual awareness especially in type 2 diabetes, it's still a mild condition (Participant 2, Area D, Dietician).

The insidious nature of diabetes and a better diagnosis of the disease are also seen as part of the reasons contributing to non-attendance. According to a participant, patients do not see the value of education when they are well:

I think it's interesting, I've seen a difference over the last ten years, people felt more unwell when they had been diagnosed because they were not picked up as early as they are now. When they actually had the symptoms they would be more inclined to access help, unlike when they feel perfectly well and fine (Participant 7, Area C, DSN).

A participant opined that offering education in the hospital environment may create some degree of fear in certain groups of patients:

I think there is a lot of fear attached because the teaching sessions are based at a hospital and I think that plays quite a large role, the fact that they come to hospital for education (Participant 3, Area A, Podiatrist).

This sub-theme illustrates that non-attendance is sometimes due to an unavoidable reasons while some patients failed to attend because of lack of adequate understanding of the nature of the disease. Also, holding the education session in the hospital setting is perceived to be a contributory factor.

4.4.2. Preference for group learning

The probability of group education being an issue for some patients was mentioned several times by different participants. However, some participants argued for and against the method of learning stressing the fact that SPE can be given individually or in groups. A participant seized the opportunity to stress the recommendations in the NICE guidelines on SPE:

No, the recommendation is that they (the patients) should have structured education, that doesn't necessarily mean in a group, it could be one to one or online. For structured education, you need a shared curriculum, lesson plans, it needs to be auditable, you must have quality assurance for it and it has to be delivered by trained educators or set up by trained educators (Participant 1, Area D, DSN).

Although the previous speaker itemized the qualities of a SPE which does not necessarily have to be in group, nevertheless, the centre mainly offers a group session. On this note, a participant felt that group education may be intimidating to some patients and could therefore contribute to non-attendance. Some of the excerpts on this statement are thus:

But a group setting may not be a benefit for some shy patient (Participant 8, Area D, Dietician).

Some patients do not feel comfortable in a group setting, may be a bit shy and therefore not a benefit. (Participant 10, Area B, DSN).

I think a group session can sometimes be a little intimidating or they think so initially (Participant 6, Area C, DSN).

Whereas another participant stated that the length of the session may be too long for some patients:

And I think sometimes the three hours spent in a single diabetes education session, I've got to sit for three hours (Participant 9, Area B, Podiatrist).

Regardless of the negative aspects of group education, the practitioners identified some positive aspects as well. Apart from the fact that group education is cheaper than one to one session, some participants believed that patients can support and learn from each other through group education:

Plus the fact that people learn from each other and it's nice to think that you're not the only person with diabetes. It's like any other disease, when you're diagnosed with something you feel you're the only one diagnosed so people come here and help each other (Participant 1, Area D, DSN).

Participant eight offered a broader view on this issue by saying this statement:

Both have got its benefits - in groups, questions may be asked from others, there is a staffing benefit – delivery to more than one person at a time, interaction among patient may be helpful, they may not feel they are on their own (Participant 8, Area D, Dietician).

The next statement also corroborated what has been said before:

Also, in a group setting, it may benefit the patient as questions can be asked by other group members of the group. (Participant 10, Area B, DSN).

The possible benefits of group education were also mentioned by another participant:

I think in terms of a bigger group of people, people don't feel they are on their own (Participant 9, Area B, Podiatrist).

Although this section showed the merits and demerits of group learning, nevertheless, it also suggested that some patients may not feel comfortable with group learning.

4.4.3. Patients socio-cultural background

Another recurrent statement was the issue of socio-cultural background of the patients. A participant stated that the practitioners need to consider ceremonies like Ramadan and Diwali:

I was just thinking, for example, if they have got ceremonies like Ramadan or Diwali or some other events going on. I think we need to be sensitive not to send the appointments on a particular month or whatever at least the DNA rate would decrease (Participant 4, Area A, DSN).

The body language of this participant showed that she strongly felt that cultural difference is a contributory factor. She believed that there is a different cultural perception to health issues and further said:

It comes like cultural again, for instance this afternoon, I rang somebody up that her appointment was at one o'clock, I'm still waiting here now and it is two o'clock – it was oh, some of my friends came along – so is your diabetes appointment more important or your friends? Then, the sudden reply is, oh well can I come now then? (Participant 4, Area A, DSN).

This same participant said there is a difference in the way people relate to health:

.... and of course for lots of people who have the condition they've been born and brought up or come here and been in a culture where they just go to the doctor and get the cure, get the fix, get the tablet. It is changing the whole way that people relate to health (Participant 4, Area A, DSN).

Another participant stated that culture may be part of the barrier and probably, it is necessary to consider the influence of socio –cultural background on attendance:

Well, certainly in Area A, we offer group education in different two languages, which is not the case in Area B and C which are the two areas that I cover. I think we need to think more about culture and diversity of the group and ways to address their needs. We have high Polish group of people in Area C (Participant 10, Area B, DSN).

Another participant corroborated this notion by acknowledging the possibility of language barrier:

No, I don't have a lot of patients from the minority ethnic group, but that is not to say they are not more. Different languages as well, I think Punjabi is offered in Area A, but I don't know of any other language being offered which could be a major barrier as well ---- language barrier could be one of the reasons why people are not coming . (Participant 9, Area B, Podiatrist).

Another participant was of the opinion that the socio-economic background of patient may be different from one locality to another:

Maybe other localities have a different socio economic group to Area A (Participant 1, Area D, DSN).

The statements under this theme identified further possible reasons for non-attendance, language barrier, cultural background, preference for one-to-one teaching sessions and the length of the session. The possible effects of patients understanding and perception of attendance (perception of the disease and the benefits of the session) were also highlighted. In addition, individual

circumstances in terms of genuine reasons such as work-related problems was mentioned few times.

4.5. Personal circumstances

A participant felt that some patients do have a genuine reason for non-attendance and they tend to re-arrange another appointment. For example, some may not get their letter of appointment; English may not be their first language and some general practitioners are not sensitive to patient literacy levels:

I think inadequacy of the letters we are sending out. Patients are not sure why they are coming to see us. Another reason could be that a relative of patients have diabetes and they may think they know everything already. It could be due to work or study or any other thing that could get in the way because we are offering appointments during the day which could interfere. It could be due to having it in the hospital and they are concerned that it is a specialist thing. They may be nervous or concerned about coming to the hospital to discuss things (Participant 9, Area B, Podiatrist).

This view was shared by another participant who stated that the reason for non-attendance varied from patient to patient and is often genuine. Based on the participants' experience, she summarised the reasons that may hinder patients' attendance thus:

From my experience, reasons that may affect attendance are inadequacy of letters, patient relatives with diabetes, work/studies may prevent them, because it is in the hospital – I mean concerned/nervous to discuss in the hospital setting and language barriers (Participant 8, Area D, Dietician).

In agreement with the previous statement, another participant stated that some patients have genuine reasons for not attending:

Yes, occasionally, they have genuine reasons ----- younger patient may not come due to inability to get out of work, some may be on annual leave and travelled on holiday, and there is no weekend/evening around 6pm (Participant 9, Area B, DSN).

Whilst there are numerous reasons for non-attendance, it is sometimes due to practical reasons. However, whether the reason is genuine or not, a participant felt that the patients should call to cancel their appointment as a matter of courtesy.

4.6. Official protocol and self - management education resources

The role of organisational structure in the delivery of diabetes health education is seen as crucial to promoting attendance. The key concepts under this theme are offering an appropriate referral system, a better appointment system, flexible delivery of the service and provision of adequate resources.

4.6.1. Inappropriate referral system and a rigid appointment system

Apart from patients' characteristics that may hinder attendance, the referral and appointment systems was a recurrent focus of discussion. Many of the participants expressed concern about the quality of information given by the GP during referral. A participant suggested that the referring GP must inform the patients about where, why and what to expect:

I think it is best to start when the G.P. is referring and assessing the patient. I think the primary aim is really to inform the patient why they are going, what they are going for, what they are going to learn from there and what they are going to achieve from there (Participant 4, Area A, DSN).

Although the tone of her voice was soft, the sighing and body language further highlighted her feelings that inadequate information was often given during referral:

Definitely. Yes definitely, I mean if somebody gives you a little letter saying here you are, you've got diabetes, now you've got to go there, what for? As I have said earlier, when they come to see us their perception is that they have to have a blood test done, an ECG done, this and that done, they are not aware they are coming for an education session (Participant 4, Area A, DSN).

A participant disagreed, suggesting that there is a geographical variation in practice. She thought that appointment system is not great in some localities:

I think the appointment system isn't great but it is improving depending on different localities, Area C is quite good (Participant 6, Area C, DSN).

In terms of patients' preferences, a participant found that holding the session at unsuitable times may be part of the problem. This same participant further stated that some patients keep their diabetes as a secret; therefore, they would not like to take permission from work:

It is not held at suitable times for instance we don't offer weekends, lunch time, evenings, it potentially means that people taking time out of work. They may not have told their employer that they have diabetes or they may not want anyone to know (Participant 3, Area A, Podiatrist).

A participant felt that the waiting time between referral and date of education may also have a role to play:

I don't know if waiting time has a role to play. I mean if you are waiting two months for education, you are going to either not bother or get it somewhere else yourself (Participant 6, Area C, DSN).

The body language of some participants showed disagreement to the statement. In particular, a participant stated a contrary opinion by saying that waiting times may allow the patient to plan for work and other life routine:

On the other hand, if you've got time they can rearrange work. I think if you have a couple of months then you are more likely to take the time off to go to the education (Participant 5, Area D, Dietician).

Another participant also thinks that different people have different needs:

I think there are different needs for different people, don't you think so? (Participant 7, Area C, DSN).

With head down and lack of eye contact during the statement, a participant proposed the option of offering a different choice of education, for example, delivering education through e-learning which will take individual lifestyle and preferences into account:

I mean if you have the option to do an e-learning course because that fits in with your lifestyle you could access it straight away. Some people might prefer that option whereas some people might prefer to come to a group session and I think we have limited choice by only having one way of delivering the education (Participant 2, Area D, Dietician).

This view was supported by another participant who said their aim is to design a website where patients can choose their appointment:

Yes, a website for different sessions. We've talked about this before and it is our ideal wish, so that people could actually look on the system and choose when they wanted to come (Participant 1, Area D, DSN).

On the issue of on-line teaching, a participant offered a different view by saying that we need to consider the ability of the patient to use computer:

Again that would only meet the needs of a certain percentage of the population. Some people wouldn't even go on the web; they don't know what a website is, so I think you have to look at the other side (Participant 7, Area C, DSN).

Another participant shared the view that follow-up might help to aid attendance. Normally the G.P would refer them to the education centre and if the secretary from these places can call the patient, this might help to promote attendance. However, ringing several patients from time to time seems impossible now in the education centres:

Yes she does send the letters out but at the moment she is not ringing anybody and realistically I'm not sure whether she would have the time to take that number of telephone calls, we are talking about several patients a month (Participant 7, Area C, DSN).

A participant also supported the view by saying:

Oh so she's just sending a letter out saying you've been booked for this date and time. A better way is to say if it is not convenient, ring me and there are other sessions you can go to in the locality and at different times etc. or days of the week, but there is no way she could contact 50 odd people (Participant 1, Area D, DSN).

Although, a follow-up call or letter is seen as a possible way to motivate attendance, it is fraught with some organizational barriers such as personnel

input. Another participant also corroborated this idea by adding that follow-up requires time:

Could she send a letter and say please confirm....but even then she would not have the time available to do that (Participant 6, Area C, DSN).

This sub-theme identified the problems of poor referral and appointment systems. On a different note, whilst a follow-up call seems to be a welcome idea, this is linked to a funding problem.

4.6.2. Resources

Funding issues were mentioned by several participants while most participants thought that the government is not doing enough to fund diabetes education. Few participants believed that funding has always been an issue and will continue to be an issue. Some of the statements on this sub-theme are:

Lack of resources and the booking system is part of the problem (Participant 7, Area C, DSN).

The same participant expressed lack of sufficient funding from the government by linking it to the National Service Framework for diabetes:

Because there is no adequate funding accompanying what the NSF has asked us to deliver. There is no pot to say this is for structured patient education, this is for retinal screening so you have to find the money yourself (Participant 7, Area C, DSN).

Lack of resources was also mentioned by another participant thus:

But that is the actual basis of all the healthcare delivery in the NHS today, the quality and the numbers of staff that we have as resources has greatly reduced, delivering high quality service that we would like to do seems to be actually impossible because there is not enough resources to do it (Participant 2, Area D, Dietician).

A participant expressed the same opinion by implying that the government is not sensitive to the growing incidence of diabetes. According to her, more resources are required to cope with the current level of diagnosis:

The other thing is that the Government put their funds in 10 years or maybe 20 years ago when there were fewer patients and now there are more diagnoses, more resources are needed so they haven't really taken that into consideration either (Participant 4, Area A, DSN).

The issue of money was raised by another participant by saying:

We don't get any money to provide education for the Trust. Apart from our time and the venues, we don't get any other money at the moment to provide the education (Participant 1, Area D, DSN).

In contrast, a participant stated that lack of enough money and resources will always be a problem:

I think it's a fact that there is never going to be enough resources, not enough money (Participant 1, Area D, DSN).

A participant narrated her recent experience with a GP surgery. According to her, the surgery lacks enough time and basic resources such as adequate space and personnel:

I went to a surgery last week and they had so many patients, they didn't know what to do so we offered perhaps that I would do a group session or I could do some of the clinic, but they had no space to put me, no education room, you can offer anything but if they don't have the resources or time, then it becomes impossible. A lot of practice nurses work part time and they're not just dealing with diabetes clinics (Participant 1, Area D, DSN).

Although, some practitioners identified the need to seek more fund, the practitioners lacked the knowledge and skills to pursue this idea. A practitioner stated:

We need to develop business plans and go and knock on the door of the PCT board to build a case why we need the money and unfortunately we haven't got those business skills or necessarily the time to do that (Participant 7, area C, DSN).

No doubt, inadequate resources seems to be part of the problem, however, some participants viewed that the problem of funding had been and would always be an issue in the current NHS provision.

4.7. Strategies to improve attendance

In relation to my research questions, and based on the overall aim of the study, the participants were asked to offer their opinion about the ways to improve attendance. Several participants perceived the official protocol that is tailored to the need of patients as a way to aid attendance. Some of the suggested measures are government incentives, adaptable official protocol, flexible delivery of education and offering the education service earlier in life.

When asked about the best way to improve the system, a participant said:

That's your job, isn't it? That's why we're doing this - I thought you were going to tell us. To improve the system, a better appointment system and more resources to support a coordinated effort (Participant 1, Area D, DSN).

Some participants believed that offering a flexible service might help. A participant suggested the possibility of giving diabetes education to all pupils at secondary school before having diabetes:

But then you could argue that there is those who get all the education and they don't make any changes in their lifestyle...that's their choice...you could also argue are we leaving it too late? If you give this education at school before the disease process even began, prevention is better than cure. I mean they're young when they get their sex education. Bring back food, physical education – I mean competitive sports and nutrition to the school (Participant 6, Area C, DSN).

Another participant also thought that diabetes education could be considered to be part of the national school curriculum:

Whether it should actually be like other education delivered in schools, because of the growing obesity in children, should this be something that is part of the national curriculum (Participant 6, Area C, DSN).

This view was supported by another participant who suggested targeting high risk groups before they developed the disease. In her words, health promotion in the form of talking to vulnerable people before they have diabetes might help:

Yes. I mean the other way of influencing people is through health promotion, a lot of our work can be done in identifying groups of people who are vulnerable to developing diabetes and actually going out and talking to them with the hope that if they do develop diabetes, they'll then understand the importance of accessing care (Participant 4, Area A, DSN).

The issue of accommodating flexible time was repeatedly mentioned by some participants and seen as a way forward in order to enhance attendance. A participant said:

I think, work could be a problem and because there is a trend of younger patients coming to the session and they are unable to get out of work – employer may not allow them to leave at that particular time. We have to be flexible about time like morning, afternoon, week-end or evening (Participant 10, Area B, DSN).

This view was further echoed by another participant who stated that offering varied periods of education sessions could probably improve the attendance rate:

It might make a difference if we have a late start like 6oclock in the evening so people can go to work and come in afterward (Participant 9, Area B, Podiatrist).

A participant suggested the idea of going to deliver the diabetes education in the community:

But wouldn't that demonstrate the need to go out into the community to deliver the education (Participant 4, Area A, DSN).

Another participant supported giving the responsibility to book for education session to patients and offering choice of time to patients:

They could send a letter to the patient asking them to ring to make an appointment. Some localities had a choice, so it was really put on the patient to ring and say yes they would go to the diabetes education centre and attend the education on a particular day (Participant 7, Area C, DSN).

In addition to patients taking more responsibility, some practitioners thought it may be necessary to introduce another way of delivering the education service such as giving a booklet on group education at the point of diagnosis.

Could we not do a policy that at the point of diagnosis all patients are given an elaborate booklet on group education? (Participant 3, Area A, Podiatrist).

This view was supported by another participant:

We did put one together for our pilot, if we get the go ahead from the PCT about what they want to do, then part of the new deal will be an elaborate literature at diagnosis so they know what they are coming for (Participant 1, Area D, DSN).

Another participant suggested the use of more leaflets to inform patients:

Certainly in the area that I work, hem, in podiatry, they are looking at different type of government approaches, for example, the Scottish system offers more support in form of leaflets they can give to the patient. Not a group education but leaflets that they can download and free to order --- but in the UK we do not have such education leaflet policy. (Participant 9, Area B, Podiatrist).

This participant further stated the possible limitation of this approach in terms of funding:

Yeah, particularly for leaflet education, we need to think about financing this type of project as funding is always an issue (Participant 9, Area B, Podiatrist).

A participant suggested the use of health activists to contact patients. In her opinion, it may help to enhance attendance:

I think there might be a role for the health activists here, because area A had some health activists working with them in their locality. These are perhaps people who may have diabetes themselves or who have an interest in chronic long term conditions, who may actually be able to act as an advocate and they would have the time to ring up and speak to the person saying I understand you have been recently diagnosed – this is what’s happening, this can help (Participant 5, Area D, Dietician).

This was supported by another participant who said a Health activist calling the patient does help and we need to be sensitive to individual culture:

It’s certainly improved our uptake of attendance because when we use the health activist who was a diabetes patient herself and because she speaks the lingo, she stressed what would be discussed at the education centre and the

attendance did improve. So I think in a way we need to be sensitive as well to the culture (Participant 4, Area A, DSN).

At this point, another participant echoed the need to be more innovative in delivering the sessions:

Oh, one area we are looking at is a flexible approach, this is to have a continuous education in which case patient may come for just one hour to discuss different aspects of care e.g. foot care etc. --- a continuous roll of education that patient can opt in and out and they can come if they need to know anything. But a newly diagnosed, I think they need a lot to start with. (Participant 9, Area B, Podiatrist).

Finally, a participant summarised her own views on what can be done to reduce non-attendance thus:

We need to consider one to one education if they don't like group, offer a flexible approach – start roll on education with an option to opt in and out, try the Scottish approach which allows them to download or order more leaflets (Participant 8, Area D, Dietician).

Although this theme focused on resources and organisational operations, it has also identified some ways of enhancing attendance rate. Amongst other measures, the findings under this theme identified that improved organisational operation and more resources are areas to consider.

4.8. Discussion of findings

The practitioner's attitudes were thought to affect the way they raised the level of awareness of diabetes education among the patients. The practitioners' stated that the patients often turn up at an education session with the wrong impression that they were coming for medical treatment. In a similar way, Larme and Pugh

(1998) studied the attitudes of healthcare providers on possible barriers preventing optimal care of patients with diabetes and they found that negative attitudes of healthcare providers towards patients with diabetes are part of the barriers. Rosenbery and Fenley (2008) study also found that the attitude of healthcare workers may have a major influence on the decisions made by the patients.

The issue of communication with use of terminology that the patient cannot understand was seen as one of the barriers to attendance. The data of this study showed that practitioners are sometimes vague in explaining the purpose of the referral and often use terminology which may lead to misconceptions. This view mirrors the results of Chin et al's (2001) study which found that issues with provider-patient communication are a perceived barrier affecting patients' compliance to self-care. If the practitioners use simple and clear language when talking to the patient, this could reduce misunderstandings. On this issue, McEwen and Harris (2010) affirm that professionals need to be careful about the choice of words they use when interacting with patients because the patients might misunderstand their meanings.

From some of the comments made by the practitioners, there was an issue of mistrust between different professionals as some practitioners were trying to push the blame to the referring practitioners. Sutter et al (2009) stated that the ability of different professionals to collaborate is a crucial element of good professional practice. Chin et al (2001) emphasised the need for effective

communication and collaboration between multi-disciplinary team. Therefore, this lack of effective communication between all the stakeholders involved in the policy implementation could affect attendance. In contrast, a few practitioners in this current research stressed the view that it is the responsibility of all practitioners involved in diabetes care to make the education a success as opposed to pushing the blame to the doctor and practice nurses who make the referral. Trevithick et al (2008) state that it is important for all professionals to collaborate effectively to build a strong relationship which is necessary for patients care. Therefore, the other practitioners (Dieticians, Diabetes specialist nurses and Podiatrist) need to collaborate with the GPs and practice nurses to improve the referring process.

Although, there are several influences that may shape the attitudes of the practitioners, the need to meet the targets set by the government is seen as one of the factors underpinning this attitude. The practitioners' felt that a quick fix to get the blood glucose levels down is high on the doctor's agenda. The Larne and Pugh (1998) study also found that the practitioner's eagerness to control diabetes contrasts with the patient's lack of awareness of the need to comply with a treatment regime. The implications of the eagerness of the practitioners to bring the blood sugar level down very quickly in order to meet the government target does not consider a patient's personal problems that could influence non-attendance. Therefore, there is a tendency to judge the patients as non-compliant.

On this issue, Hadley-Brown (2009) sees the Quality Outcome Framework (QOF) concentration on quantifiable parameters as a limitation and argued that lack of consideration for other clinical parameters such as, the quality of education provided need to be considered. It seems evident that having a separate benchmark for several practitioners involved in managing diabetes education service has implications for its delivery. Unlike the nursing benchmarks which focused on areas such as nurse/patient ratio and patient focused outcome (RCN 2007), the Quality and Outcome Framework (QOF) which is part of the GP contract linked a significant proportion of their income to performance against its targets, such as HbA1c (Glycosylated haemoglobin) and reduction in blood pressure. Regardless of having different benchmarks for various professionals, the common goal of care on this occasion is to enhance the self-care ability of the patient through improved knowledge of the disease condition. Therefore, the practitioners need to be cognisant of both their corporate and individual responsibilities in meeting the same goal.

The study suggested that some patients are not taking adequate moral responsibility for their health. On this theme, the practitioners recognized that some patients failed to cancel the appointment through their lack of motivation and deliberately choose to ignore the letter. The idea of shifting more responsibility for self-care to the patient by either rewarding or imposing sanctions was an idea proposed by some of the practitioners in order to motivate patients. In a similar way, Rana and Upton (2009) identified social punishment such as withdrawal or disapproval, as a form of negative reinforcement.

According to these practitioners, it may be necessary for the doctor to either discharge them or fine them if they fail to attend. However, there was a divided opinion about imposing penalties as this may further fuel non-attendance. A few practitioners felt that this category of patients are likely to present with more serious complications, this may worsen their situation and it could invariably cost more to treat in the end.

Although both positive and negative reinforcement is used to aid a particular behaviour, the use of lack of encouragement is less favoured to motivate patient's behaviour. Unlike a negative stimulus, the use of constructive reinforcement raises self-esteem and may promote the required behaviour. Rana and Upton (2009) state that praise and reward has been found to play a role in motivating certain behaviour and to aid patients in self-efficacy. Although the study suggests the need for patients' to take greater responsibility for their health, nevertheless, the use of punishment is not supported by any known NHS framework. In reference to diabetes education, withdrawing the opportunity for diabetes education is not a good option because this will promote poor prognosis of the disease condition. Also, relevant legal and health regulations, such as fundamental human rights (DH 2008), and the patient's charter do not favour imposing any form of sanction. Instead, Rana and Upton (2009) identified several social rewards such as, approval, raising awareness of complications, non-verbal communication such as, smiling and nodding, as forms of positive reinforcement. In this case, raising the awareness of both acute and chronic complications of diabetes may be applicable.

The data collected from the practitioners showed that there was a perception among the patients that diabetes is a mild condition. This concurs with Graziani et al (1999) and Gucciardi et al's (2007) studies which identified that the perceived seriousness of diabetes was a factor contributing to attrition behaviour in patients with diabetes. The healthcare practitioners also felt that the insidious nature of diabetes may contribute to lack of motivation because patients are not likely to access help when they feel perfectly well. According to Forgerty (2008), type 2 diabetes develops gradually in a way that sufferers may get used to the symptoms. The idea from the practitioners suggested that patients may not seek help when they are not seriously sick.

Structured Patient Education such as DESMOND (Diabetes education and self-management for on-going and newly diagnosed patients) is a planned and adaptable joint education session provided by various professionals to a group of patients affected by diabetes. As a result of using group education to empower patients, the practitioners perceived that group learning may be a contributory factor to non-attendance. Some of the excerpts on the possible impact of group education on attendance revealed that a group setting may not benefit a shy patient and could initially be deemed as intimidating by some patients. Despite the perceived negative effects of group education, some practitioners stated that group learning has its own merits.

Constructivism as a form of androgogy stresses the importance of active engagement with an educational instruction (Dankay 2003) and this is based on

the premise that learning is socially constructed (Reece and Walker 2000; HEA 2004; Fry et al 1999). Hence, collaborative learning and group discussion is crucial to structured patient education and this is the essence of government directives and NICE guidance. The practitioners considered that group education may allow patients to support each other and suggested that it is cheaper than one to one education. Some of the views of the practitioners showed that group learning may reduce the sense of isolation by knowing that affected patients are not the only ones and questions asked by the group members may help to clarify certain issues. Nute (2004) argues that group education may improve peer support and aid active learning.

The appointment and referral system was identified as a barrier to attendance. Many of the practitioners involved in the study perceived that the quality of information relayed by the GP during referral is not good enough to signpost the value of the session. In a similar way, Zailinawati et al (2006) found that administrative issues were responsible for missed appointments among patients with long-term condition. However, it is not clear why the patients often failed to ask the surgery staff for further information. Again, the issue of limited time might have contributed to rushing through the information and consequently missing the essential part of the message. The length of time devoted by the GP to a patient may have an impact on the quality of doctor/patient communication (Morecroft et al 2006); therefore, this may lead to misunderstanding and non-compliance.

According to the data, some patients had certain personal difficulties that prevented them from attending the session. The practitioners also identified patient's work schedules as a barrier to attendance. Zailinawati et al (2006) study identified work as a factor responsible for missed appointment in patients with chronic disease. Some patients could not attend the sessions due to inconvenient time of the session. This finding is similar to Hamilton et al (2002) study which identified inconvenient appointment dates and traffic problems as barriers to attendance. Therefore, the organisational arrangements may need to consider a flexible timing of the sessions.

There was a discussion as to whether a long waiting time could be a part of the barrier. Some practitioners stated that waiting time may allow the patients to plan for work and other life routine. Whilst, it is possible for patients to seize the opportunity of a long waiting time to enhance attendance, practice error and lack of follow -up was shown as a barrier to attendance. Similar to this finding, Hamilton et al (2002) and Temple and Epp (2009) studies have found practice error to be one of the reasons for non-attendance in general practice, nevertheless, patients may need to take more responsibility for their care and therefore, make some effort to contact the centre except if there is a complete administrative problem such as lack of contact details of the education centre to be visited.

Some practitioners gave parking problems as a reason that might have prevented them from attending the session. However, some practitioners

perceived that patients should be able to work round this potential barrier. This participant was trying to compare their possible participation in a leisure centre such as the gym with the hospital attendance. However, it is difficult to substantiate whether the patients often engage in such recreational activities. All the same, other studies (Gucciardi et al 2007; Stone et al 1999) have shown the influence of inaccessible locations on compliance in other clinical settings. In a similar way, the findings from both the practitioners and patients in this study identified the impact of location on attendance.

According to McGough (2004), health decisions may be influenced by culture and peers. Some practitioners suggested that their colleagues need to be sensitive to different cultural beliefs and make some adjustments during certain period of the year such as Ramadan fasting period and Diwali festival periods. The practitioners acknowledged that different cultural beliefs may impact on attendance. Paul and Penson (2008) states that different ethnic groups and their significant others make sense of their health in various ways. Based on this finding, the practitioners considered that patient's cultural background such as perceptions to health and illness and festivities may hinder attendance. This implies that the practitioners need to take cultural differences into consideration during the referral process and during the delivery of the session.

The practitioners felt that a lack of adequate funding is a barrier to attendance, for example, shortage of staff to follow-up cases. The practitioners stated that more funds are required to cope with the current incidence and prevalence level

of diabetes. Diabetes UK (2011) affirm that, at a time when the rates of other long-term conditions, such as many cancers and stroke are steady or declining, diabetes continues to grow at a fast rate with huge human and economic cost. On the impact of growing incidence of diabetes on funding, some practitioners stated that the government is not sensitive to the growing rate of diabetes. Arguably, this additional funding for diabetes education could be used to develop other sources of education, such as on-line packages and employ administrative staff to phone patients to follow-up non-attenders or to remind prospective patients of their appointment.

Although a lack of adequate resources was seen as a barrier, the practitioners suggested that it has always been a problem and it will continue to be a recurrent problem in the modern NHS sector. Incidentally, the results showed a wide preference for different locations and time which may be very difficult to accommodate in terms of financial and human resources point of view. Whilst some participants perceived that funding has always been a problem, a majority believed that funding issue requires some attention from the government. However, the practitioner's idea on the government funding system could be challenged because of the competing allocation of resources. In contrast to focusing on the government funding parameters, the PCT may need to allocate more money for the NHS centres where diabetes education is offered in order to promote the delivery of diabetes education. Therefore, it could be argued that

the local PCT (and the now CCG) need to allocate more money for the delivery of diabetes education.

4.9. SUMMARY

This Chapter explored the practitioners views about factors associated with non-attendance and identified ways to break some of the barriers to advancing government policy of education for all patients affected by diabetes. Four main themes with sub-themes emerged from the findings as barriers to attendance with a theme on strategies to overcome the barriers (Table 4.1, page 112). Although some patients are deemed to have a negative attitude towards attendance, the study also showed that patients do occasionally have genuine reasons for non-attendance. These include personal circumstances such as lack of time, work-related issues, feelings about group education session and location of the session. In addition, the study revealed that cultural background, organizational structure, the need to meet government targets and professionals' perceptions and attitudes to diabetes health education may aid or hinder attendance.

The study identified some strategies to enhance attendance, this includes improved referral and appointment systems, additional resources, flexible delivery in terms of time and location, and the use of volunteers as health activist. This phase of the study has identified valuable evidence regarding the reasons why patients may not attend diabetes education sessions and some ways to

address the problems of non-attendance. By understanding the perspectives of the practitioners, it is hoped that looking at the patients' perspectives will help to present robust evidence regarding the phenomenon. Therefore, these initial findings of healthcare practitioners' view will be followed by the report of questionnaire survey of patients looking at identifying potential barriers to diabetes group education.

CHAPTER 5

BARRIERS AND FACILITATORS TO ATTENDANCE IN DIABETES EDUCATION CENTRES: A QUESTIONNAIRE SURVEY OF PATIENTS

5.1. Introduction

This Chapter aims to present the analysis of the returned questionnaires (see Chapter 4, section 3.19) from both attenders and non-attenders in four Diabetes Education Centres located within a Primary Care Trust in the South East of England. Based on the key objectives of this study, the questionnaire aimed to identify the barriers associated with non-attendance and explore responses that would inform ways to aid attendance. The first section of the questionnaire sought to ascertain the influence of certain demographical data and socio-economic factors on the attitudes of participants towards engaging with education for self-care. The second section of the questionnaire covered specific questions which investigate the personal beliefs of the participants concerning the value of Diabetes Education. The third section posed the questions that are related to the organisation of the educational delivery. The latter part of this Chapter will present the analysis of qualitative data collated from the questionnaire survey of both participants that failed to attend the sessions and those that did attend. The final part of this Chapter will present the discussion of findings and a conclusion.

5.1.1 Background

Diabetes is a long-term condition that can lead to various complications (Bailey and Feher 2009, Brown 2012); however, there is substantial evidence to support the benefits of a continuing education programme in reducing the complications. Regardless of the evidence, motivating attendance in Diabetes Education Centres remains problematic. Failure to attend hospital appointments is a challenge for the National Health Service (NHS) and there are many reasons responsible for non-attendance in hospital settings. Whatever the reasons for non-attendance, it constitutes a waste of scarce resources within the NHS. The systematic review conducted on non-attendance in Diabetes Education Centres (Chapter 2 section 2.2) revealed a serious gap in research in the UK, hence, the reason for this current questionnaire study.

5.1.2 Aims and objectives of the study

As previously described, the principal objective of the study was to explore why certain participants attend or fail to attend Diabetes Education Programmes and identify ways to aid successful implementation of the national policy of education for all newly diagnosed diabetes participants. In particular, this survey study sought to identify the socio-demographic characteristics that might be associated with attendance and non-attendance. In addition, it sought to assess whether there are any differences in the health beliefs held by both the attenders and non-attenders in respect of the value of Diabetes Education. Finally, the survey investigated the impact of some organisational protocols on attendance with the

intention of disseminating this information back to the participating Primary Care Trust in the form of a report. The assumption was that this survey will identify the general barriers and some beliefs that are associated with non-attendance.

5.1.3 Survey method

102 attenders and 105 non-attenders were surveyed to investigate potential barriers to attendance in Diabetes Education Centres as detailed in the methodology. As previously described (Chapter 3, section 3.15), the survey was designed to include common barriers identified by a review of the literature and also items identified in the original Health Belief Model (Becker 1978). The validation processes used were content and face validity and reliability testing using Cronbach's alpha and a split-half reliability test (full details available in the methodology section, Chapter 3 section 3.15). The instruments were administered through face-to-face and postal techniques and data analysis was carried out in three phases as previously described in Chapter 3 section 3.19.

5.2. Data analysis strategy

The analysis of all the data will start by using descriptive statistics such as frequency distribution and percentages. To further demonstrate links between variables among the attending and non-attending group, cross tabulations and correlations between variables that are deemed to be important in answering the research questions will be presented. The aim was to show if there were any relationships, their strength as well as significance. In addition, the chi-square

test will be used to compare both groups and therefore show if there are differences between the expected and observed frequencies between the two groups.

5.2.1. Comparison of mean scores

In addition to the above statistical analysis which was performed for all the data, the questions relating to the participants' perceptions and beliefs about health used an independent t-test to explore differences in attendance behaviour between the two participant groups (Attendees and Non-attendees). To facilitate this statistical test, a new variable titled 'Attitudes to Diabetes Education' was computed using the four Likert scale items which formed Part A of the Questionnaire (see Chapter 3 section 3.19).

5.2.2. Logistic regression

In predicting attendance from demographic variables, the analysis of the demographic data will progress to propose a logistic regression model which was used to assess the influence of the key demographical data on attendance behaviour.

5.2.3. Analysis of Free-text questions

Free text questions were included in section B of the questionnaire (See Chapter 3, section 3.19) and these will be analysed using thematic analysis (Holliday 2002).

Finally, the results will be reported by using American Psychological Association (APA) style which is commonly used to present data. Tables and visual presentations will be used to illustrate the responses of the participants as appropriate.

5.3. Results

A total of 207 participants completed the survey, however, every participant did not complete all the questions and this missing data will be reflected in the sample responses of each question. The sample comprised 102 participants who attended the sessions and 105 participants who did not attend as detailed in the methodology Chapter (refer to Chapter 3 section 3.16).

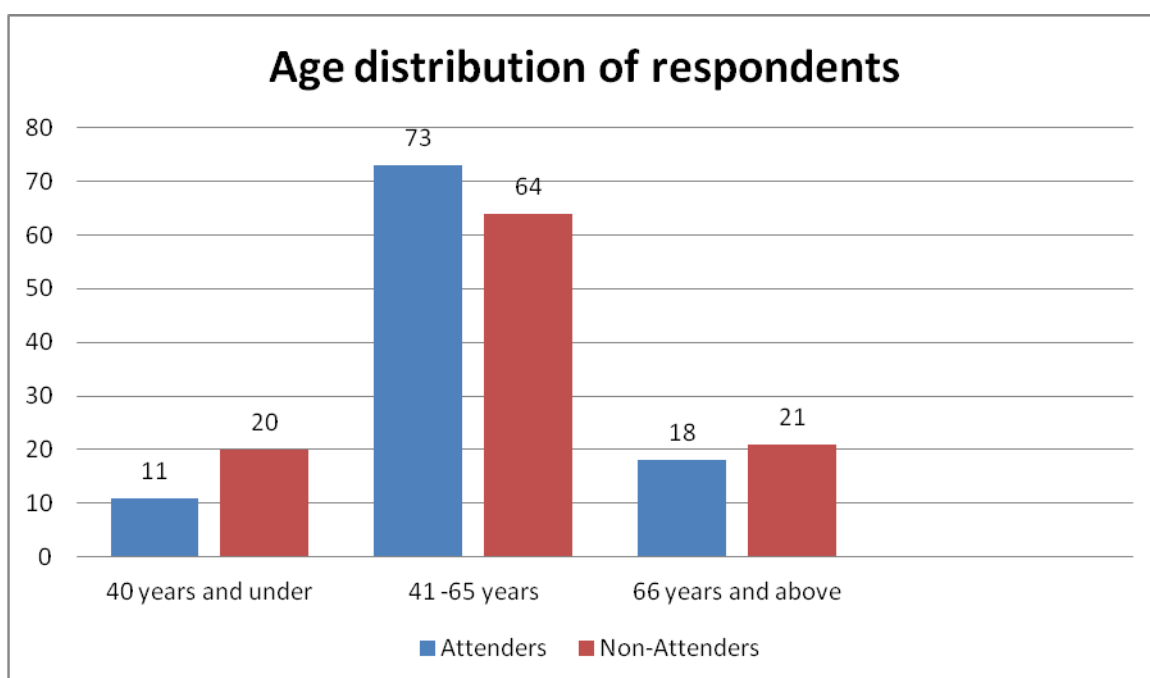
Analysis of the socio-demographic data

This section will provide the analysis of the socio-demographic data of the participants surveyed in section B of the questionnaire and illustrates the similarities and differences between the demographic status of both attenders and non-attenders. It will cover age, sex, ethnicity, work commitments, living arrangements, family history of diabetes, communication and specific learning needs pertaining to the participants.

5.3.1. Age distribution of participants

Figure 5.1 below showing the age distribution of participants revealed that the majority of both attenders and non-attenders fell between the age range of 41 - 65 years (n=137, 66%) and approximately one-fifth (n=39, 19%) were over 66 years of age. There was an equal number of females (n=7) in both groups within the age range of 40 years and below.

Figure 5.1: Age of Participants



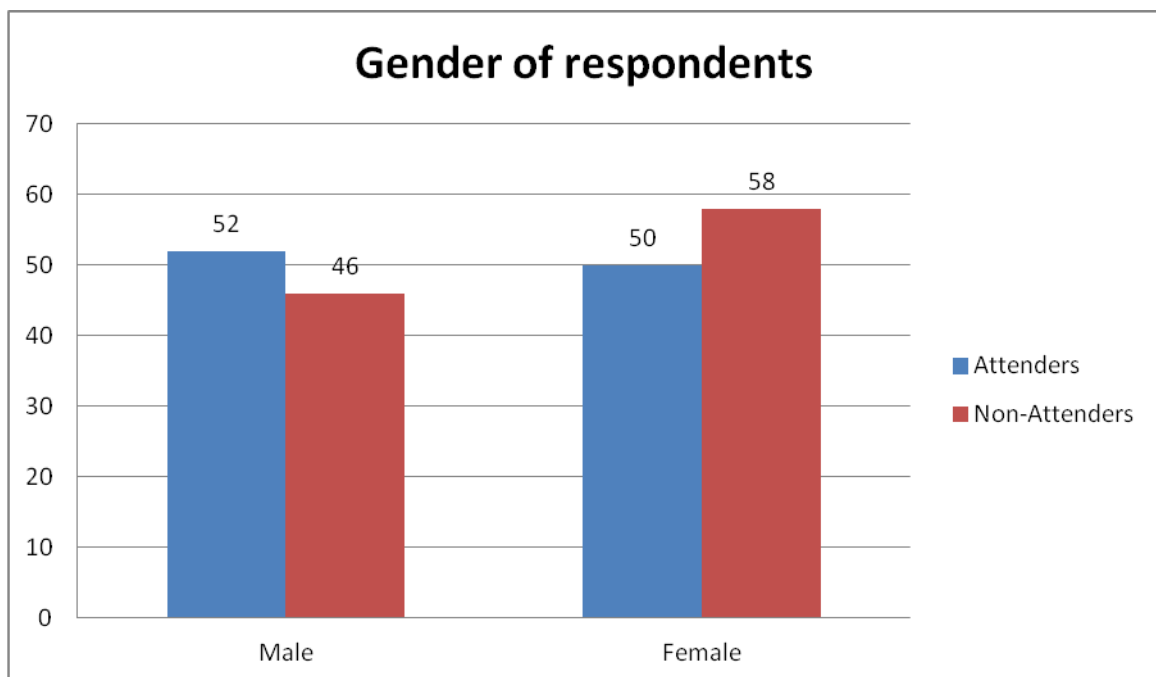
Of the 31 participants that were under 40 years, (n=19) were living alone while (n=7) were living with family. The majority of the middle aged participants within the age range of 40 – 65 years were living with a partner. The number of attenders (n=25) that were living with family also was double the number of non-attenders (n=12) in the age band of 66 years and above. There were more white

attenders (n=46) in the age band of 41-65 years as compared to non-attenders (n=27). On the other hand, there were more Asian/Asian British in this age band in the non-attenders group (n=29) in relation to the attenders (n=13). There were more attenders than non-attenders in the age band of 41 – 65 years and fewer attenders than non-attenders in the age bands of 40 years and below and over 66 years. Nevertheless, Chi-square analysis of this data showed no statistically significant association between the age of both groups and attendance behaviour $\chi^2(2, N=207), = 3.39, p = .183$.

5.3.2. Gender of participants

As shown in Figure 5.2, the gender distribution of both groups is similar. However, there were overall fewer males (n=10) than females.

Figure 5.2



There were two more males than females among the attenders while the non-attenders had fewer males than females (n = 12). In all, 42 males were white, 23 were Asian/Asian British and 20 were Black/Black British while 66 females were white, 29 were Asian/Asian British and 7 were Black/Black British. Out of this number, there were more males (n=34) in the attenders group in comparison to the non-attenders (n=21) who were living with a partner. Similarly, a higher number of males in the non-attenders group (n=21) were living alone as compared to the attenders (n=7). In all, the data on male/female ratio of the participants in both groups showed no statistically significant association between gender and attendance behaviour $\chi^2(1, N=206), = .94, p = .203$.

5.3.3. Ethnic origin of participants

Table 5.1 shows the ethnic origin of participants. This reveals that slightly more than half (n=109, 53%) of the participants were from a Caucasian background and a quarter were Asians (n=52, 25%).

Table 5.1 - Ethnic origin of participants.

Ethnicity	Attenders		Non-attenders		Total number of questionnaire response rate
	n	%	n	%	
White	n=67	65%	n=42	40%	n=109(53.5%)
Asian/Asian British	n=16	16%	n=36	34%	n=52 (25%)
Black/Black British	n=13	13%	n=14	13%	n=27 (13%)
Mixed Race	n=2	2%	n=4	4%	n=6 (3%)
Chinese	n=1	1%	n=6	6%	n=7 (3%)
Others	n=1	1%	n=0	0%	n=1 (0.5%)
Total responses	100	98%	102	97%	n=202 (98%)

Other minority ethnic groups constituted less than a quarter (n=41, 20%) of the participants. There was an almost equal number of Black/Black British in both groups while the number of mixed race in the non-attenders group (n=4) is twice the number in the attenders group (n=2). Also, there was a great disparity in the number of Chinese in both groups. Again, the number of Asian/Asian British in the non-attenders (n=36) was double the number in the attenders (n=16) group. Also, the number of white participants in the attenders group (n=67) was higher than the non-attenders group (n=41). Out of 58 participants that were living alone, 21 are white, 17 are Asian/Asian British and Black/Black/British account for (n=10). Equal numbers of mixed race and Chinese were living alone (n=5). The majority of the white participants (n=75) did not have a family history of diabetes while more than half of Asian participants (n=36) had history of diabetes in their family. The data revealed that more white participants among the attenders (n=54) have flexible working commitments as opposed to the non-attenders (n=19). In contrast, Black/Black British (n=12) in the attenders group and (n=1) in the non-attenders group have flexible work commitments. Out of 100 attenders, 67 were white and had flexible work arrangements and of the 99 non-attenders 40 were white and had flexible work commitments. The Pearson chi-square analysis of this data indicated an association that achieved statistical significance between attendance behaviour and ethnicity $\chi^2(5, N=202), = 18.68, p = .002$.

5.3.4. Type of working environment of the participants

From the data in Table 5.2, 24 (24%) of the participants that attended the session had an inflexible work environment whilst more than three-quarters (n=78, 76%) had a flexible work environment. Against this figure, the data for non-attenders revealed that more than half of them (n=59, 56%) did not have a flexible working environment and (n= 43, 41%) did whilst (n=3, 3%) did not answer the question.

Table 5.2 - Flexible working commitments

Flexible working	Attenders		Non-attenders		Total number of questionnaire response rate	
	n	%	n	%	n	%
Has flexible working commitments	78	76%	43	41%	121	58%
Does not have flexible working commitments	24	24%	59	56%	83	40%
Total responses	102	100%	102	97%	204	98%

The total number of participants who had a flexible working environment was (n=121, 58%) as against (n=83, 40%) who do not have a flexible working environment. Out of these 83 participants, a substantial number of participants were non-attenders compared to slightly over a quarter from the attenders group. Less than half of non-attenders (n=26) in the age range of 41-65 years in comparison to (n=58) in the attenders group had a flexible working environment. Unlike the non-attenders with a close margin, the margin between those that had flexible working environments (76%) and those that did not have flexible working

environments (24%) amongst the attenders is very wide. This data shows an association that is statistically significant between working commitments and attendance behaviour $\chi^2(1, N=204) = 24.88, p = .001$.

5.3.5. Living arrangements of the participants

The living arrangements of participants that attended the session revealed that almost two-thirds (63%) were living with a partner while less than half (47%) of non-attenders were living with a partner. On the other hand, a greater number of non-attenders were living alone $n=46$ (44%) as opposed to $n=13$ (13%) amongst the attenders. Also, a fewer number of non-attenders ($n=7$, 7%) were living with a family compared to $n=24$ (23%) in the attending group.

Table 5.3- Living Arrangements

Living condition	Attenders		Non-attenders		Total number of questionnaire response rate	
	n	%	n	%	N	%
Living alone	13	13%	46	44%	59	28%
Living with partner	64	63%	49	47%	113	55%
Living with family	24	23%	7	6%	31	15%
Other	0	0%	3	3%	3	1.5%
Total responses	101	99%	105	100%	206	99.5%

The overall data showed that more participants that were living with a partner ($n=112$) or living with a family ($n=30$) had a flexible work environment as compared to those living alone ($n=59$). An association that achieved statistical significance was observed between the living arrangements and attendance

between the two groups χ^2 (3, N=206) = 32.71, P = .001 as shown in Table 5.3 above.

5.3.6. Family history of diabetes amongst participants

Table 5.4 below showed that the response to the question of whether there is a history of diabetes in their family varies between the two groups.

Table 5.4 -Family history of diabetes

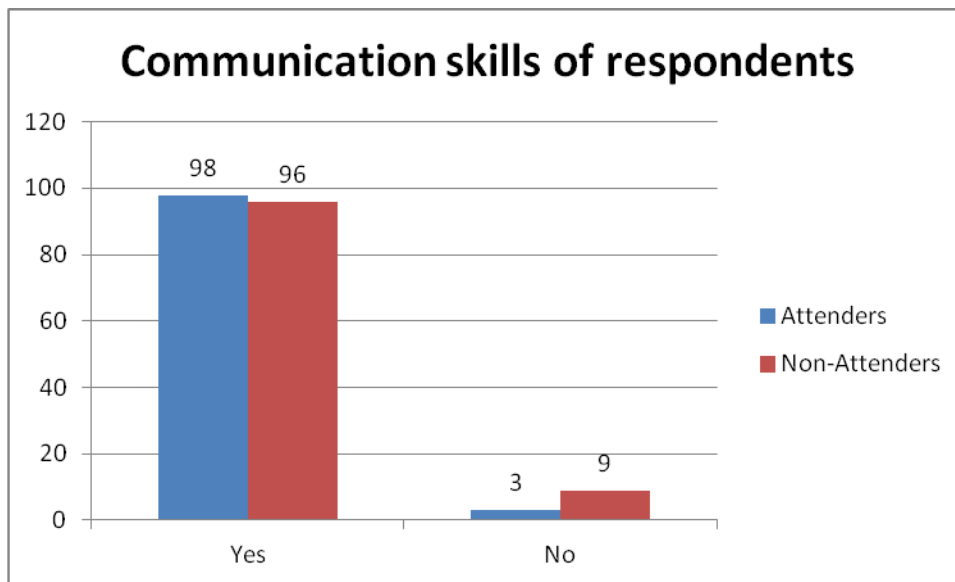
There is history of diabetes in my family	Attendees		Non-attendees		Total number of questionnaire response rate	
	n	%	n	%	n	%
Yes	29	28%	64	61%	93	45%
No	73	72%	39	37%	112	54%
Total responses	102	100%	103	98%	205	99%

More attendees did not have a family history of diabetes while almost two-thirds of non-attendees (n=64, 61%) had a history of diabetes in their family. Although more than half of the total number of participants had no family history of diabetes (n=112, 54%), the majority of them were attendees (n=73, 65%) showing a statistically significant association between family history and attendance behaviour between the two groups χ^2 (1, N=205), =23.49, p = .001.

5.3.7. Level of communication of participants

As shown in Figure 5.3, only a minority of participants have problems with speaking English. Out of this minority (n=12), the number of non-attenders (n=9) that cannot communicate well in the English language was triple in the number of attenders (n=3). Out of these 12 participants, more than half were non-attenders from Asian/Asian British (n=7) and Black/Black British (n=2).

Figure 5.3



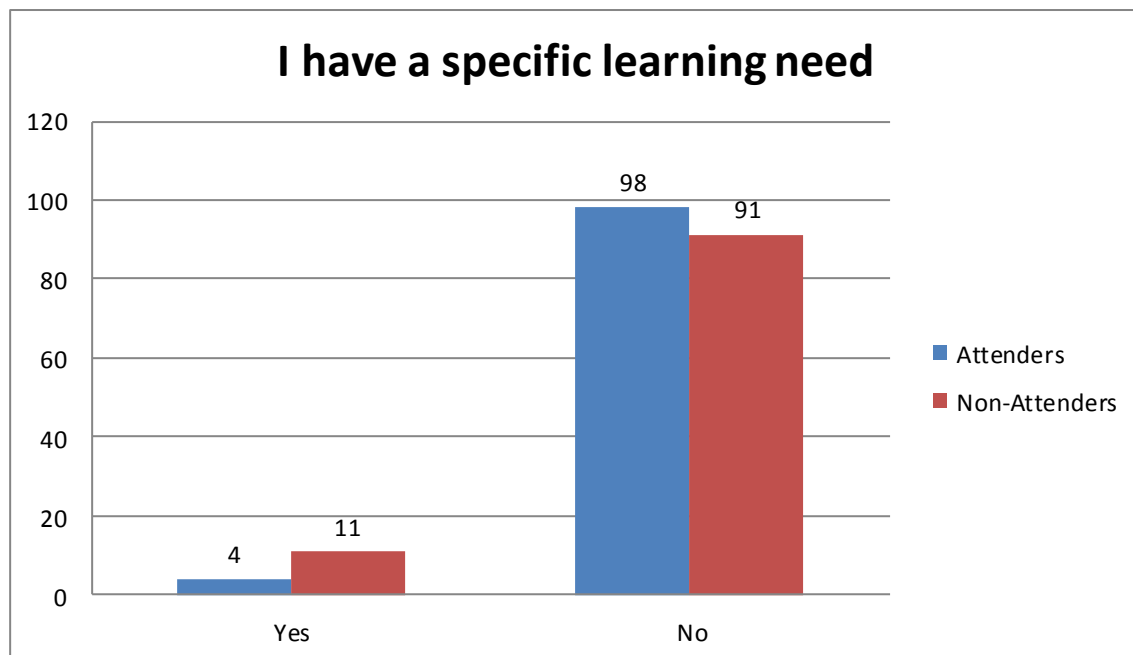
The study found no statistically significant association ($\chi^2 (1, N=206) = 2.94, p = .077$) between communication and attendance behaviour as the majority of both groups can communicate well in English Language. Although this statistical analysis showed that there is a similarity in the level of English speaking between the two groups; nevertheless, the provision of education in an area of the Trust

with a high ethnic minority covers a separate session in another language (Punjabi) as well as sessions run in the English language.

5.3.8. Learning needs requirement of participants

The question on socio-economic data presented in figure 5.4 showed that an overwhelming number of both groups had no specific learning needs (n=189, 91%) which unsurprisingly revealed no statistically significant association between learning needs and attendance behaviour $\chi^2 (1, N=204), = 3.53, p = .052$. There was an equal number of participants in both groups within the age range of 41-65 years (n=4) that had a specific learning need and seven non-attenders below the age of 40 years.

Figure 5.4



Out of 15 participants that had a specific learning need, (n=9) were female and (n=6) were male. Almost half of the non-attenders with a specific learning need were from Asian/Asian British background (n=5).

5.4. Regression Analysis

The series of Chi-square tests of association between attending behaviour and the various socio-demographic variables identified four variables that showed statistically significant associations. Therefore, in addition to the Chi-square tests shown above, logistic regression was performed on the identified socio-demographic variables: ethnicity, living arrangements, family history of diabetes and flexibility of working environment. The aim was to assess the influence of these factors on attendance and to discern whether these factors predict attending/non-attending behaviour. A binomial logistic regression was selected as the data was categorical and therefore not suitable for analysis using multiple linear regression (Field 2009). A dichotomous variable 'Attendance' was generated from the grouping variable 'Group' and dummy coded in which Non-attender was coded '0' and Attender was coded '1'. A logistic regression was then performed to ascertain the effects of ethnicity, employment, family history of diabetes and living arrangements on the likelihood that participants will attend the diabetes education sessions. The logistic regression model was statistically significant $\chi^2(8) = 78.19, p < .001$ and the model explained 43% (Nagalkerke R^2) of the variance in attendance and correctly classified 80% of cases. The variables included in the model are shown in table 5.5 below.

Table 5.5: Logistic regression analysis of demographic data of the participants

<u>Independent variable</u>	<u>b</u>	<u>se</u>	<u>Wald</u>	<u>Sig</u>	<u>Odds Ratio</u>	95% C.I. for EXP (B)	
						Lower	Upper
Living Arrangements			20.063	.000			
Living with family	1.201	.422	8.113	.004	3.33	1.45	7.59
Living with partner	2.794	.636	19.292	.000	16.35	4.69	56.88
Living alone	-	27243.76	.000	.999	.000	.000	20.174
Ethnicity			8.401	.038			
White	-1.113	.462	5.803	.016	.328	.133	.813
Asian/Asian British	-.219	.569	.148	.701	.803	.263	2.45
Black/Black British	-1.367	.686	3.972	.046	.255	.066	.978
Flexible working	1.478	.370	15.973	.000	4.38	2.123	9.04
Family history of diabetes	-.722	.3688	3.847	.050	.456	.236	1.00
Constant	-1.212	.500	5.877	.015	.298		

Model $\chi^2 = 78.19$, $p < .001$

Pseudo $R^2 = .43$ (Nagelkerke R-square)

N=207

The results in Table 5.5 above show that living arrangements ($p < .001$), employment ($p < .001$) and family history of diabetes ($p = .05$) added significantly to the prediction, while ethnicity ($P > .05$) did not add significantly to the model. The category 'living arrangements 1' (living with family) is a significant predictor of attendance ($p = .004$) and the odds ratio is 3.33. This indicates that the participants that were living with family are three times more likely to attend. Equally, the category 'living arrangements 2' (living with partner) is also a significant predictor ($p = .001$) and the odds ratio is 16.35 denoting that participants that were living with partners are sixteen times more likely to attend the session than those do not. However, category 'living arrangements 3' (living alone) is not a significant predictor ($p = .999$). As shown in the table above, employment is also a significant predictor ($p = .001$) and the odds ratio is 4.38. This shows that participants that have a flexible working environment are four times more likely to attend the sessions. The white ethnic participants were also more likely to attend although ethnicity was not a significant predictor overall ($p > .05$) whilst family history of diabetes achieved significance ($p = .05$) but the odds ratio was low, however, it does merit further research in future in terms of its predictive ability. The odds ratios confirmed these results as the odds ratio for attendance among the different ethnic groups and participants with family history of diabetes were less than 1. The confidence interval for living with family (OR 3.33) and living with a partner (OR 16.35) ranges from 1.45 to 7.59 and 4.69 to 56.88 respectively denoting that the result is statistically significant at $p < .05$. Also, the confidence interval for working environment (OR 4.38) ranges from 2.12

to 9.04 at 95% confidence interval. Thus, the results suggested that although all these four categorical variables have value in predicting attendance behaviour, the two key predictors for the sample in this study are living arrangements and working environment.

5.5. Health beliefs and attendance behaviour

This section will present the analysis of the Likert-scale questions in Section A which relate to personal beliefs that may either aid or hinder attendance. It will cover data relating to health beliefs concerning self-care, perception about the benefits of education, belief about the nature of diabetes and participant beliefs about the usefulness of other sources of information as a substitute for Diabetes Education Programmes.

5.5.1 Belief in self-care activities

The responses of those that attended the session on the question of their belief in taking responsibility for self-care (Table 5.6) revealed that an overwhelming majority of attenders (n=97, 95%) strongly agree/agree to taking responsibility for self-care.

Table 5.6 -Belief about taking responsibility for self-care

I believe that taking responsibility to care for myself is an important aspect of my care	Attenders		Non-attenders		Total number of questionnaire response rate	
	n	%	n	%	n	%
Strongly agree	58	57%	51	49%	109	52%
Agree	39	38%	19	18%	58	28%
Neither agree nor disagree	2	2%	12	11%	14	7%
Disagree	2	2%	16	15%	18	9%
Strongly disagree	1	1%	7	7%	8	4%
Total responses	102	100%	105	100%	207	100%

The number of people among this group that either strongly disagree/disagree or unsure is negligible (n=5, 5%). In contrast, the opinion of participants' that did not attend differs slightly and fewer non-attenders (n=70) strongly agree/agree with the statement. Again, the number of non-attenders that strongly disagree/disagree or are unsure are significantly more than the attenders group (n=35). Out of 26 participants that either strongly disagree/disagree to taking responsibility for self-care, the majority (n=23, 88%) are non-attenders showing a statistically significant association between belief about self-care and attendance behaviour $\chi^2(4, N=207) = 75.39, p = .001$.

Table 5.7: Correlation between age and belief about taking responsibility for self-care.

I belief in self-care	Attenders		Non-attenders	
	Correlation number	P-value and significance	Correlation number	P-value and significance
Age	.068	.500	.263**	.007

r = Pearson correlation (**= p < .01, *= p < .05)

Table 5.7 showed no significant correlations between the age of attenders and "belief 'in taking responsibility for self-care'". However, for the non-attenders, the correlation coefficient between age and belief in taking responsibility revealed a correlation that was statistically significant ($p < 0.01$). This shows that age is positively correlated with this belief and the older participants among the non-attenders are more likely to believe in taking responsibility for self-care. There were no other significant relationships revealed between other demographic variables and 'I believe in taking responsibility for self-care' ($p > .05$).

5.5.2. Belief about the level of diabetes control and the need to attend the session

The findings of the question that enquire about the nature of diabetes and the need to attend the sessions shown in table 5.8 indicated that a negligible number of attenders (n=7, 7%) strongly agree/agree that their diabetes is well controlled and do not need to attend the session as against almost half of the non-attenders group (n=49, 47%). The number of attenders (n=16) that were unsure is almost half of the non-attenders (n=30).

Table 5.8 -Belief about the level of diabetes control and the need for attendance

I believe that my diabetes is well controlled	Attenders		Non-attenders		Total number of questionnaire response rate	
	n	%	n	%	n	%
Strongly agree	2	2%	17	16%	19	9%
Agree	5	5%	32	31%	37	18%
Neither agree nor disagree	16	16%	30	29%	46	22%
Disagree	36	35%	22	21%	58	28%
Strongly disagree	40	39%	4	4%	44	21%
Total responses	99	97%	105	100%	204	98%

Again, roughly a quarter of non-attenders (n=26, 25%) strongly disagree/disagree with the statement in comparison to almost three quarters (n=76, 74%) in the other group. In all, the number of participants' that attended the session who strongly disagree/disagree that their diabetes is well controlled and may not need the session is significantly higher than the non-attenders. This result showed a significant association between belief about diabetes control and attendance

behaviour χ^2 (4, N=204), 68.52, $p = .001$. The correlation analysis showed no significant correlation ($p>0.05$) between age, gender, ethnicity and 'my diabetes is well controlled and I don't need to attend the session' among both the attenders and non-attenders.

5.5.3. Belief about the importance of the session

On the question of whether it is important to attend the session in order to develop self-care abilities, the findings of participants' that failed to attend shows that half ($n=52$, 50%) strongly disagree/disagree.

Table 5.9 -Attending the session is important to develop self-care ability

Attending the session is important to aid my self-care	Attenders		Non-attenders		Total number of questionnaire response rate	
	n	%	n	%	n	%
Strongly agree	44	43%	13	12%	57	27%
Agree	50	49%	22	21%	72	35%
Neither agree nor disagree	4	4%	12	11%	16	8%
Disagree	2	2%	35	34%	37	18%
Strongly disagree	1	1%	17	16%	18	9%
Total responses	101	99%	99	95%	200	97%

By comparison, three (3%) attenders as against almost half ($n=52$, 52%) of non-attenders strongly disagree or disagree that attending the planned sessions at an education centre is important to develop their ability to care for themselves. In all, there was $n=94$ (92%) agreement among the participants that attended the sessions as against $n=35$ (33%) agreement among the non-attenders. Six non-

attenders as opposed to only one attender did not complete this question. These findings showed a statistically significant association between their belief about the importance of the session in developing self-care abilities and attendance behaviour χ^2 (4, N=200), = 75.39, $p = .001$. In terms of correlation with the demographical characteristics, age, sex and ethnicity were not significantly correlated ($p > .05$) with importance of attending the session between both the attenders and non-attenders.

5.5.4. Perception about the usefulness of other sources of information

The responses of non-attenders on their perception about the effectiveness of other sources of information apart from the session are presented below. Table 5.10 shows that $n=12$ (12%) non-attenders strongly disagree/disagree and $n=22$ (21%) neither agree nor disagree.

Table 5.10: Using the internet and talking to others offers adequate information

Using the internet and talking to other people is a good way to learn about diabetes	Attenders		Non-attenders		Total number of questionnaire response rate	
	n	%	n	%	N	%
Strongly agree	8	8%	18	17%	26	13%
Agree	12	12%	52	50%	64	31%
Neither agree nor disagree	18	17%	22	21%	40	19%
Disagree	47	46%	11	11%	58	28%
Strongly disagree	16	16%	1	1%	17	8%
Total responses	101	99%	104	99%	205	99%

Against this result from the non-attenders, the responses of the attenders revealed that almost two thirds (n=63, 60%) strongly disagree/ disagree, whilst (n=18, 17%) are uncertain. The question on the usefulness of other sources of information shows that almost two-thirds of non-attenders n=70 (67%) agree/strongly agree that it is possible to obtain adequate information from other sources apart from attending the session as opposed to n=20 (20%) attenders. A comparison of both groups showed a statistically significant association between perception about the usefulness of the education and attendance behaviour χ^2 (4, N=205), 64.79, p = .001.

There were no significant correlations between age and *'using the internet and talking to others is enough'* among the attenders group. Conversely, age was negatively correlated with the belief in adequacy of internet and talking to others as a means of gaining diabetes knowledge without any significance in the non-attenders group. This suggests that the older the non-attenders get, the less they are likely to believe in the adequacy of the internet. The correlation between the two variables indicated that increase in age of non-attenders reflected a decrease in belief in the adequacy of other sources of information as a means to provide diabetes education.

5.6. Test of difference (t-test)

The Chi-square tests run on the data relating to the health beliefs held by both groups suggested differences between attenders and non-attenders attitudes

towards the uptake of Diabetes Education Programmes. Therefore, a new multiple item scale entitled “*Attitude towards diabetes education*” was computed from the four item Likert scale questionnaire section. Then, an independent samples t-tests was run on the data collected from section A of the questionnaire to investigate the differences between groups (attenders and non-attenders) in relation to their health beliefs and how these impact on attending behaviour. Table 5.11 below displays the descriptive statistics.

Table 5.11: Descriptive statistics

Group	Mean Score	Standard deviation
Attenders	16.41	2.10
Non-attenders	11.54	3.26

Inspection of the means revealed that Attenders were likely to score more highly in their favourable attitude towards Diabetes Education. This was confirmed by the result of the Independent T-test, $t(165.69) = 12.43, p < .001$. (Please note as Levene’s test of homogeneity of Variance was significant ($F(195) = 17.58, p < .001$), the adjusted result was reported. The results indicated that attenders in this study reported a more positive belief about self-care, importance of the diabetes education session and belief about the seriousness of diabetes as a medical condition in comparison to the people that failed to attend the session. The mean difference in attitude towards diabetes education is 4.87 and higher in the attenders than the non-attenders (mean for attenders is 16.41 while 11.54 for

the non-attenders). The t-test results showed that there was a significant difference between the population on beliefs and attitude towards diabetes education. The comparison of mean scores on attitude towards diabetes education suggests that the observed difference could not be due to chance. Therefore, the difference and its statistical significance led the researcher to conclude that there is a difference in attitude towards education between the attenders and non-attenders. These results give further support to the Logistic Regression Model previously discussed.

5.7. Organisation of care

This section seeks to analyse some questions relating to the possible effect of organisational operation such as the quality of pre-education information provided by the Trust and access to clarify information on attendance. This part will also present data on possible impact of group education, location and time of the education session.

5.7.1. Access to pre-education information

As shown in Table 5.12, more than half of non-attenders (n=60, 57%) stated that the Doctor or Practice nurse told them what to expect while (n=45, 43%) stated that they did not have this privilege. The attenders (n=82, 80%) stated yes while (n=19, 19%) stated that they were not given adequate information. This showed a wide margin of approximately a ratio 4 to 1 within the group of attenders.

Table 5.12 - Information given during referral

The doctor or practice nurse told me what to expect	Attendees		Non-attendees		Total number of questionnaire response rate
	n	%	n	%	
Yes	n=82	80%	n=60	57%	n=142 (68.5%)
No	n=19	19%	n=45	43%	n=64 (31%)
Total responses	101	99%	105	100%	n=206 (99.5%)

Although, a substantial number of both groups of participants (n=142, 68.5%) stated they were given adequate information, slightly more than two-thirds of the participants that said they were not given adequate information were non-attendees, the Chi-square analysis shows a significant association between the level of information given and attendance behaviour $\chi^2 (2, N=206) = 14.93, p = .001$. The relationship between family history of diabetes among the non-attendees and information received from either the Doctor or Practice Nurse shows a significant positive correlation with information received ($r (103) = .241, p < .05$). This correlation revealed that people with family history of diabetes are more satisfied with the information received.

5.7.2. Chance to clarify information

Eighty eight (86%) attendees as opposed to n=74 (70%) non-attendees had the opportunity to clarify information from the education clinic while the number of non-attendees n=31 (30%) that reported lack of access was almost triple the number of attendees n=11 (11%). The majority of participants (n=162, 78.5%)

were positive about the service, nevertheless, 31 (74%) out of the 42 participants who stated that there was no access to clarify information were non-attenders showing a statistically significant association between their opinion about access to clarify information and attendance behaviour $\chi^2 (1, N=204), = 10.57, p = .001$. In addition to the disparity in the frequency distribution, the disparity of ratio 1 to 8 (n= 11:88) within the attendees group as opposed to the close margin within the non-attenders group also contributed to the differences.

Table 5.13 -Chance to clarify information

There was chance to clarify information from the clinic	Attendees		Non-attenders		Total number of questionnaire response rate
	n	%	n	%	
Yes	n=88	86%	n=74	70%	n=162 (78.5%)
No	n=11	11%	n=31	30%	n=42 (20%)
Total responses	99	97%	105	100%	n=204(98.5%)

There was a positive correlation between gender and chance to clarify information ($r (102) = .3, p < .01$) which showed that males are more satisfied that there is opportunity to clarify information in the non-attenders group. However, gender was not associated with the chance to clarify information from the education centre ($p > .05$) among the attendees.

5.7.3. Opinion about the clarity of the invitation letter

The breakdown of the findings in Table 5.14 showed that 18 more attenders were satisfied with the letter of invitation in comparison to the non-attenders. More than a third n= 36 (34%) of non-attenders believed that the letter of invitation was not clear in comparison to less than half of this number n=15 (15%) in the attending group. Three out of every four participants (n=156, 75%) perceived that the letter of invitation was clear while a quarter opposed this view. A greater number of non-attenders (n=36, 34%) perceived that the letter of invitation is not clear as against attenders (n=15, 15%) showing a statistically significant association between attendance behaviour and clarity of the letter of invitation χ^2 (1, N=207), = 10.68, p = .001.

Table 5.14 - Clarity of letter of invitation

The letter of invitation is clear	Attenders		Non-attenders		Total number of questionnaire response rate
	n	%	n	%	
Yes	n=87	85%	n=69	66%	n=156 (75%)
No	n=15	15%	n=36	34%	n=51 (25%)
Total responses	102	100%	105	100%	n=207 (100%)

The cross tabulation showed that more White and Asian participants stated that the letter of invitation is clear compared to the Black/Black British and participants from mixed background among the non-attenders. The cross tabulation of living arrangements and clarity of the invitation letter also showed that more people living with a partner or a family member found the letter of invitation to be clear in comparison to the participants that are living alone.

Opinion about diabetes group education

These two questions relate to the possible impact of group learning on attendance. Therefore this section will present the analysis of the participant's opinion about group education as a way of gaining knowledge of diabetes and personal preference to share their experience of their diabetes journey with other participants.

5.7.4. Opinion about group learning

A majority of the total participants (n=157, 76%) stated that group education is a good way to learn about diabetes as against less than a quarter (n=48, 23%) who disagreed. Out of the total number that agreed, almost three-fifths n=96 (61%) are attenders while two-fifths n=61 (39%) are non-attenders. A small percentage (n=5, 2%) of attenders as against one-fifth (n=43, 21%) of non-attenders did not perceive group education as a good method of learning about diabetes. This data showed a wide margin of difference within the attenders group in comparison to the other group. As a result, a statistically significant association was observed between preference for group learning and attendance behaviour as shown in Table 5.15 = χ^2 (1, N=205) = 37.85, p = .001.

Table 5.15 -Diabetes group education is a good way to learn

Diabetes group education is a good way to learn	Attendees		Non-attendees		Total number of questionnaire response rate
	n	%	n	%	
Yes	n=96	94%	n=61	58%	n=157 (76%)
No	n=5	5%	n=43	41%	n=48 (23%)
Total responses	101	99%	104	99%	n=205 (99%)

The correlation coefficient (Table 5.16) revealed that age of non-attendees was significant and negatively correlated to the belief that group education is a good way to learn about diabetes ($p < .05$). This data revealed that the older participants of over 66 years are less likely to favour group education among the non-attendees.

Table 5.16: Significant correlations relating to diabetes group education is a good way to learn.

	Attendees		Non-attendees	
	Correlation number	P-value and significance	Correlation number	P-value and significance
Age	.113	.260	-.205*	.037
Gender	-.139	.165	-.230*	.020

r = Pearson correlation (**= $p < 0.01$, *= $p < 0.05$)

As shown in the table above, gender was negatively correlated with belief about group education among the non-attendees ($p < .05$) with more females $n = 30$

(70%) as against n=13 (30%) males subscribing to the view that diabetes group education may not be a good way to learn about self-care management. Conversely, gender was not strongly correlated with the belief that group education is a good way to learn in the attenders group ($p > .05$).

5.7.5. Opinion about sharing their experience

Findings on whether the participants would like to share their experience with others (Table 5.17) showed that the number of non-attenders (n=60) that did not like to share their experience with other participants was triple that of the attenders (n=17) with a similar view. Also, this data revealed that the number of attenders (n=84, 82%) that would like to share their experience was almost double the number of non-attenders (n=44, 42%) who shared the same opinion showing a statistically significant association between willingness to share information and attendance behaviour $\chi^2 (1, N=205), = 36.48, p = .001$. Again, there is a wider margin in the difference of opinion on this question within the attenders group.

Table 5.17 -Satisfaction about sharing their experience

I like to share my experience with other patient	Attenders		Non-attenders		Total number of questionnaire response rate
	n	%	n	%	
Yes	n=84	82%	n=44	42%	n=128 (62%)
No	n=17	17%	n=60	57%	n=77 (37%)
Total responses	101	99%	104	99%	n=205 (99%)

5.7.6. Personal preferences

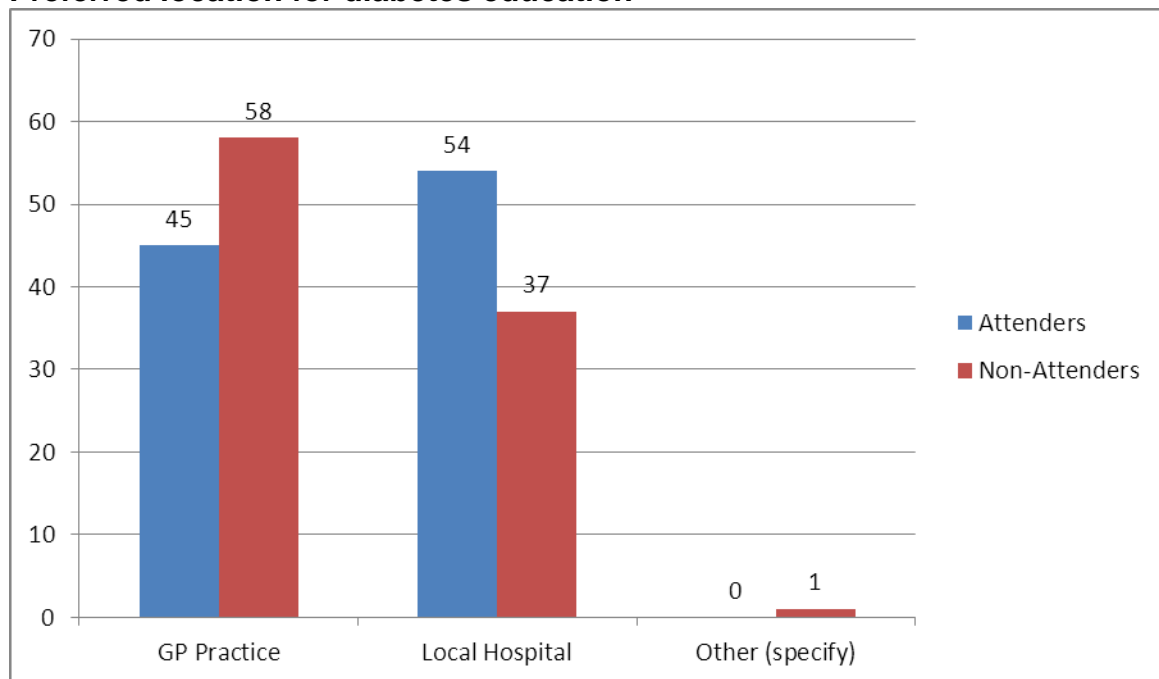
This section will show the findings of the questions relating to participants' preference for a particular location or a specific time for the session and its possible effect on attendance.

Preferred location of the education service

The question on the preferred location for the education service shown in Figure 5.5 revealed that more non-attenders $n=58$ (56%) in comparison to attenders $n=45$ (44%) preferred the education service to be provided in a GP practice. More than half of attenders $n=54$ (53%) and just a third of non-attenders $n=37$ (35%) preferred the local hospital.

Figure 5.5

Preferred location for diabetes education



Again, the number of non-attenders n=9 (3%) that did not complete this section was triple the number of attenders n=3 (1%). Only one (1%) non-attender preferred the session in the community. In total, half of the participants preferred the session to be held in a GP surgery and almost half preferred a local hospital. The response from both groups are very similar as the findings relating to preferred location revealed that both groups prefer either the GP surgery or their local hospital and as a result the association with attendance behaviour did not achieve statistical significance $\chi^2 (2, N=195), = 5.77, p = .056$.

5.7.7. Preference for a particular time

The findings of the question enquiring about the impact of timing on attendance that is presented in Table 5.18 showed that half of the attenders (n=52, 50%) as opposed to less than a quarter of non-attenders (n=23, 22%) who would like the education to be held in the morning. The number of non-attenders (n=28) that preferred the afternoon session was double the number of attenders (n=14).

Table 5.18: Preferred time for learning

What time would prefer the education	Attenders		Non-attenders		Total number of questionnaire response rate	
	n	%	n	%	n	%
Morning	n=52	50%	n=23	22%	75	36%
Afternoon	n=14	14%	n=28	27%	42	20%
Evening	n=21	20%	n=32	30%	53	26%
Weekend	n=9	9%	n=17	17%	26	12.5%
Other	n=0	0%	n=0	0%	0	0%
Missing data	n=6	6%	n=5	5%	11	5.5%
Total responses	102	100%	105	100%	207	100%

There were also slightly more non-attenders than attenders who would be more inclined to attend weekend and/or evening sessions. The data showed a statistically significant association between preference for a particular period of the day and attendance behaviour $\chi^2(3, N=196) = 20.55, p = .001$.

5.8. QUALITATIVE DATA FROM THE QUESTIONNAIRE SURVEY

This section aims to present the qualitative element of the questionnaire which explored the reasons for non-attendance and ways to improve attendance. The last two open-ended questions on the questionnaires offered the participants the opportunity to supply additional information. A total of 31 non-attenders (30%) provided additional information on the open-ended questions in the questionnaire survey and this yielded some themes. Similarly, 46 attenders (45%) gave additional information on their questionnaire. Quotations are provided to give examples of the participant's responses. Each quotation will be coded with a letter to reflect responses from the two sets of data thus: NA will precede the number for participants from the non-attenders group while A will precede the responses for the attenders group of participants. Based on thematic analysis described in the methodology Chapter, the findings from the qualitative data is summarised under the following three themes shown in table 5.19 below:

Table 5.19 - Summary of findings

Theme 1- Motivation Sub themes are: <ul style="list-style-type: none">- Desire to learn- The role of professionals
Theme 2- Personal Circumstances <ul style="list-style-type: none">- Illness- Work commitments- Child care- Personal crisis- Forgetfulness- Personal Idiosyncrasies- Away on holiday- Timing and location of the session
Theme 3 – Organisational protocol <ul style="list-style-type: none">- Administrative errors- Additional support

5.9. Motivation

The questionnaire asked the participants that attended to state the reasons why they attended the education sessions. Although, the participants attended for various reasons, some participants were motivated to attend the session because of their desire to gain more knowledge about their medical condition.

5.9.1. Desire to Learn

Several participants (n=14) mentioned the desire to learn more about diabetes as their key motivating factor. Some of the excerpts on the desire to learn as a key reasons for attendance are:

To learn about diabetes (Participant A111, area C)

I wanted to know more about diabetes (Participant A195, area A)

Some participants acknowledged their lack of sufficient knowledge about the disease condition as their motivating factor. This was verbalised thus:

I had no real understanding of diabetes (Participant A198, area A)
I wanted to become better informed (Participant A168, area D)
The need to understand my illness (Participant A178, area D)
I wanted to find out any new information (Participant A115, area C)

For some participants, their motivating factor was to gain more understanding of how diabetes affects their body: I wanted to know the effects of diabetes on my body (Participant A183, area A). Another patient said:

I need to gather as much information as I can on how diabetes can affect me (Participant A206, area A)

In the same way, some participants (n= 5) attended the sessions because they needed certain information that was specific to them:

Because I needed specific information (Participant A184, area A)
Because I needed certain information (Participant A130, area B)

Some of the participants presented their quest for more knowledge as a way to empower themselves in order to manage the condition.

I need to understand what I need to do to control the diabetes (Participant A124, area C)
I needed to get as much information as possible in order to know what I am dealing with and what to do about it. (Participant A150, area B)

Some participants demonstrate a knowledge deficit by equating diabetes knowledge to learning more about diet. No doubt, the multi-disciplinary health education covers other several aspects of diabetes care apart from the dietary management. According to them:

I needed to know more about diet. (Participant A187, area A)

I want to know the foods that I can and cannot eat including quantities
(Participant A183, area A)

Living with a long-term condition is difficult and collaborating with people who have the same medical condition may be helpful to some participants. As a result, the reason why some participants attended the sessions was to meet other participants with diabetes:

To have contact with other diabetes participants (Participant A130, area B)
To meet others (Participant A168, area D)

A recent diagnosis of any long-term condition may be challenging to a patient. Consequently, it often necessitates various coping mechanisms ranging from denial to seeking further information on the illness. Some participants (n=8) attributed their motivation to attend the sessions to the sudden news of having diabetes. They said:

Recent diabetes diagnosis (Participant A145, area B)
Knowing that I have impaired glucose (Participant A120, area C)

Overall, 14 participants from the attenders group have the desire to know more about their condition. Some participants attended the session(s) because they wanted specific information (n= 5), certain participants attended the session in order to have a better grasp of the benefits of appropriate nutrition in diabetes care while some participants attended the sessions so as to gain some support from other participants with similar medical condition.

5.9.2. The role of Professionals

Another recurring statement is the influence of professionals in encouraging the participants to attend the sessions. According to several participants (n=5), they attended the sessions because they were referred by their GP:

Recommended by the GP (Participant A127, area C)
My GP recommended it and the practice has a focus/specialty concerning diabetes and is respected (Participant A174, area D)

Similarly, some participants (n=2) attended the sessions because the practice nurse advised them to come to the centre:

Nurse advised it. (Participant A201, area A)
I was referred by the practice nurse (Participant A191, area A)

For some participants, both the GP and the nurse recommended the session:

GP and Practice Nurse suggested it (Participant A113, area C)

Although some participants attended the session based on other peoples recommendations, some participants did not specify who advised them to attend:

I was told I had to (Participant A146, area B)
I was advised to come (Participant A116, area C)

However, as exemplified by the quotations below, two participants from the non-attenders group stated that they failed to attend the session because their GP did not tell them to do so. According to them:

I always do what my GP says (Participant NA9, area A)
I was neither advised nor referred by my GP (Participant NA28, area A)

Although, these were isolated comments, nevertheless, it may contribute to reasons for non-attendance. A participant stated that she did not attend the session because of her previous experience of the session. Although most participants affected by type 2 diabetes are treated with tablets and lifestyle modifications, however, uncontrolled type 2 diabetes is managed with insulin. According to her, the session did not address the needs of participants with type 2 diabetes who are being treated with insulin. This was expressed thus:

Attention should be paid to those with diabetes that are dependent on insulin. During the session that I attended with my husband (who's also diabetic) no one mentioned anything about the use of insulin. (Participant NA35, area B)

This section demonstrates the importance of recommendations offered by the GP, nurses or others in motivating attendance. Similarly, previous negative experience seems to be a contributory factor to non-attendance. In contrast to the positive influence of professionals' advice, the data also showed that lack of specific direction on the need to attend the session had a negative outcome.

The findings under this major theme relate to motivating factors to attendance include (1) the desire to gain more knowledge of the disease condition regardless of the fact that some participants equate diabetes education to learning more about diet. (2) The unexpected diagnosis of diabetes and (3) the role of the professionals in terms of recommending the session. The next section will focus on personal problems that may hinder /hindered attendance.

5.10. Personal Circumstances

An individual is unique and our circumstances are also different from time to time. As a result, participants are often confronted with various personal difficulties that may prevent them from attending the sessions. For this study, some personal difficulties, such as child care, personal crisis, illness and work commitments were reported as reasons for non-attendance. Other personal issues reported were being away on holiday, forgetfulness and personal conviction.

5.10.1. Illness

Having been ill during the allocated time was mentioned by the attenders as shown by the following quotations:

Health problems (Participant A116, area C)
Illness (Participant A201, area A)

In the same way, illness was given as a reason by some non-attenders as well:

I was too ill at the time of the session. But I attended the diabetes clinic at the hospital. They were so helpful and answered any questions that I needed to ask (Participant NA14, area A)
I was ill with Throat Infection (Participant NA29, area A)

As shown by the quotations under this sub-theme, inability to attend the session(s) as a result of ill-health was reported by the participants.

5.10.2. Work commitments

Several attenders stated that work-related issues were a key factor that could have prevented them from attending:

Work commitments (Participant A124, area C)
Not getting time from work (Participant A139, area B)
If it was during the day that I was working (Participant A183, area A)
Working away from home which my job entails (Participant A186, area A)

Likewise, work commitments prevented some non-attenders from attending the session:

Because of my work hours and because when I finish my shift (Participant NA26, area A)
Working day duties makes it difficult to attend the session (Participant NA62, area C)

This sub-theme clearly indicates evidence to support the view that work patterns sometimes make it impossible for certain participants to attend the session. This finding also strengthens and supports the statistical analysis previously reported in this chapter.

5.10.3. Child care

Some (n=2) of the attenders cited child care issue as one of the reasons that could have prevented them from attending the session:

Someone to look after children (Participant A185, area A)
Child care problems (Participant A124, area C)

Similarly, in terms of personal difficulties for the non-attenders, some participants could not come because of child care:

I am looking after some of my grandchildren until 7:30- 8 pm (Participant NA26, area A)

As a result of the age of onset of type 2 diabetes, some participants have the responsibility of caring for either their own children or grandchildren and this may

prevent those affected people from attending the session.

5.10.4. Personal crisis

A few participants stated that they could not attend due to some unforeseen circumstances including death of partners; family crisis; and bad weather:

My wife died and I informed GP of my situation. My daughter looks after me now as I have Alzheimer (Participant NA43, area B)
Something else urgent cropped up in the family (Participant NA30, area A)
Because of personal crisis (Participant NA49, area B)
The snow (Participant A155, area D)
Snow (Participant NA62, area C)

Illness, work commitments and child-care were also mentioned. Some participants were prevented from attending the sessions due to personal problems which ranges from work-related problems and personal crisis to sudden death of a spouse and a very bad weather.

5.10.5. Forgetfulness

The data suggested that some of the non-attenders may not be motivated enough to take adequate responsibility for the management of their condition. While it could be argued that they are using forgetfulness as an excuse to cover their lack of motivation, this may equally be due to old age, added stress of recognizing the severity of the disease or due to other personal or family issues in their life at that particular time. For some, they either forgot or not aware of the appointment date:

I forget because of mix - up of dates (Participant NA1, area A)
Keep forgetting (Participant NA3, area A)

Another reason for non-attendance identified by this study is the problem of either forgetting the details of the appointment such as the time and date or completely forgetting that they had an appointment at all.

5.10.6. Personal Idiosyncrasies

Absence of the desire to attend the education sessions for certain personal belief or behaviour was revealed by the data. In contrast to forgetfulness, some participants showed complete lack of interest in the session by saying:

I do not want to attend (Participant NA54, area B)

I don't have interest in the education (Participant NA58, area B)

In a similar way, some participants do not attend because they have the opinion that they already possessed adequate knowledge:

I know enough. (Participant NA19, area A)

and some participants elaborated further on this by saying that they have a family history of diabetes and the family does discuss diabetes care and they perceived that this is sufficient to equip them for self-care abilities:

I'm doing okay. My mother and my daughter of 11 years old have type 1 diabetes. So we all talk about diabetes and discuss new ideas that have come to help us. (Participant NA14, area A).

This sub-theme revealed that some participants did not attend because of their personal perception about the level of diabetes knowledge they possessed or believed that they could gain sufficient information by searching the web or

through family discussions. In contrast to this personal belief, some participants were not interested in the teaching sessions regardless of whether they thought the sessions may enhance their self-management knowledge and skills.

5.10.7. Holiday

Some participants were out of the country during the planned sessions, therefore, it was impossible to attend the sessions:

I was on holiday (Participant NA57, area B) and
I was away. (Participant NA94, area D)

Being on holiday during the planned session was verbalised as the reason for non-attendance by some non-attenders. This may be due to the fact that the participants have booked the holiday in advance before the appointment or due to inability to claim a refund in case of any cancellation. In addition, some holidays may be linked to a particular event such as a wedding ceremony which may make it difficult to change.

The attenders attributed the reasons that could prevent them from attending to similar factors that prevented the non-attenders from attending the session. The reasons that cut across both groups of participants ranges from child care and illness to work commitments and the timing and location of the education session. Some non-attenders also failed to attend because they were away on holiday, forgot or due to personal problems. Some non-attenders believed they possessed adequate knowledge while some were just not interested in the education session.

5.11. Organisational protocols

Some of the participants identified administrative constraints and additional administrative support that could aid or hinder attendance.

5.11.1. Poor appointment system

A few participants stated that there seems to be an administrative error on the part of the Diabetes Education Unit because they have either attended or not been invited.

I did attend (Participant NA51, area B)

I was not invited (Participant NA31, area A)

I have not been given an invitation! (Participant NA77, area C)

I was not aware that a session was scheduled (Participant NA28, area A)

I have been asking for information about Diabetes for 6 months! No help has been provided (Participant NA78, area C)

5.11.2. Timing and location of the session.

On the question relating to the reasons that might have prevented the attendees from attending the session, their responses revolved round barriers such as inconvenient date, location and time of the session. Some attendees (n=5) stated that time and distance was a barrier. One example was:

I find it difficult to get around to different locations and I rely on public transport. (Participant A191, area A)

Again, the time and location of the session was cited by some non-attendees as the reason that prevented them from attending the sessions. These are some of the quotations in terms of inconvenient location, date and time:

The location was too far away (Participant NA58, area B)

Inconvenient time and place (Participant NA84, area D)

I couldn't attend the education because of the distance (Participant NA32, area A)

The days/ times were not convenient (Participant NA34, area B)

The timing of the session seems to be sometimes closely linked with work-related issues as shown by the following excerpts:

Timing-cannot go during day because of job (Participant A168, area D)

The timing-I had to take half day off work to attend (Participant A146, area B)

I cannot go during day due to work activities (Participant A197, area A)

Again, Respondent A203, area A gave parking problems as a reason that may prevent her from attending the session.

This section showed that a poor appointment system and organization of the session in terms of time and location has a role to play in non-attendance. Nevertheless, it could be argued that the participants also need to clarify and ask for further information and possibly try to re-schedule the time if the location of the session cannot be changed.

5.12. Strategies to promote attendance

Regarding additional information on what can be done to motivate the non-attenders to attend; some participants who completed this section sought further help in terms of a more flexible time and closer location. In regards to location, these are some of the comments:

Offering it in a local community (Participant NA2, area A)

Providing the education closer to my house (Participant NA47, area B)

Another place that is nearer (Participant NA50, area B)
More choice of time and place (Participant NA84, area D)
In a local area (Participant NA94, area D)
Location must be in area 3 (Participant NA77, area C)

In terms of timing of the session, some participants would like a varied time as shown below:

Giving me another day that I can attend (Participant NA17, area A)
I am able to come to the education session on Thursday or Saturday
in the morning (After 10 O'clock) (Participant NA32, area A)

In addition to a flexible time and location, some participants wanted some help with transport:

Transport and language support (Participant NA28, area A)
Assistance with transport (Participant NA29, area A)
A lot of help with transport (Participant NA59, area B)
Transport problems (Participant NA116, area C)

5.13. Discussion of findings

5.13.1. Socio-demographic data

The results showed that the age of majority of the majority of the participants in this survey ranged between 41 – 65 years, which reflects the epidemiology of the disease. According to (Diabetes UK 2010; WHO 2006; Waugh and Grant 2010), type 2 diabetes accounts for 90% of people with diabetes which usually occurs in people over 40 years of age. The gender of participants among the patients showed that there were more females than males. The findings of the ethnic origin of the participants for the questionnaire survey showed a wide variation between the two groups of patients within the four localities (Table 5.1 in Chapter 5). This demographic variation in the localities reflects Britain's multi-cultural

society and according to Dunnell (2007), the UK population growth continues to be increasingly diverse. The variation of ethnicity can affect attendance, as shown by Townsend et al (2000); Naidoo and Willis (2000); and Helman (2001) who indicated that ethnicity can influence health outcomes.

The communication skills and educational learning needs requirements of participants among the two groups of patients surveyed did not reveal significant differences through their self-assessment on the questionnaire. Arguably, some of these patients may not attend because of their low level of education despite self-assessment of their ability to communicate well in the English language. In contrast, Rhee et al (2005) study of patients who attended Diabetes Education Centres found that reading problems and low level of education are the common concerns associated with lack of engagement in diabetes education. Unlike Rhee et al's (2005) study which found learning needs to be a barrier to diabetes education, the current questionnaire did not specify risk categories owing to the need to make the questions easily comprehensible and not to put off the harder to engage patients from responding to the questionnaire. Therefore, some of the participants in this study might have specific learning needs. There may also be a problem with the patients' self- assessment of their abilities to communicate or to identify learning needs.

5.13.2. Health beliefs and attendance behaviour

The questionnaire survey revealed that some participants felt that their diabetes is mild and therefore well controlled. Similarly, the findings from the practitioners confirmed the findings from the non-attenders about the belief that their diabetes is mild. These findings from both the patients and practitioners are consistent with Graziani et al (1999), Hammersley et al (1985), Glasgow et al (1997) and Hamilton et al (2002) studies which showed that beliefs about the seriousness of their medical condition influenced the level of their preparedness to engage with self-management programmes.

No doubt, diabetes is a serious medical condition (WHO 2011; Diabetes UK 2012b) and it can lead to various complications such as retinopathy and kidney failure (Bailey and Feher 2009; Diabetes UK 2008e; Marie and Whitaker 2004). Therefore, this perception requires some strategies that could help to re-orientate them to alter their perceptions of the level of severity of the disease and the potential for having serious diabetes complications. A good way of addressing this barrier is to give adequate information on the severity of diabetes and possible complications upon diagnosis when the practitioners are referring the patients for structured patient education. Another method is putting pamphlets with good graphical display of patients with complications in accessible places. Cinar et al (2010) suggested putting diabetes education pamphlets at accessible places such as local GP surgeries, Day centres, and popular retail outlets such as Tesco and ASDA.

The data collated from the patients indicated that their perception in relation to the benefits of the new behaviour was a key determinant of attendance and this is consistent with the findings of the Phase 1 study of the current research. By analysing some of the statements, the patients do not see the importance of attending the session. This can possibly be likened to the group of patients that the practitioners described as the unmotivated clients that often deliberately ignored the letter without any genuine reason. Arguably, negative perceptions and beliefs about the value of education may hinder attendance as shown by the DH (2004) document on 'Making healthy choices' which stated that making healthy choices may not be easy for everyone, therefore, individual motivation and support is crucial. Again, there was a complete lack of interest and resentment from a few patients who failed to attend the sessions and some patients demonstrated a lack of desire to attend the education session due to personal beliefs or behaviours. Consequently, this set of patient requires some degree of support to enable them to understand the benefits of attending the sessions.

According to some surveyed patients' perceptions about other sources of information resulted in them failing to attend the sessions. To this group of non-attenders, their opinion of the potential usefulness and relevance of the session is influenced by their personal and family understanding of the disease in contrast to the additional benefits that the session can offer in equipping them for their own self-care experience. This finding is important because diabetes has an identified genetic tendency (Waugh and Grant 2010; Diabetes UK 2008b; Dixon

and Salamanson 2006) and two-thirds of the referrals for the education sessions had a family history of diabetes and this may invariably influence their decision to either attend the session or not. Although a family with a history of diabetes may be knowledgeable about diabetes, nevertheless, the education is given by experts in various aspects of diabetes care. This means that the education presents more accurate and better information that could aid self-care management.

The self-perception of those who consider that they possessed an adequate level of knowledge appears to be a hindrance to attendance. Ryder (2001) states that increased access to health information through sources such as television and the internet present a danger of information overload and may lead to confusion. This suggests that the patient might believe that their personal effort and financial cost required to attend the session is not worthwhile. This supposition agrees with findings reported by Gucciardi et al (2007) who also identified perceived level of knowledge of diabetes as a barrier to attendance. Consequently, altering the patient's perception of their level of knowledge may influence attendance if the cost of changing their health related behaviours can be justified. Again, the healthcare practitioners (HCPs) have a role to play in emphasising the benefits of the session in equipping them with additional knowledge to further improve their self-care management skills.

Several initiatives such as the National Service Frameworks, the expert patients programme, and the public health white paper on 'Choosing Health and Supporting People with Long Term Conditions' support self-care management (DH 2001 and DH 2005). DH (2005) sees self-care as part of daily living and exemplifies this fact by stating that diabetes patients spend a limited number of hours in a year with health professionals and engage in self-care for most of the year. However, although a significant number of the participants in the non-attenders group believed in taking responsibility for self-care (n=70, 67%), this was not reflected in their attitude towards attendance. This showed that there is a dissonance with the recognition of taking responsibility to promote self-care.

5.13.3. Organisation of care

The third theme revolved round administrative constraints that could hinder attendance. A recurrent focus of data collected from both the practitioners and patients revealed that inappropriate referral systems, location, timing and self-management education resources were contributory factors to non-attendance.

5.13.3.i. Inappropriate referral system

The views of the surveyed patients revealed that the quality of information given during referral and the chance to clarify information are part of the administrative constraints that may hinder attendance. The issue of giving inadequate information and inability to clarify the information signified a poor referral process.

This view was replicated in the responses of the practitioners in the Phase 1 study. This suggested that some patients did not attend the sessions because the purpose and other details of the session were not communicated very well. In support of this view, Stone et al (1999) identified administrative problems, such as failure to inform the patients about the appointment date and time or failure to update their record as an issue associated with non-attendance. This idea demonstrated that if the patients are given a letter explaining the aim of the session and contact details of the education centres after being told that they would require an on-going education programme, this might aid attendance.

5.13.3.ii. The impact of timing and location on attendance

The impact of timing on attendance was demonstrated by the data collected from both the patients and practitioners. The data showed that more non-attenders preferred afternoon, evening and weekend sessions than the attenders. The timing of the session was occasionally linked to work-related problems. The effects of location of the session were observed by both the practitioners and patients. In terms of the preferred location for the education service, the study indicated that distance, transport and parking problems constituted a barrier. Previous studies have found that inconvenient and inaccessible locations (Gucciardi et al 2007) and transport problems (Stone et al 1999, Graziani et al 1999) are a hindrance to attendance in clinical practice.

5.13.3.iii. Perception about diabetes group education

Tang et al (2008) supported the view that diabetes group education can be cost effective and equally provide greater patient satisfaction and better behaviour modifications. Some attendees in the survey also attended the session because they wanted to meet other people with diabetes in order to share their knowledge and support each other. Although there is a perception that group education may not be suitable for every patient, the emerging data showed that using the idea of socially constructive knowledge to empower patients is relevant to diabetes education (Zreibiec 2003).

5.13.4. Personal circumstances

The personal causes for non-attendees ranged from illness and work commitments to child care and forgetfulness. These were some of the personal issues that prevented some patients from attending the sessions and are discussed below:

5.13.4.i. Illness

Some patients attributed the reason for their non-attendance to illness and co-morbidity resulting from old age and diabetes. Zailinawati et al (2006) studied why people with a long-term condition failed to keep their hospital appointments and found that being unwell was a factor. Hamilton et al's (2002) study found that reasons responsible for non-attendance included patients who were sick and admitted to a hospital or some that went to an accident and emergency unit

during the planned time of another hospital appointment. Also, Stone et al's (1999) study observed that illness was one of the reasons for non-attendance at outpatient clinics. Although, patients could be using sickness as an excuse, several other worldwide studies such as Zailinawati et al (2006); Hamilton et al (2002) and Stone et al (1999) have identified the role of sickness in non-attendance; therefore, it could be a genuine reason that needs to be considered.

5.13.4.ii. Work commitments

Some patients couldn't attend the session because of work-related problems. The data collected from both the practitioners and patients showed that there was a conflict between the timing of the session and their work schedule. This could be due to various reasons, such as inability to take the day off as a result of official commitments, not knowing that they will be on duty on the day or a change to their working shift. In a previous study, Ngwenya et al (2009) study found work/school commitments as a barrier to attendance in a diabetes clinic. This finding is consistent with previous studies who found that a higher number of unemployed patients with type 2 diabetes attended their follow-up diabetes education programme (Gucciardi et al 2009). Hamilton et al (2002) and Stone et al (1999) studies also found work-related problems as a reason for non-attendance in general practice. As shown by the questionnaire data and focus group interview of practitioners, being in employment and a lack of flexibility in working pattern were identified as barriers. Diabetes is a chronic long standing disease, and taking time off from work on several occasions to attend different

medical appointments such as, diabetic education sessions as well as regular GP appointments may be difficult.

5.13.4.iii. Child care

The data from both the practitioners and patients found that child care was a personal difficulty that prevented some patients from attending the session. In a similar way, other studies such as Zailinawati et al (2006) and Dyer et al (1998) showed that attendance in clinical practice is affected by child care issues. Although this is not within the control of hospital staff, problems with child care arrangements may be a possible reason responsible for non-attendance.

5.13.4.iv. Personal crisis

A personal crisis, such as sudden death of a spouse and being confronted with unforeseen circumstances were identified as a barrier by both the patients and practitioners. A research conducted by Ngwenya et al (2009) found attending a funeral to be one of the reasons for non-attendance in diabetes clinics. Therefore, having emergencies, such as bereavement and problems at work could prevent patients from attending the scheduled sessions.

5.13.4.v. Weather conditions

Another personal problem verbalised by both groups of patients was the inability of some patients to attend the sessions owing to weather related problems, particularly, a heavy snow fall on the day of the appointment. This finding is

similar to results of Ngwenya et al's (2009) research which identified bad weather as a reason contributing to non-attendance of patients in the clinic. It could be logical to assume that having a heavy snowfall on the appointment day is a genuine reason for non-attendance; hence it may be sensible for the practitioners to follow-up patients that could not attend the session on any day with bad weather or even reschedule the session. Also, it could be argued that respective patients could phone to re-book another appointment.

5.13.4.vi. Holidays

The barriers to attendance for some patients were as a result of being out of the country as evidenced by the excerpts from the transcripts. Again, it may be difficult for patients to re-schedule a booked holiday because they might lose the money if they cancel or re-schedule the flight. Similarly, certain planned holiday may coincide with a family event such as a wedding ceremony and this might limit their flexibility. This concurs with the findings of Ngwenya et al's (2009) study which identified being out of town as a barrier to attendance in diabetes clinics. However, there is an issue of not calling to cancel or re-arrange the appointment, particularly when adequate time has been provided in the appointment arrangements to effect a change of date.

5.13.4.vii. Forgetfulness

The barriers to attendance identified by the patients included forgetfulness. Other research studies have shown that forgetfulness contributes to failure to attend hospital appointments, for example, Masding et al (2010) study showed that

some patients with diabetes failed to attend the clinic because they forgot the appointment. Also, Ngwenya et al (2009), Hamilton et al (2002), Stone et al (1999) and Hill-Briggs et al (2005) studies identified forgetfulness as a barrier to compliance to attendance and adhere to a medical regime. This suggests that patients occasionally forget the appointment which may be due to several reasons, such as pressure from other life problems and level of personal organisation.

5.13.5. Motivation

Motivation is the driving force to achieve an accomplishment and it is crucial to any endeavour (Race 2005; Beard and Senior 1980; Elton 1973). The practitioner's view indicated that motivated patients who have genuine or unavoidable reasons will often call to cancel the appointment. The patients' views presented more elaborate views on motivation to attend than those of the practitioners who just broadly classified patients into either a motivated or non-motivated group. The motivating factors to attendance stated by the attenders were the quest for more knowledge, the desire to empower themselves and the unexpected diagnosis of diabetes. Hopkins (2004), Maclean et al (2002) and Carlson (1997) states that motivation of the patient is essential for the success of any treatment regime, therefore, attendance at the diabetes education centre requires some degree of motivation. One of the premises of the HBM (Becker et al 1978) is health motivation which postulates that perceived need to improve one's health may gear patients to engage with a specific health intervention.

Therefore, patients who perceived that they needed to find out more information about diabetes were more motivated to attend the session.

The sudden diagnosis of a long-term condition may be challenging and often requires some positive coping strategies such as seeking further knowledge about the medical diagnosis and talking to other people. In contrast, some people will engage strategies of dealing with it in a negative way, for example, by not showing interest in attending the sessions. Nute (2004) states that some patients tend to exhibit emotions, such as, fear and anger following diagnosis of a long-term condition. Therefore, it is normal to be upset and display signs of negative emotions such as fear, anger, frustration or apprehension following the news of a long-term condition. However, individual reactions to a sudden diagnosis of a long-term condition differ. Whilst, few patients reacted by seeking more knowledge, some patients have responded by showing a negative reaction and report that they are happy with the level of type 2 diabetes knowledge they already possess. This disjunction in what they know in comparison to what they need to know to aid self-care management ought to be explained to the patient in order to facilitate attendance.

According to Maslow (1943), a motivated behaviour is based on willingness to satisfy one or more needs and human needs are arranged hierarchically. Therefore, it could be argued that attending the session is not high on some of the patient's hierarchy of needs or it could be possible that the circumstances of the arrangements of the session do not fulfil their basic needs as identified by Maslow. Again, the motivation for attendance was presented by some patients

as a form of knowledge deficit. There were situations whereby some patients equate the Structured Patient Education (SPE) with learning about diet in contrast to an education programme that deals with all aspects of diabetes care. An illustrative statement on this type of motivation was verbalised by one of the attenders thus: *'I needed to know more about the diet'* (Participant 155, area D). This view was also corroborated by the data collected from the practitioners. Structured Patient Education for patients with diabetes uses a constructive approach to teach a broad range of topics on diabetes management. Although the perception that 'SPE is just learning about diet' underscored the purpose of the session, however, this type of motivation is significant because it prompted certain patients to attend the session.

5.14. SUMMARY

This Chapter reported the findings of 207 questionnaire responses administered to both attendees and non-attenders which aimed to find out about participants' attitudes towards education for diabetes self-care. The overall results of the socio-demographic data revealed that ethnicity, working pattern, living arrangements and family history of diabetes can be used to predict attendance behaviour. This quantitative analysis revealed that beliefs held by the participants have an impact on attendance behaviour. Similarly, the results revealed the influence of organizational protocols on attendance behaviour.

The findings of the qualitative data yielded three key themes: motivation, personal circumstances and organisational issues. Participant's opinions and rationale about why they attended the sessions, ranged from the desire to learn more about their medical condition, and the need to meet others to the influence of healthcare practitioners, and a sudden diagnosis of diabetes. In terms of barriers to attendance, the participants identified personal difficulties due to various reasons such as work issues, childcare problems, ill-health, lack of interest, inconvenient date, location and timing of the sessions. Lastly, the findings of this qualitative data identified that certain groups of participants appeared not to be interested in the session at all.

In summary, this Chapter has fulfilled its aim of identifying the barriers and enhancing factors to attendance. These results and their implications are discussed in depth in Chapters' Seven to Nine with the findings from Phases 1 and 3 of this research study. In addition to the barriers that have been identified by the qualitative study (Phase 1), and the reporting of this questionnaire survey (Phase 2), the findings of face-to-face interviews with healthcare practitioners (Phase 3) will be used to further explore the phenomenon in the next Chapter.

CHAPTER 6

NON-ATTENDANCE IN DIABETES EDUCATION CENTRES: PERSPECTIVE OF PRACTITIONERS

6.1. Introduction

This Chapter aims to present the results of Phase 3 of the current research which used qualitative methods (individual face-to-face interviews) to solicit the views of referring practitioners to address my research questions from their perspective. This Phase of the study broadly examined the reasons for non-attendance and ways to improve attendance from the practitioners' perspective. Being a sequential study, it further explored the findings from Phases 2 and 3 of the research. In addition to these aims, it examined whether the recent NHS reform has made significant changes to the threat of non-attendance in Diabetes Education Centres due to the time gap (see appendix 16 for the question guide). Thus, it will cover the findings of the interviews conducted with the practice nurses and a GP.

6.2. Results

Thematic analysis using four stages of coding (previously described in Chapter 3) was used to analyse the raw data. It followed the process of level 1 coding with direct statements, level 2 coding with explanations and initial comments, level 3 coding which clustered the codes into sub-themes and finally arrived at major themes in level 4 coding. Level 1 were quotations selected from the transcript (Appendix 17) used to develop level 2 codes (Appendix 18). Level 3

codes (Appendix 19) identified relevant concepts essential to the aims of the study and were used as the building blocks for level 4 major themes (Appendix 20). Based on Thematic Analysis, the findings from the qualitative data are summarised under the following four themes shown in table 6.1 below:

Table 6.1 - Summary of findings

Major themes:	Sub themes:
Organisation of care	<ul style="list-style-type: none"> - Importance of meeting government targets - Service overload/waiting time - Working practices - Practitioners lack of time - Inadequate information - Poor referral system - Lack of follow-up - Perceptions and attitude of practitioners towards diabetes education - Introducing sanctions - Inter-professional working - Inconvenient time and location of the session - Administrative errors
Personal circumstances of the patient	<ul style="list-style-type: none"> - Employment and education related barriers - Child care issues - Personal dispositions - Forgetfulness - Language barrier
Perceptions and attitudes of patients to diabetes education	<ul style="list-style-type: none"> - Perceptions and belief about diabetes - Perceptions and beliefs about self-care management and diabetes education - Preference for group education - Motivation
Strategies to aid attendance	<ul style="list-style-type: none"> - Flexibility of delivery - Resources - Training and Development - Collaborative practice

6.3. Organisation of care

There is documentary evidence to suggest that employees in general tend to resist organisational change because it is easier and more convenient to carry out their functions in the usual way. However, this may not be the case; the participants felt that frequent organisational changes are impacting on their work:

Yes so much in terms of organisation and it's not just in this one thing it's in every area and I have been practicing nursing over 19 years and in the last couple of years we have had the GP commissioning the..... Federation we have had on-going QOF changes, the care planning being brought in, the ICP being brought in (Participant 6, area 2, Practice Nurse (PN)).

6.3.1. Targets

Although, there were series of organisational changes resulting from the introduction of different regulations by the government, the latest Quality Outcome Framework (QOF) for diabetes was particularly seen as a contributory factor to the barriers to attendance. The introduction of QOF points remain a controversial topic among practitioners with arguments for performance-related pay. There was a view that the introduction of QOF point to diabetes education led to service overload which eventually overwhelmed the system:

When QOF came in, other less proactive GPs said oh there's QOF points here so they were firing off all these referrals for patients that they've never sent so it overwhelmed the system, the system can't cope (Participant 3, area 1, PN)

There was a suggestion that the new QOF motivated some practitioners to increase their referral rate. As stated by some participants, the new government

regulations and incentives system resulted in a barrier to attendance in terms of leading to a longer waiting period between referral and invitation. Although longer waiting time could help the patients to plan their diary in advance, it has proved otherwise:

there was a six month waiting list and I think if there is a long wait, people will give up and they can't be bothered by the time there is a place available (Participant 6, area 2, PN)

Nevertheless, it is important to meet the government targets; therefore, this factor was reported by the participants as part of the problems associated with non-attendance:

It is very difficult because the government needs to see statistics, they can't work in any other way they cannot be interested in minute level of individual lives can they, it's ridiculous, so you know you've got this target that everyone sees (Participant 5, area 2, PN)

Again the GP practices are responsible for treating different types of ailments apart from diabetes and acute medical conditions may require some degree of urgency. To buttress this view, some participants identified the impact of competing demand of care resulting from the present organisation of care:

And again you have too many people walking in with all these sick bugs and that seems to be more important anyway because we are being judged and the boxes need to be ticked (Participant 1, area 1, PN)

Shockingly, some participants therefore saw referring patients to the diabetes education centre as a box ticking exercise:

QOF in a way started as a good idea but there are too many tick boxes and too many things to look at and too many things we have to do to get the money and in a way it spoilt the way we look after the patients (Participant 1, area 1, PN)

Regardless of the negative impact of this government incentive system, a participant stated that the intention was good. There was a view that this government regulation is still serving a good purpose for the fact that it reminded them to refer all the newly diagnosed patients to the Diabetes Education Centre:

I think it's a memory jogger so that when they are in with us and we are going through the template at their diabetic review and have you referred them to the diabetes education programme pops up, that is our trigger (Participant 2, area 1, PN)

In contrast to the practice nurses views, the some participants felt that the QOF reward system has not led to ticking boxes:

It is not about ticking boxes at all (Participant 4, area 1, GP)
We follow the NICE guidelines and we are not just ticking a box (Participant 8, area 3, PN)

However, a participant viewed that the practitioners need to follow the stipulated protocol of the organization:

You need staff who know what they are doing, staff who can follow guidelines (Participant 4, area 1, GP)

Nevertheless, the new changes which led to financial reward based on ticking the referral box on the form has brought some associated problems:

I won't say there is any significant change to the process but increase inadequate staff, more administrative work and lack of training (Participant 7, area 3, PN).

This subsequently impacted on working practices because it became a

game of number:

Cost is an issue and the people sitting at the top are thinking about how many patients you have seen (Participant 7, area 3, PN).

6.3.2. Lack of time

Anderson and Funnell (2009) state that there are some misconceptions about the patient empowerment approach. In contrast to convincing and persuading patient to change, empowerment is about facilitating and supporting patients to reflect on their personal experience of living with diabetes. Therefore, this process requires a reasonable amount of time to sustain the interest of patient. Contrarily, due to service overload, all the participants verbalised that lack of time was a major organisational barrier:

It really requires time and time is one of the things we don't have, we are constantly fighting the clock so that is the problem as I see it (Participant 6, area 2, PN)

A participant also stated that the lack of time could be compounded with poor level of English communication skills of the patients:

We have language problems so that takes a lot of the time when somebody doesn't speak English and I don't speak Punjabi or anything (Participant 1, area 1, PN)

The practitioners' responses revealed that the shortage of time is impacting on the quality of information given to the patients during the referral process. The participants shed more light on this issue by stating that the referral was often rushed due to lack of time and adequate information to guide their attendance was not always given:

Yes its time – we need to cover so much and if you only have a short amount of time then it's taking that long to do the blood pressure, the weight and you've got to do their full foot check and you have to discuss their BM and try to go through what the structured education is as well, when you don't know that person very well unless you go through it fully they will not understand it then (Practitioner 8 area 3, PN)

The shortage of time was so severe that some participants also stated that they don't have time to call patients to find out whether they have attended and to ask the reason(s) for their non-attendance:

But I wouldn't follow it up anymore; because we have thousands of diabetic patients and you know we would follow them up in an ideal world (Participant 1, area 1, PN).

Another participant stated that following patients up requires time:

That in its self is time consuming as you have to have somebody yourself that has got the time to actually make sure that happens (Participant 5, area 2, PN)

Arguably, the present working climate has affected the perceptions of practitioners who were suggesting an alternative approach to the current system. Nevertheless, the introduction of structured patient education resulted from dissatisfaction from the old method of diabetes educational delivery.

The practice nurses can do a lot of the education so it's not as though the patients are not getting any and most of the practice nurses do basic education for them and you know we tell them to look at Diabetes UK website and things like that so they can do a bit of research themselves (Participant 1, area 1, PN).

6.3.3. Perceptions and attitudes of patients

In addition, it appears that the working conditions have shaped the practitioners attitude towards the patients:

A lot of it depends on attitude doesn't it, put yourself in a place that a person has diabetes and you come in to see me and I'm here typing on the computer saying right got to check your blood pressure, look at your feet and test your urine what does that say to you? It says that I don't care doesn't it and it says to you that I need to tick boxes (Participant 5, area 2, PN).

Similarly, this might have influenced the practitioners views about non-attendance as some of the participants stated that non-compliance is a common phenomenon in the whole healthcare sector suggesting the view that it therefore does not matter. Although non-attendance in clinical practice is an old problem (Ajay and Rubin 2003; Neal et al 2001; Denner et al 2005; Bech 2005), it is an hindrance to effective care management:

Non-compliance is always a problem. I see it every day, you see patient telling you that I don't take my water tablet when I am going out for a social event and you look down at their foot, it is very oedematous (Participant 7, area 3, PN).

From public health perspectives, there are some preventable complications associated with diabetes for example, cardiovascular diseases and nephropathy (WHO 2011; Waugh and Grant 2010). Consequently, patients' failure to attend diabetes education sessions geared towards prevention and health promotion could be frustrating to the professionals. Although motivation and personal belief may promote change in health behaviour, the practitioners need to explore the reasons why patients have not engaged with the invitation instead of perceiving

them as an unmotivated group of patients. All the same, by simply apportioning blame to the patient and labelling them as unmotivated without understanding the cause of non-attendance falls short of proposing solutions to the problem of non-attendance. Equally, the issue of using any form of penalty to motivate patients to engage with any health intervention is controversial (Ekpe 2001; Rana and Upton 2009; Petty 2004). However, on the question of whether any form of sanction can be used to aid attendance, all the participants perceived the use of negative motivational technique as counterproductive:

I don't feel comfortable with sanctions as there must be a better way (Participant 4, area 1, GP)

Regardless of the negative impact of non-attendance, some participants perceived any form of sanction negatively because the NHS is free at the point of delivery:

I don't think any financial sanction will work; after all, the NHS is free (Participant 7, area 3, PN).

Whilst some participants perceived any form of sanction as a punishment:

If that is what the government is thinking or looking to go it would be very sad actually as it is almost like punishing those who are already punished (Participant 9, area 3, PN)

And some participants perceived it as a futile approach:

I think there would be an outcry, a complete outcry; patients won't even pay their fine (Participant 7, area 3, PN)

Hamilton (2002) suggested sending a warning letter following non-attendance but stated that strategies of using a penalty such as a fine should be treated with

caution. Although some practitioners in Phase 1 felt that lessons can be learnt from other areas such as dentistry by imposing sanctions for non-attendance, this Phase 3 data suggested that sanctions or any punitive measure may bring criticisms, therefore, giving an incentive was seen as a better approach to motivate patients.

6.3.4. Inter-professional working

Inter-professional working is significant in encouraging communication between several healthcare practitioners with the intention to provide quality care. Another key issue is a weak practitioner/practitioner communication in the process of organisation of the educational programmes. This bureaucratic burden appears to be driven by targets and regulations as the data suggested limited exchange of information between the referring practitioners and education provider:

But they have never encouraged us to come and see but I think if I ring up and asked they would probably not say no! It would be so much more helpful in terms of telling the patient what happens and what to expect if I had actually been to the course myself (Participant 6, area 2, PN)

In contrast, a participant reflected on the referring versus delivery practitioners divide by saying:

But what I don't know is that perhaps this is highlighting something that is lacking in me to go and look at what actually happen, therefore, what it is and it's not something that we need to have lots of information (Participant 9 area 3, PN).

A participant identified occasional administrative errors on the part of the Diabetes Education Unit, for example, calling a patient who has attended a

session on a day that she was not scheduled to attend. This administrative oversight was verbalised thus:

She had total organisational chaos and then they checked their records and said oh yes oh yes you did, sorry (Participant 6 area 2, PN)

Another participant viewed that some patients are sensitive to minor administrative inconsistencies and this may impact on their trust and confidence in the system:

Do they trust the advice we give because you know again today I had a patient who said one doctor told me one thing and another told me quite the opposite so who am I to believe (Participant 6 area 2, PN)

Availability of information is crucial to planning and organisational efficiency; however, there appears to be poor data gathering and sharing:

Another issue is poor data collection, not knowing the number that has turned up within a reasonable space of time (Participant 4, area 1, GP)

In all organisation of care was perceived as a key barrier to attendance:

So many of these things are organisation where things often fall down (Participant 6, area 2).

6.3.4. Inconvenient time and location

The practitioners' responses revealed barriers such as inconvenient date, location and time of the session:

It's not having maybe the education at the right time or in the right place (Participant 1, area 1, PN)

Again, it was felt that some patients don't like to travel while some patients like to

stay in a familiar environment:

Patients don't like to travel they like to be in their own area with their own people (Participant 3, area 1, PN)

While the timing may not suit patients that are working:

For working people is that in this area there often aren't classes in the evening or weekends and time when they could actually get to them (Participant 7, area 2, PN)

In addition, the length of the sessions might prevent patients that can only commit to shorter sessions from attending:

The session is not run at different times and they are quite long sessions (Participant 6 area 2, PN).

This theme showed the impact of organisation of care on non-attendance and identified barriers associated with government incentive system leading to service overload, altered working practices and poor inter-professional working. The barriers also include a poor appointment system, lack of follow-up and administrative errors. Also, the timing and location of the session was cited by some participants as the reason that may prevent the patients from attending the sessions. However, it could be argued that this was motivated by lack of time and the drive to meet targets set by the government. Although patients' circumstances and attitude towards the education has a role to play in non-attendance, the referring practitioners had a negative view to the use of sanctions to motivate patients.

6.4. Personal circumstances of the patient

Patients are often confronted with various personal difficulties that may prevent them from attending the sessions. This finding is similar to the previous two phases of the study, illness, education, child care, language difficulties and work commitments were reported as reasons that could be responsible for patients' non-attendance.

6.4.1. Work commitments and studies

Several practitioners stated that work commitments and academic study were key factors that could have prevented the patients from attending the sessions:

It could be work commitments (Participant 4, area 1, GP)

and another participant verbalised a barrier relating to loss of income, for example if the patient is self-employed or being paid based on the number of working hours:

These patients are not going to give up working or they may not be allowed to leave work and if you are going to lose income or your work won't let you go then that is not feasible (Participant 3 area 1, PN).

Likewise, academic study could have prevented some non-attenders from attending the session:

Education and other things that can disturb them from attending the education session (Participant 7, area 3)

6.4.2. Childcare problems

Some practitioners cited child care issues as one of the reasons that could have prevented the patients from attending the session:

I mean they have childcare problems (Participant 7, area 3)

Although the age of onset for Type 2 diabetes is 40 years and above, some patients may still have the responsibilities to care for either their own children or grandchildren and this may prevent the affected people from attending the session.

6.4.3. Individual circumstances

Beside work commitments and child-care, some participants stated that some patients may be prevented from attending the sessions due to personal problems which ranged from partners sickness and mobility problems to more chaotic life situations. Some of these unforeseen circumstances support the findings of Phases 1 and 2 results:

Sometimes its health issues because they don't feel well enough to attend (Participant 4, area 1, GP)
Life is too busy for a youngster and too chaotic (Participant 6, area 2, PN)
With the elderly sometimes it is transport and mobility (Participant 6, area 2, PN)

The data from practitioners suggested that some of the non-attenders may forget or not being motivated enough to take adequate responsibility for the management of their condition. While it could be argued that they are using forgetfulness as an excuse to cover their lack of motivation, this may equally be

due to old age, added stress of recognising the severity of the disease or due to other personal or family issues in their life at that particular time.

I forgot or I was too busy and life gets in the way and it's not always that easy and I think a lot of people often forget because people don't want diabetes –no one wants to be diabetic(Participant 6, area 2, PN)

According to DH (2005), self-care is the care undertaken by individuals to promote and maintain their physical, mental, social and psychological wellbeing. There is evidence to support the benefits of self-care management of long-term conditions in promoting the wellbeing of people and enabling a better quality of life (DH 2002 and Hughes 2004). However, absence of the desire to attend the education sessions for their personal conviction was revealed by the data. In contrast to forgetfulness, some practitioners thought that patients sometimes showed complete lack of interest in the session:

They say they can't be bothered to go and to get a bus
(Participant 1, area 1, PN)

Some practitioners also felt that their lack of interest could be due to being resistant to the diagnosis. Arguably, the patients may not be aware of the degree of disability that can result from unmanaged diabetes; therefore, further raising the awareness of their susceptibility to complications could aid attendance:

and a lot of these patients just don't want to have diabetes so they are very resistant to their diagnosis in the first place so anything else that they have to do on top of it, like just coming here, they are not at that point where they are willing to accept that (Participant 9, area 3, PN)

6.4.4. Language barrier

On the issue of diversity in education, the Department of Health (DH 2004b) states that facilitators of patients learning are required to recognise and value the beliefs, and life experiences of others. On this note, the diabetes educators need to consider personal characteristics of the patient such as, age, marital status, language, culture, level of education, gender and so on before referring them for diabetes education. NICE (2009) states that educational programmes must meet the cultural, linguistic, cognitive and literacy needs of the people within the locality. Being a diverse population, some of the interviewees also attributed the reason for non-attendance to language related problems:

Obviously language in my demographics, my practice we have a large Asian community and 7% of our practice are diabetic and that is just growing so a lot of the Asians if English is not their first language they do not feel comfortable to go out of our area (Participant 3, area 2, PN)

Similarly, if they are overweight in addition to inability to speak English language, patients might think that the issue of reducing their weight will come up in the discussion and they may already be struggling with it:

Yes, those that can't speak English and that have come to live with their sons and daughters and the people that are very overweight are sometimes hard to help (Participant 5, area 2, PN)

Again, some participants elaborated further on the issue by saying that people speak an array of languages within the community:

If English is not their first language that sometimes can be a barrier and there are lots of different people speaking other languages (Participant 3, area 2, PN)

Also, there was a major shift in the immigration law within the country due to the Nations membership of the European Union and this appears to have introduced another dimension to the diverse nature of the patients:

Language is a barrier, for example, we have a lot of EU people, too many dialects (Participant 7, area 3, PN)

This theme provided some evidence to support the view that personal difficulties such as employment, education, childcare problems and language difficulties sometimes make it impossible for certain patients to attend the session. An individual is unique and our circumstances are also different from time to time, therefore, this theme showed that one of the reasons for non-attendance could be personal dispositions and a complete lack of interest in the education programme. Another reason for non-attendance identified by this study is the problem of either forgetting the details of the appointment such as the time and date or completely forgetting that they had an appointment at all.

6.5. Perceptions and attitudes of patients to diabetes education

Empowerment means equipping the patients with adequate knowledge and skills to manage themselves (Anderson and Funnell, 2009), hence, being passive about taking control of their diabetes care undermine the principles of empowerment. The patients' perceptions and beliefs were seen as part of the barriers and this may either be their perception towards self-care management

as a whole or towards the medical condition. The patients' perceptions of diabetes were mentioned by some practitioners:

It's a huge shock to be told you are a diabetic as there are all sorts of myths that go round about diabetes, you know like how you're going to go blind and you will lose your legs those sort of things so they need to understand why they have got to learn about it (Participant 1, area 1, PN)

This psychological impact of the diagnosis is compounded with their view about whether it can be cured:

a lot of my patients say to me oh my mother died of diabetes so they have a lot of maybe wrong ideas about how diabetes can be treated, or maybe they don't even know it can be treated (Participant 1, area 1, PN)

Similar to phase 1 findings, the anxiety created by the sudden diagnosis of diabetes could lead to a form of denial:

Some of my patients will say they are borderline; therefore, they don't put enough effort (Participant 7, area 3, PN)

Anderson and Funnell (2009) stated that internal motivation is more effective in promoting adherence to treatment in comparison to external motivation. Health behaviours are influenced by individual perceptions and beliefs about the role of the physician in managing their medical condition. A participant stated that patients may abstain because:

Some may believe that God brought the disease and the GP has nothing to do with it (Participant 4, area 1, GP)

Also, diabetes is an insidious disease; therefore, they don't feel sick at this stage:

And they say to us well I don't feel ill... I haven't got diabetes as I don't feel ill. (Participant 2, area 1, PN).

Similarly to the findings of Phases 1 and 2, some participants stated that the socio-cultural background of the patients does influence their perceptions and consequently their healthcare decisions:

Yes the health beliefs can be quite different, can't they and I think some people can put their trust in herbal things like if I chew this particular leaf then my diabetes will go away and I don't know what they are chewing. We have a guy who has a long history of diabetes from Northern India and he is convinced that chewing this leaf his mother gave him is going to take away his diabetes and he's probably getting the hang of it now after about eight years (Participant 5, area 2, PN)

Regardless of the benefits of self-care management of long-term conditions in promoting the wellbeing of people (DH 2002; Hughes 2004), perceptions of patients about taking responsibility for their health and perceiving the education as beneficial were given as reasons for non-attendance by some participants as well. The practitioners stated that the patients' perceptions and attitudes towards curative care are different from preventive care:

We don't have that mind set yet that this is preventive care, what they are going for when they've got their appointment with a Consultant is therapy – in this case they are sometimes in a very bad state of health. For the education, they don't feel any different at this stage (Participant 2, area 1, PN)

To support this view, a participant stated:

With gestational diabetes, the attendance is significantly Different and the process is the same (Participant 4 area 1 GP)

Also, some people might have a negative view about any form of education which could stem up from their previous life experiences:

I suppose you know you go to something if you think there is value in it if there is something in it for you and if you think you are not going to get anything from it you don't go. I suspect some people have very negative experience of any sort of class and may have had a bad time at school and didn't engage at school or didn't like school or don't like the whole idea of being taught in a class and so if they hear that this is a class you know and then to come here it might just make them turn off (Participant 6, area 2, PN)

Again some patients have the opinion that it is the responsibility of the healthcare practitioners to care for them. This view was also verbalized by the participants in Phase 1 of the current study.

It's a sort of side line because they don't see the importance of looking after themselves (Participant 1, area 1, PN)

Group education is seen as a method to deliver diabetes health education for newly diagnosed patients, however, individual preferences differ. Some participants acknowledged that their reason for non- attendance might be due to the fact that it was a group session:

And they think oh that's too far and I may not feel comfortable mixing with other people and may not understand what they are saying. (Participant 3, area 1, PN)

In support of Phase 1 findings on individual preferences for a particular method of education, it was stated that some patients are private people:

Some people I think don't like being in groups they feel that their condition is private and they don't want to discuss it with other people (Participant 7, area 2, PN)

Although, the data suggested that some patients either preferred or disliked group education, there is no evidence to support negative effects of group learning on self-care management (Duke 2009; Tang 2006). However, some participants expressed that some patients might have a liking for group education by saying:

I found the elderly patients are more compliant. For example, if they live alone, it gets them out of the house to meet other people and they may enjoy the programme (Participant 8, area 3, PN)

Motivation was seen as a key factor in attendance and the practitioners viewed that some patients are not well motivated. The perceptions and beliefs about the importance of diabetes education could undermine their motivation for attendance and this issue was represented thus:

Generally, some patients don't see it as part and parcel of their diabetes management (Participant 6, area 2, PN).

Whilst, some patients might think they know enough about diabetes:

He said he knew more... than they could teach him (Participant 1, area 1, PN)

Conversely, some patients may decide to learn about the disease on their own. According to DH (2004), individuals obtain health information from various

sources, such as friends, family, advertisements and the media. This is because, these sources of information are easily accessible and they do not have to set a specific time aside to attend a session or travel to the education centre. Hence, this group of patients who are confident in other sources of information may not consider the value of attending the education session. As a result of this data, providing further information to sign-post the superiority of structured patient education may be helpful in overcoming this barrier. Furthermore, a questionnaire survey by Gucciardi et al (2006) identified a wide variety of sources of information used by diabetes patients as physicians, diabetes educators, magazines, newspapers, books or television:

They go and actually research the information themselves they may feel that they don't actually need an education programme (Participant 9, area 3, PN)

However, unstructured self-managed education has its shortcoming:

Some also think they can get information from friends, family and internet. They even go to American Diabetes association website and Canadian Diabetes association website without checking or thinking that their approaches might be different from us (Participant 6, area 2, PN)

Also, the issue of freedom of choice may affect their motivation to engage with the service:

Again, there is an issue with I have got a choice, I know what I am doing; they think they know everything and don't really think about the decisions they are making. (Participant 7, area 3, PN)

Non-attendance is influenced by several factors, and this study suggested a poor balance between the patients' rights and responsibilities. The perceptions and

beliefs about the nature of diabetes and their responsibilities for self-care appear to impact on their motivation for attendance:

Because he was trying to feel that it was out of his hands
(Participant 9, area 3, PN).

The patients that are internally motivated attended the session because they possessed the will power to seek further knowledge of self-management and belief in preventive measures. Regardless of their reason for lack of motivation, the patient that does not believe in self-care could be more difficult to engage in the process:

It's a bit tricky to motivate somebody who doesn't belief in
taking responsibility for his/her health (Participant 1, area 1,
PN).

However, the level of motivation varies across patients with different social status and education and wealth may influence attendance:

I found the more educated and the more affluent are quite
keen and ask you what is this education and yes I want to
be referred and generally what you find with diabetics, they
just want to get along with life (Participant 9, area 3, PN)

This section revealed that some patients may not attend the education sessions because of their personal perception and belief about the nature of diabetes, the level of diabetes knowledge they possessed or believed that they could gain sufficient information by searching the web or through family discussions. In addition to these personal beliefs, some patients may not be interested in the teaching sessions because they could not see how it may enhance their self-management knowledge and skills. The data showed that group education may

constitute a barrier for a number of patients. Also, these different perceptions and beliefs may impact on their motivation to engage with the service.

6.6. Strategies to promote attendance

The participants view on ways to promote attendance was sought. On the whole, there are several barriers identified; therefore, interventions need to be diverse. Regarding this, some participants viewed that flexible delivery, improving staffing level and staff training could help. In regard to location, nearness was perceived to be a key factor and this was verbalised thus:

If the education was near to the patient and at a time they could go because a lot of the patients work so they can't really go in the daytime (Participant 1, area 1, PN)

To get round the barrier relating to distance, some participants supported the view to introduce a practice-based education session:

You know if the education is here whether other practices in my locality would come here rather than go up to the main hospital or go to a very far community centre (Participant 2, area 1, PN)

Likewise, some participants thought that offering the education at the GP surgery could encourage patients to attend because they would meet familiar people:

I'm sure they would come because they are already familiar with the GP surgery and then seeing an old faces. They can see the nurse that they are used to and they would know (Participant 1, area 1, PN)

However, this may have some resource implications:

I wish we could do it here but we don't have enough rooms at the moment because the Walk-in Centre takes up a lot of space (Participant 1 area 1, PN)

In terms of time, some participants stated that varied time and accessible locations may help to curb non-attendance which is due to their working schedule or other life commitments:

I think putting it at convenient times, so have evening sessions maybe a Saturday morning session, in places that are accessible and close to public transport systems and not off the railway station and not too far from the patients' homes (Participant 6 area 2, PN) and

They may need to do more sessions in the summer holiday (Participant 4, area 1, GP)

Another strategy proposed by the participants in Phase 3 is similar to Phase 1 results and this relate to flexibility of delivery:

I think it'll be far better off putting energy into developing programmes that people could either do online, interactively, have some sort of helpline available, developing GP practices to deliver more personalised care i.e. more time perhaps talking about nurses holding small group sessions in various practices (Participant 5, area 2, PN)

Due to the barriers associated with lack of time, some participants also suggested enhanced staffing level as part of the solution:

Staffing of course if there were twice as many nurses doing the job that would be fine (Participant 5, area 2, PN)

Increase staffing level might lead to increase time that is available for the practitioners to attend to the patients. The importance of offering adequate information was mentioned by all the participants:

We need to make sure and try to explain and make it as easy as possible to access it (Participant 8, area 3)

It is considered that professional development is necessary for personal, professional and clinical advancement and this need to cover all levels of staff within the National Health Service involved in the implementation of the policy. Sully and Dallas (2010) advocate for regular training of practitioners to ensure effective professional-patient communication. In a similar way, some participants suggested personal developmental training for the practitioners as a way to enhance attendance through improved knowledge of the whole procedure. In contrast to the findings collected from the practice nurses that GPs don't usually fund training:

Appropriate training is funded from time to time on the basis of need and equity (Participant 4, area 1, GP)

Some practitioners also thought that additional publicity is required to motivate attendance:

Making sure there is funding and adequate advertising of the service and to make sure the service is resourced to have adequate time to go through what it is, offering it at different times and different places (Participant 9 area 3, PN)

On the issue of government assistance, some participants stated that the Government could further help by facilitating patients release from work to attend the sessions:

I think the government needs to make some reimbursement to their place of work (Participant 7 area 3, PN)

And a participant likened it to the process of undertaking the jury service:

I mean something similar to the jury service; the employer is legally bounded to release them from work (Participant 7 area 3, PN)

In contrast to strategies relating to the individual, organisation and the Government, a participant identified the role of external agency in supporting the delivery of the programme:

The big industries or companies could also help with education, instead of just sending different types of glucose meters all the time, they could help with things like translation of pamphlets to other languages because we are curtailed with finances (Participant 7 area 3, PN).

There is an indication that enhanced inter-professional working could aid attendance as some of the responses suggested a fragile relationship between the referring practitioners and the practitioners delivering the education:

The people that organise the programme need to get that information out because as far as I'm aware it's unknown so that information is not good and if that information isn't coming out to me I can't give it to the patient (Participant 2 area 1, PN)

Also, some participants suggested that the education providers should further publicise the programme with little or no ownership of the situation which suggests a fragile inter-professional relationship:

I think if they are running the course then they should design the leaflet because they know what they are advertising and I don't know what they are advertising exactly (Participant 6 area 2, PN)

Some participants suggested prompt patient contact to sustain patients' interest:

I think something like a welcoming letter or a phone call from the person leading the class before they come which I think would motivate people and they would think oh they are expecting me and somebody is concerned that I am coming if there is a sense that really someone is going to notice if I turn up or not obviously they are more likely to attend (Participant 6 area 2, PN)

Again, early educational intervention was seen as part of the solution:

We should be going into the schools and do it before people come to that stage if we could pick out and educate children better in schools and also things like women who get gestational diabetes in pregnancy if we could send them off to classes (Participant 6 area 2, PN)

This section identified some strategies such as flexible delivery, additional human and material resources and inter-professional collaboration to enhance attendance. Some participants suggested flexible delivery of education in terms of time, location and mode of delivery as possible solutions to overcome some of these barriers. The timing of the session seems to be sometimes linked with work and education related barriers, therefore, offering it at different times could help. In a similar way, some participants viewed that additional resources could help because some patients might be encouraged to attend if the practitioners offers additional advertising and devoted more time to explain the benefits of the sessions to the patients. The participants also stated that enhanced collaborative work might aid attendance as this could reduce some of the organisational glitches.

6.7. Discussion of findings

The government regulations and guidance are crucial to the delivery of healthcare (DH 2002); however, Moore (2012) argued that one of the criticisms why the National Health Service has run into present difficulty is because the NHS managers have focused on meeting government targets and balancing their books instead of ensuring that patients' needs are met. In a similar way, the findings of Phases 1 and 3 of this research showed that the desire to meet government targets shapes the attitudes of the practitioners toward the patients and this appears to be a contributory factor to the tension among the practitioners and invariably it impacted on attendance.

The government white paper titled 'Reducing regulation made simple: less regulation, better regulation and regulation as a last resort (HM Government 2010) acknowledged the need to strike a balance in the regulatory system in order to eliminate the avoidable burdens of regulation and bureaucracy. The recent Francis (2013) report of the Mid Staffordshire NHS Foundation Trust Public Inquiry also identified the culture of focusing on finance and targets to the detriment of patient care. Thus, the regulatory challenges need to be jointly addressed by the practitioners. Shaw (2007) states that the current healthcare system where funding is based on results and targets poses a challenge to the healthcare practitioners. This concurs with the findings of Gallagher et al (2014) which concluded that QOF points has impacted on the management of newly diagnosed people with diabetes. It may be argued that the practitioners' desire to

achieve government targets overrides the importance of meeting patients' needs and this require reappraisal and training to make a good balance between the two important concepts.

All 3 Phases of this research identified the impact of organisational protocols on attendance. These are the timing of the session, location, access to information, method of delivery and self-management education resources. These barriers have also been found by other research studies (Graber 1992; Gucciardi 2008). Hence, effort should be targeted to address the organisation of education and delivery of the session. Paul and Penson (2008) argue that services are seldom set up to deal with health problems but not necessarily considering the strengths, competence and resources of patients and their circumstances. Stiles (2011) suggested that it is better to simplify the processes and procedures. Thus, encouraging and facilitating a simple two-way process for communication and enabling flexibility in delivery of the education may help. The focus of primary care is to provide close healthcare services within the patient's environment (DH 2009) in order to respond to socio-economic, epidemiological and demographic changes. In the same way, the findings of this study showed that delivering the session in the local environment may improve attendance.

The findings of this study have highlighted a poor referral process and weak inter-professional relationships between the GP surgeries and the education centres. In order to bridge the gap between invitation and attendance, effective collaboration between the referring practitioners and those that are delivering the education sessions is necessary to address the problem of poor communication. The educators need to work more closely with the practice nurses in the surgeries to produce guidance on effective referral to minimise poor communication of important information. It may also be helpful to organise a multi-professional workshop that will explore best practice that will reduce barriers associated with attendance. Oandasan and Reeves (2005) and Day (2007) affirm that health and social care professionals need to maintain a good balance of collaborative and autonomous practice to provide a high quality of care to patients entrusted to them.

Every human being is unique; hence, individual circumstances are different and subject to change. In addition to Phase 1 and 2 findings, this Phase 3 study demonstrates that personal circumstances such as child care, illness, personal crisis, and forgetfulness also contributed to non-attendance. Other personal reasons identified for non-attendance were work commitments, studies, language problem or preference for one-to-one education. This indicates that the patients may not be able to control some of these barriers on some occasions. Previous studies have also noted the impact of these personal circumstances on attendance at Diabetes Education Centre (Schafer 2013; Temple and Epp 2009).

A key solution is enhanced communication, for example, making follow-up contacts of non-attenders as soon as possible to explore the best possible option to aid attendance. Evidence suggests that language barriers could constitute a communication barrier and communication needs differ from one patient to another. Therefore, it is important for practitioners to consider the language differences, age and cultural differences of the patient (Leever 2011; Mughal 2010) during referral and invitation. The standard 3 of the National Service Framework for diabetes (DH 2001) and NICE (2009) advocated partnership working and collaborative decision making between patients and the professionals in order to improve clinical outcomes.

Apart from the physiological impact of long-term condition, the challenges of living with a long-term condition lead to anxiety and tension and this requires adaptive behaviour. This can be compounded by patients' perceptions and beliefs about diabetes as a disease, self-care management and education itself. According to Shaw (2007), individual patients are different, while some will find it difficult to face reality, some will accept that the disease is incurable and seek on-going support. However, some patients often resort to negative attitudes or responses. Nute (2004) described a form of fear which may prevent patients from attending the education clinic as 'ostrich mentality', for example, fear of prolonged self-monitoring of blood glucose levels. There is evidence to suggest that patients face grief when confronted with any kind of loss of health (Alexander et al 2006) and this appears to be true with patients affected by diabetes as well.

Therefore, the practitioners need to show understanding and support the patients that are exhibiting negative responses.

6.8. SUMMARY

This Chapter has fulfilled its aim of identifying the barriers and enhancing factors to attendance. The findings yielded four key themes: organisational issues, personal circumstances of the patient, perceptions and attitudes of the patients and strategies to overcome the barriers. The participants in Phase 3 identified personal difficulties due to various reasons such as work-related issues, childcare problems, lack of interest, and inconvenient date, location and time of the session. Other barriers are some organisational issues such as poor working practices, staffing issue and limited resources. The pressure of time and the drive to meet government target seems to play a significant role in the referral process. In terms of strategies to overcome these barriers, having some degree of flexibility in the delivery of the session such as offering it at different times and location might help. The findings of the final Phase of this study identified that certain group of patients appeared not to be interested in the session at all and this set of patients may probably need a completely different method of delivery such as providing a teaching pack or on-line resources for them. The findings from this Phase of the study are similar to Phases 1 and 2 results in some respect and therefore suggest a form of triangulation as shown in the next

Chapter. This report of the final Phase of the study will be followed by a discussion of findings of all the three Phases of this study.

CHAPTER 7

ANALYSIS OF BARRIERS ASSOCIATED WITH UPTAKE OF DIABETES EDUCATION AND STRATEGIES TO OVERCOME THE BARRIERS

7.1. Introduction

In this Chapter, the various strands of this study will be drawn together, the empirical findings will be summarised relating these to the relevant aspects of the literature review. Therefore, this section will integrate and synthesise all the data and present the key issues emerging. The features of the research process for the Phases of the study are summarized and displayed in a table format, following the Critical Appraisal Skills Programme (CASP) tool (Public Health Research Unit 2008), to triangulate the data, aid consistency and the rigour of analysis. Thereafter, this Chapter will present an in-depth analysis and evaluation of all the Phases of the study that were undertaken on the phenomenon of barriers associated with structured education for patients affected by diabetes. These barriers will be organised under three broad themes: that is barriers related to patients, practitioners and the government. Thereafter, the barriers will be discussed under 5 key concepts and the Health Belief Model (Becker et al 1978) will be used to analyse relevant aspects of the findings.

7.1.2. Summary of the study

The summary of the study (Table 7.1) shows a brief overview of the results presented in Chapters 4, 5 and 6. It covers the 3 distinct Phases to address the 3 research questions of the study from the perspective of educators, patients and

referring practitioners; it shows the sample sizes and data collection methods used. Finally, the table shows the analytical techniques used in each Phase coupled with the key emerging findings from the research. The findings of the three Phases of the study revealed a diverse range of influences that may either hinder or enhance attendance at the education centres.

Table 7.1: Summary of the Phases of study

A grid of the Phases of study						
Phases	Type of data	Objectives of the Phase	Sample size	Data collection methods	Analysis	Key factors
Phase 1	Qualitative	To explore professionals' views about barriers associated with non-attendance and explore ways to aid attendance from the perspectives of diabetes educators	Ten Practitioners (5 Diabetes Specialist Nurses, 3 Dieticians and 2 Podiatrists)	Focus group and Unstructured individual face-to-face Interviews	Thematic	Five themes emerged: (Table 4.1; page 112) - 1. Perceptions and attitudes of practitioners to diabetes education 2. Perceptions and beliefs of patients about their health and the benefits of education 3. Personal circumstances 4. Official protocols and self-management education resources 5. Strategies to improve attendance
Phase 2	Mixed methods	To investigate patients' views about barriers and facilitators to attendance in multi-disciplinary Diabetes Education Centres	207 patients (105 non-attenders & 102 attenders)	Questionnaire	Descriptive statistics, cross-tabulations, Chi-square, t-test and Logistic Regression	Five themes emerged : (Chapter 5) - 1. Health beliefs and attendance behaviour 2. Organisation of care 3. Attitude of practitioners. 4. Motivation 5. Personal circumstances 6. Strategies to improve attendance.
Phase 3	Qualitative	To explore the barriers and enabling factors to attendance from the perspectives of referring practitioners and further explore the previous findings and the influence of current NHS reform and organisation	9 practitioners (8 practice nurses and 1 GP)	Face-to-face interviews	Thematic	Four themes emerged: (Table 6.1; page 217) 1. Organisation of care. 2. Personal circumstances of the patient 3. Perceptions and attitudes of patients and 4. Strategies to aid attendance.

7.2. Motivation and barriers associated with attendance

Self-care management is the process by which the patient takes control of their own care (DH 2005). Therefore, a long-term condition such as diabetes requires a self-care management approach. Hughes (2004) argues that the self-care model of nursing is not a new concept, for example, the Orem (1980) self-care model which placed emphasis on patient's autonomy. However, several self-acquired abilities and external attributes such as values and beliefs, availability of personalised choice and self-care support provided by practitioners have an impact on individual's self-care performance (DH 2005). These factors may either hinder or motivate attendance at Diabetes Education Centres.

Based on the findings of all the Phases discussed in Chapters 4, 5 and 6 of this thesis, the barriers that emerged from the study were organised into 'Patient related barriers', 'Practitioner related barriers' and 'Barriers related to Government Regulations'. As shown in table 7.2, there was some overlap between the quantitative and qualitative findings. The Patient related barriers are perceptions, beliefs and attitudes of patients and personal circumstances that have been identified as a contributory factor to non-attendance. The Practitioner related barriers are due to reasons such as poor information delivery, inappropriate referral, rigid appointment systems and administrative errors. Added to these official practices that have been found to constitute a barrier to attendance are the attitudes of practitioners coupled with poor patient/practitioner communication and inter-professional relationships. The last theme for organising the data involved barriers associated with Government such as limited

funding and government regulations that have an impact on attendance. Some of these barriers have also been shown to influence attendance by other studies (Schafer et al 2013; Temple and Epp 2009).

Table 7.2: Summary of findings associated with barriers

Emergent findings – types of barriers	Study 1	Study 2	Study 3
Barriers related to patients			
Personal circumstances	√	√	√
Health beliefs and attendance behaviour	√	√	√
Motivation	√	√	√
Barriers related to practitioners			
Perceptions and attitudes of practitioners to diabetes education	√	√	√
Official protocols and self-management education resources	√		√
Barriers related to the Government			
Organisation of care	√	√	√
Official protocols and self-management education resources	√		√

Key: √ = Represents the participants view in relation to barriers

7.3. Analysis and evaluation of the study

This section will discuss the demographical findings and conceptualise the barriers under five headings. Having discussed all these barriers in chapters 4 - 6, the three broad barriers that captured the whole findings will be discussed under the following five key concepts namely: health-care beliefs, patient-centred care, communication, trans-cultural care management and bureaucracy (Table 7.3) and the strategies to overcome the barriers will be incorporated into the discussion. There is some overlap in the concept with some concepts lending themselves to more than one of the categories of barrier as shown in the table depicting the conceptual framework below (Table 7.3). The healthcare belief correlate with patient related barriers only while patient-centred care and communication covered all the two broad barriers: patient and practitioner related barriers. The concept of transcultural care relates to practitioners related barriers. The final concept of bureaucracy covered both practitioner and government related barriers.

Figure 7.3: Conceptual Framework for Barriers to attendance

Types of barrier	Health-care beliefs	Patient-centred care	Communication	Trans-cultural care management	Bureaucracy
Patients related barriers	√	√	√		
Practitioners related barriers		√	√	√	√
Government related barriers					√

7.4. Socio-demographic characteristics

The sample included both male and female participants who were mostly middle aged and from different ethnic backgrounds. Overall, there were similarities in age and gender with variations in living arrangements, ethnicity, employment and family history of diabetes. These findings are consistent with the results of several other similar studies. The current findings are consistent with Gaber et al (1992), Benoit et al (2004), Stead et al (2005) and Schafer (2013) studies which found that gender and age were not significant predictors of attendance. The finding of this current study is consistent with Rhee et al (2005) who found that older age is associated with non-attendance. The finding is also compatible with Hsu (2001) who found that living alone was associated with a low uptake but found no association between attendance and age. Although, there were more white participants from the attenders group in the current study, ethnicity did not add significantly to the regression model. In contrast, Benoit et al (2004) found ethnicity was a predictor in their study, however, the variable lost its significance after controlling for other factors.

The findings of the current research also suggest that whilst communication and learning needs could be a barrier to attendance, most of the participants have other reasons for non-attendance, such as work commitments and other personal difficulties such as bereavement. In this current study, reading difficulties was not identified as a barrier and this is consistent with Schafer (2013). This contradicts Rhee et al (2005) result which revealed that inability to read well was an obstacle to attendance; although, the study was done in a

different country. However, Phase 3 of the current study found that educated and affluent people are more engaging with the programme: *“I found the more educated and more affluent are more keen and ask you what is this education --- they just want to get along with life”* (Participant 9, area 3, PN).

For the purpose of this study, logistic regression was used to examine the predictive characteristics of key demographic variables on attendance and the model suggested that living arrangements, lack of work place flexibility and family history of diabetes can be used to predict non-attendance. This suggests that increasing the attendance rate at the Diabetes Education Centre requires understanding of the influence of these key demographical and social factors. However, the implications of this result should be interpreted within the context of the limitations of the study which are discussed in Chapter 3.

Patient related barriers

According to this study, some factors that hindered attendance are related to the patients and the key findings on this theme will be discussed under two concepts: healthcare beliefs and patient-centred approach.

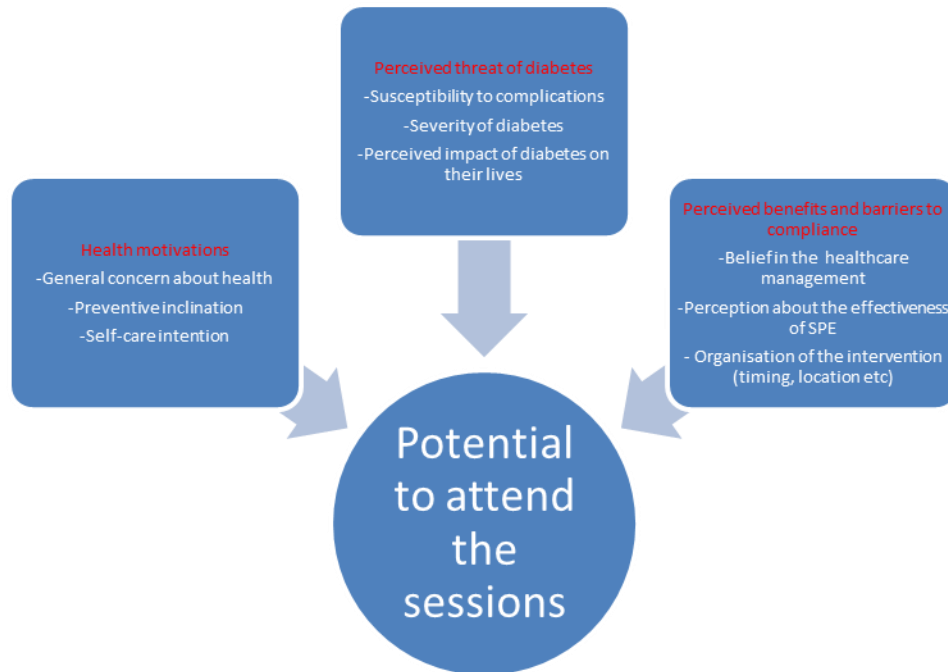
7.5. Healthcare belief

There is documentary evidence to suggest that individual behaviour to health, illness and treatment is influenced by opinions, perceptions and beliefs (Naidoo

and Willis 2000; Upton 2010; Rana and Upton 2009). Although patient self-care behaviours have an impact on diabetes management, the extent to which patients follow advice regarding self-care behaviour is influenced by individual personal beliefs (Harvey and Lawson 2009). There are different health beliefs and behaviour models developed to aid the understanding of the reasons that prompt unhealthy lifestyles. Thus, the following discussion is informed by a well-known health belief theory, the HBM (Becker et al 1978) which has been previously discussed in Chapter 2, pages 48 - 53.

In trying to view the differences in reaction of people to specific health interventions, Becker et al (1978) used a theory of Health Belief Model to predict behaviours related to adherence. The model is based on three broad assumptions which all contribute to an individual's reaction to health related interventions (Upton 2010). The HBM includes three broad assumptions: perceived threat of the disease, perceived effectiveness of a health behaviour and health motivation (Becker et al 1978; Mirotnik et al 1998). In applying the three assumptions of the theory to this study, compliance may require modification of certain beliefs held by the patient as shown in figure 7.1 and exemplified by the ensuing discussion.

Figure 7.1: Hypothesised model for explaining compliance in structured patient education programmes



Adapted from Becker et al (1978).

7.5.1. Perceived threat of the disease

The first assumption relates to the perceived susceptibility and perceived severity of the disease. The first part of the assumption underpinning the HBM presents a conceptual gap in relation to this study; nevertheless, the assumption is applicable to the findings. Although, the patients are no longer susceptible to the illness because they have already been diagnosed with the medical condition, they are susceptible to diabetes related complications if it is not well managed. The second aspect of the assumption underpinning the HBM is severity of the illness. Both the practitioners' and patients' responses showed that perceptions

of the level of the severity of diabetes constituted a barrier to attendance at an education session. This finding is consistent with HSU (2001) which found perceived seriousness and susceptibility to disease as a factor influencing utilisation of healthcare. In relating the first two assumptions of HBM to the data collected by this study, the patients with diabetes who failed to attend the sessions may think that they are less susceptible to diabetes complications because they have mild diabetes. In terms of severity of the illness, they may think that there is no need to acquire self-management knowledge and skills because they have less severe diabetes. This finding is consistent with Graziani et al (1999) findings.

7.5.2. Perceived benefits and barrier to compliance

As indicated by the Health Belief Model, this assumption relates to the patient's faith in the care management and its structural barriers in terms of location, time of the session, method of delivery etc. This finding is consistent with Charron-Prochownik et al (1993) who found that adherence was associated with perception to severity and barriers to treatment. Although it is undeniable that continuous diabetes education programmes help to increase patient's knowledge and skills with early detection of complications (Bruce et al 2007; International Diabetes Federation 2007), nevertheless, the findings from both the practitioners' and patients' have identified the perceptions about the benefits of the session as a barrier to attendance. A large number of patients who are diagnosed with

diabetes are asymptomatic (Brown 2012; Bailey and Feher 2009) and this group of patients may not be able to appreciate the benefits of the session and the insidious nature of diabetes may affect their motivation to change.

7.5.3. General Health Motivation

The final assumption of HBM is perceptions and beliefs relating to patient health and preventive actions. According to Reece and Walker (2007), learning should lead to a change in behaviour. Unlike other student's learning experiences, patients do not undergo assessment through examination; however, some factors do motivate them or hinder their motivation to learn about their medical condition. Maclean et al (2002) and Carlson (1997) state that motivation is an important factor to predict treatment outcomes for the patient. Anderson and Funnell (2009) argue that internal motivation is more beneficial in ensuring compliance to health intervention in comparison to external motivation. The findings of the questionnaire survey revealed that attenders are internally motivated and therefore are more inclined to believe in self-care management and strive to learn more about diabetes. This finding is similar to those of Mirotznik et al (1998) which showed that general health motivation and perceived severity were associated with intention to keep appointments amongst patients with chronic disease. This is also congruent with Becker, Drachman and Kirscht (1974) who found that interest in personal health, illness episode, a confidence in the system and satisfactory interactions were an aid to compliance.

The findings of the current study is supportive to those of Graziani et al (1999) who found that inhibitory health beliefs are associated with non-attendance. This current study also found the impact of family history and culturally health linked beliefs such as eating certain herbs to manage their diabetes: *'Yes the health beliefs can be quite different, can't they and I think some people can put their trust in herbal things'* (Participant 5 Area 2, PN). This concur with Maillet, Melkus and Spollet (1996) findings which suggest provision of culturally sensitive and appropriate education to patients due to issues relating to culturally linked healthcare beliefs. Compatible with the current study, Becker et al (1997) found that health motives, threat of the disease and benefit of the health action account for substantial variance in measuring compliance and adherence to appointments. This finding is also similar to the results reported by Gucciardi et al (2008) and Sprague et al (1999) who found low perceived seriousness of diabetes and lack of understanding as a barrier respectively. As anticipated, the finding is compatible with the results of a recent study (Bayat et al 2013) which showed an increase in the mean scores of perceived susceptibility, perceived severity and perceived benefits after the implementation of an educational programme on the experimental group.

Thematic analysis of the data collected from Phases 1 and 3 of the current research revealed the issue of perceived severity, perceived benefits and health motivation in relation to attendance. The multiple item scale denoting 'patients' attitude towards diabetes education' constructed from the questionnaire survey in

Phase 2 indicated that attenders reported a more positive belief about the seriousness of diabetes, importance of the session and belief about self-care in comparison to non-attenders. Therefore, when exploring attitudes of patients towards attendance, one cannot ignore the influence of individual perceptions and beliefs. Overall, this finding is consistent with the original hypothesis that a relationship exists between these three constructs and attendance (Chapter 3 page 84).

As shown above, the findings are congruent with the findings of other several prior studies (e.g. Becker et al 1997; Mirotznik et al 1998; Sprague et al 1999; Hsu 2001; Bayat et al 2013). Thus, the finding suggests the usefulness of the theoretical underpinning and complements a growing body of evidence supporting HBM as a framework to understand barriers to attendance at Diabetes Education Centres. People with diabetes are a heterogeneous group and vary in terms of their intellect, culture, psychosocial and other domains (American Association of Diabetes Educators 2007); therefore, practitioners need to recognise the beliefs and diversity of patients in implementing the educational policy and developing strategies to overcome these barriers to ensure attendance.

7.6. Patient-centred Care

Patient-centred care refers to holistic and individualised care that fosters empowerment and embrace treating patients with respect and dignity (Leplege et

al 2007). According to McCormack and McCance (2010), holistic care covers care that meets the patient's physical, social, emotional, or spiritual needs. It also involves dealing with individual response to illness and the effects of diseases on the person's ability to manage their condition (McCormack and McCance 2010). Therefore, the impact of diseases and other variables that may affect self-care management need to be considered in offering a patient-centred care. The provision of patient-centred care is a key aspect of national and social care policy in the UK (Abley 2012).

However, this study suggests that individual personal difficulties may impact on provision of patient-centred care. The personal difficulties that were identified by the data include child care problems, working commitments, education, illness, away on holiday, forgetfulness and personal crisis. In order for the professionals to support the patient in a patient-centred way, child care issues need to be considered. Although, most of the patients are above 40 years of age, there is no rigid child bearing age and some patients have responsibility for caring for their children or grandchildren. This data alongside other studies (e.g. Zailinawati et al 2006, Dyer et al 1998) has shown that patients with young children and those that are caring for their grandchildren may have some difficulty in attending the session.

According to the concept of patient-centred care, professionals need to work alongside patients by establishing a therapeutic relationship (Maley et al 2011) to understand why they failed to attend the sessions. Another barrier to attendance found by this study is sickness and this is similar to the findings of other studies

such as Zailinawati et al (2006), Hamilton et al (2002) and Stone et al (1999). Hence, being ill with other minor or serious illness may coincide with the appointment and therefore prevent some patients from attending the sessions. It could be argued that there is lack of adequate recognition of the impact of other illness on attendance in diabetes centres. Therefore, it can be suggested that regardless of the clinic, the patient may not be able to attend a booked hospital appointment due to ill-health. Although this barrier has been identified by other studies, nevertheless, it is expected that the patients could ring to book another appointment. In order to embrace a patient-centred approach, it may be necessary for practitioners to work with the patient to explore the reasons for non-attendance and offer another convenient appointment at the earliest opportunity.

Manley et al (2011) and Ruddick (2010) state that patient-centred care embrace assessing a patient's lifestyle and support networks. It is essential to consider patients working pattern and the level of support that individuals could get from their friends, families and significant other people. A personal problem that impacted on attendance was the working patterns of the patient. The questionnaire survey results (Table 5.2) showed that more attenders have flexible work commitments and comparison between the two groups showed a significant difference ($p < 0.05$). Ngwenya et al (2009) and Zailinawati et al (2006), Hamilton et al (2002) and Stone et al (1999) have also identified a link between working patterns and attendance. Therefore, the practitioners need to consider the impact of working pattern in planning the session in order to deliver a patient-

centred care approach that will consider the social and economic needs of the patient.

Patient-centred care covers involvement of patients in decision making and considering their choices and preferences (Ruddick 2010). According to the data collected in Phase 1 of this study, some patients keep their diabetes as a secret from their employer and may not be willing to take permission from work. To offer patient-centred care, the practitioners need to value the opinion of patients and allow them to decide whether they want to declare their diabetes to others or keep it as a secret. Gucciardi et al (2009) found that work-related problems contributed to non-attendance among patients affected by diabetes. This finding suggests that patients that are in full time employment or shift workers may find it more difficult to attend the session. It is also important to acknowledge that some patients with diabetes that are working will also have child care responsibilities, hence, being a worker and having children may make it extremely difficult for some patients that fall into this category.

The concept of patient-centred care involves putting the patient at the centre of care and working with the patient to plan for their own care. It involves autonomy and offering choices to the patient (McCormack and McCance 2010). The non-attenders and practitioners indicated that being on holiday prevented some patients from attending the sessions as this was not recognised in the appointment system. Regardless of this finding, the patients are autonomous individuals and they are free to go on holiday when they wish. In a similar way, Ngwenya et al (2009) and Frankel et al (1989) studies found that been away on

holiday was a factor associated with non-attendance. Whilst it may not be possible for the practitioners to fully take this barrier into account, this suggests that the patients have got some degree of responsibility to change their appointment. Also, the practitioners and patients may need to jointly plan another acceptable appointment.

The data from non-attenders in this current study demonstrated that bad weather was identified as a barrier to attendance in diabetes clinics. Also some excerpts from the non-attenders in this study showed that snow fall prevented them from attending the session. This finding is consistent with other studies such as Ngwenya et al (2009) and Stone et al (1999). This suggests that unpredictable natural occurrences might have prevented some of the referred patients from attending the sessions. Although, this is beyond the control of both parties, nevertheless, a system to reschedule the appointment needs to be put in place in order to embrace the principles of patient-centred care.

Appreciating the uniqueness of individuals with different perceptions, expectations and experiences is crucial to patient-centred care approach (Abley 2012). The individual patient is unique and may have other medical conditions such as depression, denial and Alzheimer which may predispose them to forgetfulness. This finding has been found to constitute a barrier to attendance among diabetes patients by various other studies like Masding et al (2010), Hill-Briggs et al (2005) and Stone et al (1999). It may be argued that the psychological problems associated with the diagnosis of a long-term condition like type 2 diabetes could contribute to forgetfulness. Again, type 2 diabetes is

more common in older people. The rate of dementing illness such as Alzheimer increases with age (Dementia UK 2012), and dementia causes loss of memory, mood changes and problems with reasoning (Jolley 2009). Some patients have additional diagnosis of diminished mental capacity which may contribute to forgetfulness as confirmed by a non-attender who stated that: '*I have Alzheimer*' (Participant NA 43, area B). In all, forgetting the details of the appointment is an explanation for non-attendance and requires a strategy such as follow-up telephone call to overcome this barrier. Phase 2 of the study also revealed that living alone is a predictor of non-attendance, therefore, it is important for the practitioners to remind those who live alone because there may be no other person to prompt them.

Finally, a personal crisis such as bereavement may affect attendance as shown by this research. Ngwenya et al (2009) also found that unforeseen circumstances such as a death in the family prevented some patients from attending diabetes clinics. This type of emergency cannot be factored into organisational planning; therefore, it requires good patient/practitioner communication to re-arrange another appointment. These intervening life events ought to be considered in the planning stage of the delivery of the education session. Patient-centred approach involves the professionals sharing power and expertise with the patient (Manley et al 2011). Therefore, patients need to be involved in decisions relating to issues such as timing and location of the session. Similarly, an open access to re-book appointments may be an option.

Practitioners related barriers

The practitioners' occupies a central position in the delivery of the education programme (diabetes educators and referring practitioners) and forms the interface between the government and the patient. In the day –to-day delivery of the policy, the practitioners' attitude and working practices could hinder attendance. This current study has identified some practitioners related barriers and these barriers will be discussed under two concepts: communication and trans-cultural care management.

7.6. Communication

Communication between healthcare practitioners and patients is important. Good communication promotes a therapeutic relationship (Collin 2009) and helps to realise mutually determined health goals (Harkreader 2000). The factors that can positively or negatively influence communication include language, jargon, sign language, learning defect, noise, stereotyping and assertiveness of the speaker (Webb 2011). However, communication barriers are not necessarily confined to the health professionals; it can be due to issues relating to the patients as well (Bach and Grant 2009).

The data from both the practitioners and questionnaire survey of non-attenders indicated that poor access to information and inability to clarify and ask for further information was part of the barrier to attendance. This data from the questionnaire survey signalled the importance of pre-session information and corroborated the findings of the preliminary phase of the study. In a study

investigating ways to improve attendance, Barry and Daniels (1984) found that an orientation video showing the function and process of diabetic clinic significantly reduced non-attendance in comparison to similar information given in a pamphlet. Rosenbury and Fenley (2008) said implementation of public health agenda such as supportive education requires effective referral. Therefore, this calls for a cultural shift in attitudes of practitioners in terms of the referring and invitation process.

A recent study conducted by Diabetes UK (2012) on advice given to patients showed a great disparity between the perceptions of the doctors and the patients. Diabetes UK (2012) concluded that, although the doctors are committed to giving the right advice to patients, there is a need to explore the reasons why the right information is not getting across clearly. Communication is used to build a relationship and it requires a good body language and environment that offers comfort and reassurance to the patient. However, the findings from the practitioners in Phase 3 study suggest that there is an issue of poor non-verbal communication between the practitioners and the patients. According to Crawford (2009), a poor non-verbal communication can send a wrong message to the patient as it may be construed as lack of interest and recognition which may lead to negative health outcomes such as non-compliance.

This finding showed that the professionals are not usually communicating with the patients at an appropriate level by using inappropriate terminology, therefore, leading to some ambiguities: *'it is about understanding as well, do they understand the terminology'* (Participant 4, Area A, DSN). Sully and Dallas

(2010) and Webb (2011) states that patients are commonly unfamiliar with the medical terminologies used by the professionals and often get confused with the vocabularies and terms. Again, there should be an opportunity to clarify any ambiguities. However, the survey results identified lack of access to clarify information and revealed that (n=45, 43%) non-attenders stated that the Doctor or Practice nurse did not tell them what to expect. Therefore, the professionals need to be more selective with their choice of words and ascertain that the right information is getting across to the patient. This is in support of Crawford (2009) who states that communication should be free from jargon, understandable and without being rushed.

The importance of inter-professional collaboration is well documented in the health literature to ensure effective delivery of patients care and there have been several spotlights of complaints on poor inter-professional cooperation, notably, the Baby P case (BBC 2010). All the same, effective professionals versus professionals' communication are central to inter-professional collaboration. Barr and Dowding (2012) argue that hierarchical occupational power may interfere with good inter-professional communication. The data collected from both the diabetes educators and referring practitioners showed that poor inter-professional relationships may affect attendance. There appears to be a culture of blame between the two parties of practitioners referring and delivering the service. They all have a duty of care to the patient and nurses are required to act as a patient's advocate, therefore, effective communication that could improve the service is necessary to prevent the potential risk of poor patient care. The

benefits of effective collaboration among healthcare professionals is also supported by several authors such as Sutter et al (2009); Trevithick et al (2008); Oandasan and Reeves (2005) and Day (2007). In this case, it is important to share relevant information about patient circumstances and attitude towards attendance to aid compliance.

Hudson (2002) identified the issue of professional identity and hierarchy of profession in terms of full and semi-professional status as part of the conflict interwoven with inter-professional relationship. Barr and Dowding (2012) argue that there are some power issues associated with different practitioners such as those practising in medicine, nursing, and pharmacy. Whilst some professionals are considered as fully-fledged professionals, some are considered as semi-professionals based upon perceived limitations of knowledge base, length of training and autonomy. This may be applicable to the data collected from the practitioners because of the historical status of the professionals involved in this education service; for example, medicine is a relatively old profession in comparison to nursing. This can also be linked to limitation of my sample in Phase 3 which had only one GP due to shortage and lack of time.

Toole (2008) argues that the hierarchy between nurses and doctors sometimes mean that nurses are unable to confront the doctor on patient's care. Hudson (2002) further confirmed that harmonious relationships in the health sector appear patchy and therefore require improvements. As a result, the need to improve collaboration among the doctors, practice staff and other clinic staff (Diabetes specialist nurses, podiatrist and dieticians) is essential. Therefore, a

better communication approach that will enhance the level of information that is being currently shared amongst the professionals may be helpful.

7.7. Trans-cultural care management

Transcultural care focuses on holistic care that respects individual cultural values, beliefs and ways of life (Leininger and McFarland 2005). In a similar way, Leever (2011) sees transcultural care as a humanistic approach that considers the differences and similarities among cultures with respect to health and illness. Culture can simply be defined as the learned and shared norms and values of certain sets of people which govern their thinking, practices and actions (Helman 2007). It covers daily practices such as diet, language, personal care and religious activities. The United Kingdom encompasses people from diverse racial, religious and cultural backgrounds (Office of National Statistics 2011); hence, the referral involved many people from different social and cultural backgrounds. Dealing with culturally diverse populations means that the practitioners need to be sensitive to various cultural perspectives (Maier-Lorentz 2008). The practitioners face some challenges when dealing with patients from different cultures, therefore, transcultural care management requires some flexibility, responsiveness and adaptable approaches to patient's needs (Leever 2011; Narayanasamy 2003).

The data from practitioners in both Phases 1 and 3 suggested that there was an influence of socio-cultural background on attendance: *'if they have got*

ceremonies like Ramadan or Diwali or some events going on. I think we need to be sensitive ---' (Participant 4, area A, DSN). Although, Timby (2005) argues that it is impossible for practitioners to know all the health related beliefs of all different cultures, however, it is necessary to be aware of cultural differences and value the diversity of human race. The practitioners indicated that perceptions to illness and treatment vary from one ethnic background to another and suggested that religious practices such as Ramadan fasting period and festivals like Diwali may affect attendance. In the same way, Mughal (2010) stated that cultural differences such as language, lifestyle, extended family structure, dietary habits and religious ritual needs should be considered when planning effective diabetes management. Thus, motivation to attend during certain time periods in the annual calendar may be affected by different religious rites.

The data in this study from the practitioners in this study showed that they provided a specialist education session for one ethnic group in the population because there was a high proportion of people from this group. They were aware that specific education sessions did not target other ethnic groups and specifically did not serve the needs of those patients who have language problems. Gucciardi et al's (2007) study which compared English and non-English speaking diabetes patients on attrition rates, suggested a culturally and linguistic tailored session for the non-English speaking group of patients. Also, a systematic review (Hawthorne et al 2010) concluded that culturally targeted education was more effective than normal diabetes education in improving glycaemic control and knowledge level of the patients in the short to medium

term. A culturally tailored education may meet the needs of specific groups of people in a diverse population; therefore, it is important for the practitioners to take the ethnic mix of their area into consideration.

Government related barriers

The concept that explains the government related barrier is its contribution to bureaucratic practice involved in the delivery of diabetes education. In the UK, the Government is responsible for formulating the policy, dictate various reforms that often lead to restructuring of the NHS and determine the health budget (Malin et al 2002; Lewis and Glennerster 2000). Like any other establishment, the NHS consists of structures, process, relationships and boundaries to operate effectively and changes to any of these configurations can influence the health outcomes (Johnson and Scholes 2002).

7.9. Bureaucracy

The organisation of diabetes education programmes can lead to bureaucratic administration as previously discussed in Chapter 2 (pages 34 -39) under the socio-political context of the study. In reference to this study, there is a division of labour within the structure of offering structured patient education to patients. Whilst certain professionals are responsible for referring the newly diagnosed patients, other professionals are responsible for the delivery of the sessions. Again, there is a hierarchy of authority which span through several authorities

such as the Department of Health, National Institute for Health and Care Excellence, Strategic Health Authority, Primary Care Trust and the current Clinical Commissioning Groups. Finally, the rules and regulations laid down by these authorities are followed by the professionals implementing the policy of education for all patients affected by diabetes. Although, Butcher (2000), argues that the old characteristics of the traditional NHS delivery such as bureaucracy and professionalising that underpinned the traditional NHS delivery need to be challenged, this study suggest that a system of administration characterised by red tape and routine is still part of the practices within certain practitioners working in the NHS.

Although protocols and guidance can be very helpful in improving the delivery of care (DH 2002), it may have a negative effect at times. The data from the practitioners identified that diabetes targets do not favour effective implementation of diabetes education programme in terms of appropriate referral of newly diagnosed patients with diabetes to the education centre. The findings from the practitioners showed a relationship between government targets and the GP's action that may hinder attendance: *'I think the GP practice is too down to the point that they are driven by targets'* (Participant 1, Area A, DSN). The Quality and Outcome Framework aimed to offer rewards for giving high quality care (Kenny 2009), however, it does not translate in this way in the data collected amongst the referring practitioners who sometimes see referral as a tick box exercise. In the current NHS climate, there is a renewed emphasis on health

outcomes and meeting targets, and this appears to have led to a type of bureaucratic approach which have a negative impact on attendance.

The introduction of the QOF scheme in 2004 brought about pay for performance schemes aimed to provide incentives for GPs to achieve quality related goals and the current cost is £1 billion per annum (Gallagher et al 2015). However, the inclusion of payment incentives in the QOF 2013/14 for referring patients to the diabetes education centres appears not have brought the desired outcome. According to Hatch and Cunliff (2006), formalisation tends to minimise the level of discretion utilised by the workers in the process of performing their duties. The issue of placing too much emphasis on meeting the targets is affecting the amount of time used to emphasise the importance of the sessions by the GP and the practice nurses. Richard (2009) also showed that linking a GP's pay to the attainment of targets achieved by patients with long-term conditions has its flaws. Regardless of the importance of government targets, guidelines and protocols, it could be a limitation as this current research revealed the influence of current control pressures on ability of the practitioners to practice. Therefore, there is a need to place adequate emphasis on education and allocating sufficient time to promote diabetes education programmes because this is crucial to patient empowerment.

7.9.1. Group education

Empowerment involves increased power sharing between the practitioners and patients and enabling them to be independent. In this context, empowerment is promoted through sharing experiences among patients, questioning each other and raising awareness of diabetes care. Providing structured group patient education for all newly diagnosed patients with diabetes is a governmental policy agenda (NICE 2009; DH 2002), however, the findings from the practitioners suggested that group learning may not be ideal for every patient. Smaldone et al (2006), Rickheim et al (2002) and Tang (2006) stated that the rising prevalence of diabetes and its economic impact are the driving force for group based diabetes education. Nonetheless, the government proposed the philosophy of empowerment through group education as a preferred option. Despite the efficacy and financial arguments in favour of group education proposed by the government, the findings from the practitioners identified that group education may be intimidating to some patients.

In addition to the issue of effectiveness of a specific diabetic education strategy, patient's perceptions about the various methods of delivery need to be considered because it is crucial to their development of knowledge and their empowerment in managing their disease. Although, the medium of group session attendance may help the patient to review and develop their knowledge, encouraging patients to be aware of this benefit may be challenging for practitioners. Hence, there is a dilemma on how to encourage patients who are not interested in group education to attend the session, especially, those who

have a negative perception of this form of education: *'group session can sometimes be a little intimidating or they think so initially'* (Participant 6, Area C, DSN). Weick and Westley (1999) states that bureaucracy is linked with mechanical division of labour, more rigid chain of command and technical rationality which are qualities associated with repressed qualities. Based on the data collected in all the phases of the study, although the preferred option proposed by the Government is a group session, this current study demonstrated that one-to one education or group education should be offered to the patient based on their preference and available resources. Similarly, Funnell et al (2007) argues that both group and individual education must be geared towards the needs of the individual patient.

7.9.2. Rigid appointment system

Another reason for non-attendance identified by the data from both the practitioners and non-attenders is the inappropriateness of the appointment system. This relates to a rigid timing and location that may not accommodate an individual's life schedule. Huczynski and Buchanan (2001) state that bureaucratic organisations have a set of goals but rely on rules, tradition, and standard operating procedures. Therefore, having a tradition or a standard procedure of inviting patients to the hospital environment at a certain time for all the training may need to be appraised: *'there is a lot of fear attached because it is based at the hospital'* (Participant 3, Area A, Podiatrist). It emerged from the findings from the practitioners and non-attenders that issues regarding inconvenient date and

time prevented some patients from attending the sessions. The findings of the data also showed that inconvenient location in terms of long distance made it difficult for certain patients: *'the session is not run at different times'* (Participant 6, area 2, PN). Previous studies (Gucciardi et al 2009, Gucciardi et al 2007, Hamilton et al 2002, Vijan et al 2005 and Stone et al 1999) have identified both distance and timing as barriers to attendance among diabetes patients. Again the data from both the practitioners and non-attenders in this study suggested the need to offer the session outside the hospital environment. The implication of this finding is to provide a strategy that will incorporate some degree of flexibility into the appointment systems and the location of the education session.

The data from the non-attenders also found that administrative errors such as lack of clarity on date, location, timing or not having been invited at all contributed to non-attendance as shown by excerpts in Chapters 4 to 6. Other various studies (Zailinawati et al 2006; Hamilton et al 2002) have found administrative mistakes as a barrier to attendance. Therefore, the practitioners may need to improve the administrative protocols by providing clear instructions to the patients and this needs to cover the exact date and time, site of the session and keeping an accurate record of the details of all newly diagnosed patients with type 2 diabetes. In addition, enhancing the interaction between the GPs surgeries and the diabetes centres may be helpful, for example, making the list of referred patient accessible online to the practice staff and possibly offering the session in the surgery. The World Health Organisation and European Region

policies stress the importance of inter-professional and interagency practice in the health and social care industry (Tope and Thomas 2007). In line with the guidelines relating to inter-professional cooperation, the professionals should embrace the need to enhance the existing level of collaboration that exists between the GP surgeries and various Diabetes Education Centres.

The recent Health and Social Care bill proposed spending cuts in order to save the NHS (DH 2011). This new healthcare policy initiative on funding requires adequate and efficient use of available money coupled with innovative approach to implement the healthcare education policy. With further NHS spending cuts, the practitioners may not be able to provide a service that will accommodate the varied needs of the patient such as offering the sessions at different time of the day. The findings from the practitioners in this study highlighted the importance of adequate funding in promoting attendance whilst lack of sufficient funding was perceived to be the reality of the modern day NHS by some practitioners: *'cost is an issue and the people sitting at the top are thinking about how many patients have you seen'* (Participant 7, Area 3, PN). Hatch and Cunliff (2006) identified tensions between bureaucratic conditions associated with funding versus being flexible and responsive to patient's need. Therefore, there may be a need to reduce unnecessary red tape and bureaucratic approach such as prioritising effective referral process over the need to meet the set targets to minimise wastage of scarce economic resources.

7.10. SUMMARY

This Chapter has critically appraised the findings of the study and has utilised the theoretical framework of the Health Belief Model (Becker et al 1998) as an interpretive tool for the findings. The Chapter integrates and synthesizes the research conducted by the three Phases into eleven emergent themes (Table 7.1). The findings showed a slight variation across the participants and revealed a diverse range of factors that may either hinder or enhance attendance. These barriers were broadly categorised into three: patient related barriers, practitioners associated barriers and barriers that are connected with government regulations (Table 7.2) these barriers were discussed under 5 concepts (Table 7.3).

The main findings presented in this Chapter captured participant views on issues relating to non-attendance from the perspectives of educators, patients and referring practitioners. In analysing the three Phases of the study, it emerges that patients are influenced by their own personal, social and cultural beliefs. There are also individual circumstances that impinge on a person's ability to attend. These barriers are illness, work commitments, child care problems, personal crisis, weather condition, forgetfulness, and being away on holiday. Barriers related to the delivery of a structured patient education programme emerged from patient/practitioner communication, practitioner/practitioner interaction and NHS protocols. The delivery of diabetes education programmes is also affected by current policies from the Department of Health and influenced by the healthcare practitioners. The barriers to attendance are complex and by

addressing these barriers, attendance could be enhanced. The next Chapter will explore the strategies to overcome these barriers.

CHAPTER 8

STRATEGIES TO IMPROVE ATTENDANCE

8.1. Introduction

Non-attendance in hospital settings indicates a waste of healthcare resources (Bech 2005) and it increases the workload of staff (Zalinawati et al 2006). This Chapter will review strategies to improve the uptake of diabetes education programmes as a way to minimise wastage. The proposed strategies emerged from the previous Chapters which discussed the barriers to attendance. In line with the findings discussed in Chapters 4, 5 and 6 and the discussion of findings presented in Chapter 7, the findings that emerged from the study are organised into three themes – (1) strategies to support and promote positive patient's behaviour; (2) strategies to improve practitioner's performance and minimize bureaucratic practice; (3) strategies to influence government support and aid positive guidance and regulations. There is some degree of overlap in these three themes.

The patients did not attend the structured patient education for various reasons and some were not willing to attend the sessions as shown by the findings from both the practitioners and patients. Regardless of the unwillingness of some patients to engage with the education session, the high rate of non-attendance could be reduced through some strategies. Following consensus statements from the practitioners in both Phases 1 and 3 of this study stating that the idea of structured patient education was a sound health policy; the phenomenon was

addressed by exploring the ways to enhance its implementation. Thus, the following measures are identified to overcome the recognised barriers in order to improve the implementation of diabetes education policy (Table 8.1).

Table 8.1 – Strategies to improve attendance

Strategies to support and promote positive patient attendance behaviour
<ul style="list-style-type: none"> - Influencing positive personal, social and cultural beliefs/promoting positive self-care beliefs. - Guiding and supporting patients to mitigate difficult personal circumstances.
Strategies to improve practitioners' performance and minimize bureaucracy
<ul style="list-style-type: none"> - Improve patient/practitioner communication e.g. improved cultural awareness and the use of health activists. - Reduce fragmentation/duplication through enhanced practitioner versus practitioner collaboration. - Offer flexible and diverse methods of delivery e.g. online learning, group/individual sessions, opt-in and opt-out methods, flexible timing and different locations such as within community settings and GP surgeries. - Improve referral/appointment systems, e.g. by providing an open telephone system, develop a website to choose appointments and introduce a follow-up telephone call system and/or a letter of reminder. - Providing appropriate training and personal development programmes for the practitioners to improve efficiency.
Strategies to influence government support and aid positive regulations
<ul style="list-style-type: none"> - Seeking realistic additional financial stimulus from the government. - Influencing positive and realistic targets to aid efficient patient-centred care. - Inclusion of self-management and ownership of care in long-term conditions in the national high school curriculum.

8.3. Strategies to support and promote positive patient attendance behaviour

Health decisions are mostly informed by individual beliefs as previously discussed in Chapter 2 and further explored under healthcare belief in Chapter 7. Funnell et al (2007) state that diabetes patients vary in their attitudes and beliefs about diabetes and this may affect their perceptions about the value of self-management education. In this current study, the patients' response identified poor understanding of the illness as a mild condition. Other negative perceptions and beliefs include negative belief about the importance of the session and the self-perceived knowledge of diabetes. The t-test results comparing the beliefs of attenders with non-attenders showed a significant difference ($p < 0.05$). The practitioners also verbalised the impact of beliefs on attendance: *'I think that a lot of patients don't recognise diabetes as a serious condition'* (Participant 2, Area D, Dietician). This type of negative perception appears to fuel negative health decisions. Thus, an effective strategy is required to break some of these barriers by altering negative perceptions and beliefs of patients to those of a more positive nature. In the Health Belief Model (Becker et al 1978) used in Chapter 7 for analysis, understanding the risk posed by diabetes and knowing that the benefits of attending the session outweigh the effort required to attend may improve the attendance rate of patients that are capable of performing the behaviour (Graziani et al 1999).

In line with the theory of behaviour change, individual behaviour is partly determined by the person's values, beliefs and attitudes (Naidoo and Wills 2000). The health practitioners need to understand these concepts in relation to disease

prevention. According to the participants: *'with gestational diabetes, the attendance is significantly different and the process is the same'* (Participant 4, Area A, GP). Therefore, the perceptions could be addressed through more widespread health information given by the practitioners to aid informed choices. The aim of public health is to inform, educate and empower people, particularly; the vulnerable populations such as people with long-term conditions (Anderson and Funnell 2009; Baggott 2004). The practitioners need to improve the awareness of diabetes as a serious medical condition and some practitioners suggested the idea of educating people that are more prone to develop diabetes.

Hawthorne et al (1993) argue that problems with communication and health beliefs commonly held by British Asian patients may affect their compliance with western medical treatment. Lawton et al (2006) identified that many South Asian people believe that Allah has allowed them to have diabetes and would determine the progress of the disease and they cannot change the course. A participant stated: *'Some may believe that God brought the disease and the GP has nothing to do with it'* (Participant4, area 1, GP). This fatalistic belief was seen as a source of a barrier to attending. Therefore, it may be beneficial for practitioners to understand the views and cultural beliefs of patients and families to be able to plan a culturally acceptable education. This concur with Gucciardi et al (2007) and Hawthorne (2010) who state that culturally tailored education is more effective in promoting patient care. This type of education needs to consider issues such as patient festival periods and beliefs about the role of

healthcare providers being responsible for their care without their own personal effort.

The practitioners perceived that some patients believed that their disease management solely rests with the health practitioners: *'for lots of people who have the condition, they have been born and brought up in a culture where they just go to the doctor and get the cure'* (Participant 4, Area A, DSN). Regardless of different cultural perspectives to health and illness, some practitioners stated that the patients should take responsibility for their health. Schuster and Nykilyn (2010) discussing trans-cultural communication emphasise the importance of respecting other people's culture as a way to build interpersonal relationship. Although this current study has identified the need for patients to take more responsibility for their health, individual background needs to be considered in terms of their preparedness to take more responsibility and this requires frequent assessment.

However, some patients may be limited by communication barriers due to multi-ethnicity as identified by the three Phases of the research. A practitioner stated: *'there are lots of different people speaking other languages'* (Participant 3, area 2, PN). Assisting patients from a different cultural background could be through health activists (advocates) who are interested in long-term condition or those who have diabetes and can speak the patient's native language or come from the same culture. These activists may be used to call or to make contact with the patients who failed to attend the education sessions. Mughal (2010) suggested

the use of Asian link workers to promote concordance with treatment. As a result of the above, recognizing cultural issues may assist in developing the patient's understanding of their illness and promoting them to self-manage their illness.

Although, behaviour change is not simple, Upton (2010) states that a change in health behaviour may be promoted by providing additional or different information. A practitioner in this study thought that providing alarming information about the disease may motivate some patients to attend the session: *'perhaps we should be putting pictures of three deaths per minute or this might happen'* (Participant 2, Area D, Dietician). Some diabetes educators also suggested some punishment such as introducing a fine or to discharge patients that failed to turn up for their appointments while referring practitioners did not favour this approach. The use of negative reinforcement in healthcare is controversial (EKpe 2001; Rana and Upton 2009; Petty 2004), therefore, this is not recommended because there is no pragmatic evidence to support the usefulness of this strategy in a healthcare setting. Instead, it may be better to give an incentive for attending the education sessions.

Although it may not be possible to completely militate against several life intervening life events identified by all the three phases of the research, a good patient/practitioner relationship could help to overcome some of these barriers. An excerpt on this strategy was: *'I think as long as people have the opportunity to telephone or make some form of contact if they are not able to attend'* (Participant 2, Area D, Dietician). According to DH (2001b), patients and

practitioners partnership is crucial to health promotion. This strategy may help the practitioners to identify the reason(s) for non-attendance and reschedule a fresh appointment. An effective patient/practitioner relationship embraces offering choice to patients and involving them in decision making (McCormack and McCane 2010). Giving information to patients allows them to change behaviour and enhance compliance to their treatment regime (Caress 2003). Therefore, contacting the patients by telephone as soon as they default may offer the opportunity to address these problems.

In a similar fashion, a prospective study by Hardy, O'Brien and Furlung (2001) found that sending an information pack on when and where to come with information pack detailing parking facilities followed by a telephone call a week later reduced non-attendance rates. The patient who got the invitation letter will have the telephone number for the education centre; however, some patients did not receive the letter probably due to wrong address. In revisiting the responses of the surveyed patients, the helpline telephone number could be useful on the pamphlets. All the same, having the correct address is a joint responsibility of both the patients and the GP surgeries.

8.4. Strategies to improve practitioners' performance and minimise bureaucracy

The data from the practitioners and patients in this study suggested that uptake of diabetes education can be improved by giving clear information, guidance and

support. The strategy of giving more information during the initial contact is based on the assumption that raising the awareness of the importance of the session is likely to improve attendance. Therefore, the healthcare providers need to be supportive and offer adequate information. As shown by this study, the practitioners suggested the use of appropriate terminology to aid patient/practitioner communications and therefore minimise misconceptions: '*do they understand the terminology*' (Practitioner 4, area A, DSN). This corroborates the views of Webb (2011); Stiles (2011); Sully and Dallas (2010) who stated that the use of jargon and unfamiliar terminologies by practitioners may confuse the patient. Therefore, this suggests that this is one aspect of training required for the staff in order to further equip the practitioners with the knowledge and skills to deal and communicate effectively with patients. Again the training needs to consider consultation skills as indicated by Phase 3 study. This is in line with Blakeman et al (2006) who suggested training of practitioners in relevant consultation skills that are essential to aid self-management skills of the patient. Although, continuing professional education is associated with costs, NHS England (2014) sees the NHS workforce as its biggest asset that therefore needs to possess the right skills and training.

Inter-professional working is a process by which members of different professionals work collaboratively to solve health problems that cannot be adequately resolved by one healthcare practitioner. However, from the focus group and individual interviews of the practitioners, it became clear that the

relationship between the practitioners requires some improvement. This strategy requires the input of both practitioners and the government. The King's Fund (2014) states that regardless of the current political agreement about the importance of integrated care, progress has been slow in this area of practice. The King's Fund (2014) argues that the next government should focus on minimising barriers such as fragmentation of commissioning, tackling detrimental financial incentives and ensuring competition that does not hinder collaborative practice. Therefore, the practitioners need to be more active in influencing positive directives whilst the government also needs to be receptive and consider a positive shift in its policy agenda relating to structured patient education.

The practitioners in the present research mentioned the need to deliver the session through e-learning: *'I mean if you have the option to do an e-learning course that fit into their lifestyle, they might access it'* (Participant 7, Area C, DSN). Minshull (2004) identified various advantages of virtual learning environments as access to content outside the physical learning environment. However, this strategy was a contentious option considering the level of knowledge of computer and literacy level of some patients. Although the use of computer is very popular and e-learning may have a role to play in delivering the sessions, most of the patients are over 40 years of age and not all will necessarily be competent with computer usage. Fearnley et al (2012) found that online SPE for people with type 1 diabetes with a supplemental tutorial increases the accessibility for young patients and has a positive effect on their HbA1c

levels and quality of life. Arguably, this may compensate for inability to attend the session and invariably provide some patients with the flexibility that they suggested might aid their attendance. However, engaging the patients and the practitioners is extremely important to maximise the benefits of this method of teaching and learning technique.

SPE is based on group learning, therefore, individual support may be lost in an online technique of teaching patients. It could be argued that 'webinars' which are a form of web-based seminar may be helpful in providing some sort of interaction among the patients and practitioners. Petit and Manson (2003) states that shy students may be able to contribute more in online sessions while outspoken students may benefit more from expressing their views in the classroom environment. As stated earlier, one of the major flaws of a virtual learning environment may be the patient's deficiency in terms of computer literacy ability. Although there is growing evidence to support the use of telemedicine in long-term condition management (Barlow and Hendy 2009; Darkins et al 2008), Minshull (2004) emphasised the importance of wide consultation and shared vision about online learning. Based on these arguments, combining the two approaches may offer greater opportunity to facilitate patients learning in relation to their medical condition. This may invariably increase motivation for those who do not like face to face sessions. Lawson et al's (2005) study on non-attendance concluded that practitioners should be aware that

encouraging good diabetes self-management may require different approaches to diabetes care.

Regardless of the benefits of group education such as being a cheaper option and offering the potential to gain group support (Tang 2008; Nute 2004; Zreibec 2003), this study indicated that one-to-one diabetes education should be provided to patients who preferred this method of educational approach. Funnell et al (2007) advocates for both groups and one to one education based on an individual patient's need. NICE (2009) suggests that group education should be offered as a preferred option, however, individual education should be provided for patients who are unwilling to attend a group session. Some practitioners stated that the length of time could prevent some patients from attending the session: *'I think sometimes the three hours spent in a single diabetes education session'* (Participant 9, Area B, Podiatrist). To circumvent this barrier, the practitioners' responses indicated the need for a change in the process of delivering the education. They stated that it is necessary to consider other options such as offering a continuous rolling education programme that patients can opt in and out of. However, this method of fragmenting the time of the sessions may need to be tested before implementation. As a temporary alternative, the idea of giving frequent short breaks in between sessions may be explored.

There is a considerable increase in the prevalence of type 2 diabetes (WHO 2011) and some of these patients may be in full time employment (Schafer 2013; Rhee et al 2005). All the three Phases of the study showed that employment may be a barrier with certain employers who may not be willing to release patients from their post at the specific time that the patients are booked to attend the session. Although, Phase 3 study of the current research revealed the need for government to support patients' release from work, the data from the practitioners in Phase 1 showed that some patients might not disclose their medical diagnosis of diabetes to their employer. The impact of timing has been highlighted by some other studies (Hamilton et al 2002 and Stone et al 1999). To overcome work-related barriers, this research suggests the need for flexibility of the session delivery times, therefore, it may be crucial to offer a time that will meet the need of most patients, for example, in the afternoon, evening and weekends could improve attendance (Chapter 5, Table 5.18). This finding is similar to some other studies on this phenomenon (Gucciardi et al 2007 and Hamilton et al 2002).

Another strategy suggested by the practitioners is to deliver the education in the patient's local community. Concurring with previous studies (Murphy et al 1992; Gillibrand 2010a), participants highlighted a preference for diabetes care in their local community. Arguably, this may be linked to nearness to the patient's own locality as it is presumed that an individual's GP surgery is likely to be closer to their home. Therefore, the opportunity to attend education sessions within their community as opposed to a centralized education centre in the hospital should

be provided as an option for patients that may find it difficult to travel to a further distance. Again, it was assumed that seeing familiar faces at the GP surgeries might promote attendance: *'I am sure they would come because they are already familiar with the GP surgery and then seeing old faces'* (Participant 1, Area 1, PN). This strategy is similar to a recent report on diabetes commissioning (Goenka et al 2011) which states that provider organizations should offer diabetes care at the right time and in the right place. Hence, it is suggested that patients should be given a varied day, time and location to choose their preference. Although this may aid attendance, it is worth mentioning that this strategy may have financial implications.

In order to promote attendance, the practitioners need to offer support and encouragement to the patients particularly during difficult intervening life circumstances. The practitioners suggested making a follow-up telephone call or sending a reminder letter. This strategy of using a telephone reminder in general clinical practice has long been extensively investigated by other studies (Henderson 2008; Hasrold and Wotten 2011) and found to be helpful. Therefore, to tackle forgetfulness and other barriers associated with individual personal circumstances such as illness and personal crisis, a form of reminder such as a telephone call or sending a letter could be put in place. Although associated with additional cost, the findings from both the practitioners and patients showed that reminding the patient about the date, venue and importance of the session is a useful strategy to either aid attendance or encourage the patients to re-arrange

another appointment. Hogan et al (2008) found that sending text messages would encourage half of the participants to either attend their outpatient appointment or cancel it. Therefore, patients may need to be contacted by telephone, e-mail or a letter a few days before the appointment date: *'To have a diabetes secretary who would ring up to negotiate the appointments'* (Participant 1, Area D, DSN).

8.5. Strategies to influence government support and aid positive guidance

The third category of strategy relate to ways of improving government support and guidance that will aid the delivery of diabetes education. The practitioners suggested the need to provide additional resources such as more secretarial support to follow-up cases. However, they identified a limitation in their ability to secure more funds: *'we need to develop business plans and go and knock on the door of the PCT board to build a case why need the money and unfortunately we haven't got those business skills'* (Participants 7, Area C, DSN). Therefore, practitioners may need to seek help in developing business plans. This may require additional training for practitioners involved in the delivery of the education.

The availability of more money can be used to employ an additional hospital secretary who can be phoning patients to remind them of their appointment. It may also provide more funds to offer additional comprehensive information leaflets and other methods of teaching such as online teaching packages. Cinar et al (2010) states that putting diabetes education pamphlets in popular retail

outlets like Tesco and other relevant locations such as Day Centres could make it more accessible to people. However, seeking additional funding support may be associated with problems because of diminished resources in the current healthcare service. The spending challenge has been widely acknowledged by the government (DH 2011b) and the King's fund (2013) identified some of the key drivers affecting the healthcare spending as changes in population size and structure and various developments in medical technology which is associated with increased cost.

Consequently, it is essential to use the available funds in the most efficient way. Practitioners need to maximize the benefits of changing their current practice without incurring extra personnel or other cost. This could be done by using the health activists to make contacts with the patients and providing a free phone digital answering system for re-booking and cancellation. Although making this type of innovative changes to their practice could save money, nevertheless, a realistic appeal for additional funding to improve SPE for all the newly diagnosed patients with diabetes may still be necessary. The request for economic stimulus could be based on current epidemiological data of diabetes. Diabetes, as one of the world's long-term conditions, presents a global medical problem with a rising incidence (WHO 2011; Diabetes UK 2012; Bailey and Feher 2009). Also funds can be sought from other non-governmental organisations such as the pharmaceutical companies: *'the big industries or companies could also help with education, instead of just sending different types of glucose meters'* (Practitioner 7, Area 3, PN). DH (2002) suggested that the PCTs need to be aware of financial

and training support that is available from the industry, however, cautioned that ethical issues should be considered so that the needs of the patient or service delivery is not compromised.

Whilst it is essential to meet the set targets, the short-term approach of getting a financial reward should not override the importance of long-term effect of self-care ability in managing blood glucose levels and preventing complications. Although Phase 1 study revealed that government should offer a reward for referring patients to diabetes education, this has happened without any significant impact on attendance. This set of health practitioners perceived that having a target that gives some points to the GP surgeries for referring patients to the Diabetes Education Centres may influence them to pay more attention to their process of referring the patients to the education centre. However, this has been introduced, but it only led to change in working practices and increase in the referral rate without any significant reduction in non-attendance. Arguably, linking pay to performance that does not reward diabetes group education may undermine teamwork and it may motivate some practitioners to ignore certain aspects of patients care such as structured patient education. Hardley Brown (2009) sees the focus of a Quality Outcome Framework for diabetes on quantifiable outcomes as a limitation to achieving positive patient experience. Consequently, the practitioners may need to further influence the government and key people within the CCG about setting realistic targets that can promote the effective delivery of SPE.

Analysing the data from the practitioners showed that offering diabetes education earlier in life in a way similar to sex education is a positive strategy to promote diabetes education. The findings from the practitioners revealed that emphasising the importance of engaging with diabetes education by specifically targeting high risk /vulnerable people such as obese individual and people with family history of diabetes could help. Phase 2 of the current research found that family history was a significant predictor of non-attendance, therefore, this type of universal preventive intervention is key. Thus, the practitioners may need to influence the government educational policy in terms of introducing the benefits of self-care education and management programmes into the national curriculum. Also, it may be necessary for practitioners to be going to schools to offer a short lecture on diabetes and distribute necessary pamphlets to the students as a way of improving the awareness of the medical condition. This type of policy changes is aimed to transform the negative perceptions of the disease through knowledge based information. This could invariably alter the perceptions of the young individuals and possibly result in positive health behaviour. Consequently, it may aid attendance if these students are later referred due to a diagnosis of diabetes.

Another government policy initiative that requires practitioners' influence is the schools' sporting activities. Although this does not impact on attendance, it has potential for the development of diabetes and aggravating the effects of diabetes on patients. Due to various recent health and safety legislation, there have been

some changes to the routine exercise undertaken in schools. The Health and Safety Executive (2012) acknowledged that health and safety is often used as an excuse to stop sensible activities in schools and effort is being made to simplify guidance to minimise misunderstanding of the legislations regarding sporting activities. Some practitioners in this present research felt that the old method of routine competitive sports is part of the solution: *'bring competitive sports back to schools'* (Participant 7, Area C, DSN). Arguably, this could aid in combating the incidence of obesity (Shield 2012) and maintaining a healthy weight may help to minimise the impact of diabetes on affected individuals (Matyka 2012).

8.6. Proposal for change

The strategies set up above are summed up to offer a proposal for change. These strategies aimed at targeting all the stakeholders with the intention to overcome some of the problems associated with non-attendance. The key stakeholders involved in the formulation and implementation of the policy are the patients, healthcare practitioners and the government. In putting the findings of all the three Phases of the current research in the context of the research goals, a provisional explanatory framework is hereby presented (Table 8.2). As demonstrated in the discussion above, the stakeholders may need to change to improve the service and the researcher has coined the acronym 'REPAIR' to sum up the changes required (see Table 8.2).

Table 8.2: Proposal for change	
R	Re-orientate and support the patient to take responsibility for their health
E	Enhance patients/practitioners and practitioners versus practitioners communication
P	Promote organisational efficiency
A	Appraise the practice of practitioners involved in diabetes education and offer appropriate training
I	Influence positive government directives on diabetes education
R	Reflect on the activities of the patients, practitioners and the government in promoting uptake of diabetes education

The practitioners may need to change their practice to improve their organisational performance, for example, by introducing a follow-up approach for non-attenders. In addition, the practitioners may be required to influence government directives that will promote the delivery of diabetes education programmes, for example, inclusion of self-care management of long-term conditions in the curriculum. The government also need to be responsive to the recommendations and suggestions of practitioners in formulating appropriate guidance that may promote attendance. The process of improving organisational efficiency and influencing positive government directives requires constant re-appraisal of the practitioner's practice and ensuring professional development in relevant areas such as managing the referral and invitation process and developing skills to write business plan for additional funding. Finally, offering

adequate information and support to patient may address some of the negative perceptions and reduce the impact of unforeseen life intervening circumstances. Thus, this may invariably encourage the patients to take greater responsibility for their health.

8.7. SUMMARY

To address question 3 of this project, this Chapter has presented avenues to overcome the barriers identified within the data. It shows that all stakeholders involved in the study have a pivotal role to play in enhancing effective strategies to aid attendance by promoting the implementation of policy of education for all patients affected by diabetes. In particular, healthcare practitioners need to influence beliefs, attitudes and behaviours that are necessary to promote motivation, prevention and commitment. The data also suggested the need to minimise organisational/systemic failures and promote effective systems by considering issues such as a better referral system, a better appointment system, increased staffing level and effective work organisation.

As part of future strategies to improve attendance, additional support that could aid attendance includes offering the education service in the community or GP surgery which is nearer to the patients, offering various choices of time such as evenings and weekend sessions. However, it is acknowledged that patients need to assume more responsibility for their health. The benefits of reducing non-attendance is worthwhile, hence, effective implementation of diabetes education

programme is paramount. Breaking these barriers requires a coordinated effort of both the practitioners, patients and the government. The final Chapter will present the overarching explanatory framework that summarises both the barriers and the measures that could promote attendance and reduce the rate of non-attendance. Also, recommendations for future policy directives, the contribution of the study to knowledge and directions for further research study will be covered.

CHAPTER 9

CONCLUSION AND IMPLICATIONS FOR POLICY AND PRACTICE

9.1. Introduction

This chapter reviews the results of the three research phases undertaken. In addition, it proposes a framework for clinical practice to ensure efficient referral of newly diagnosed patients with type 2 diabetes and improved levels in their attendance at Diabetes Education Centres. The problem of non-attendance in the healthcare sectors continues to receive attention from healthcare professionals (Car et al 2012; Bech 2005), policy-makers (DH 2012b) and the media (BBC 2012). Stiles (2011) states that patients may be aware that self-management strategies may reduce the risk of diabetes complications but still do not embrace them. To some extent, people know the risk of HIV, smoking, obesity etc.; however, there is often a reason why it is difficult for them to embrace healthy living. Therefore, the current research is topical and timely whilst the incidence of diabetes continues to rise.

9.2. The study

The current research sought to investigate:

- (1) Barriers relating to attendance at Diabetes Education Centres.
- (2) The predictors of attendance.
- (3) Strategies to overcome the barriers to attendance.

This research was necessary because a recent systematic review highlighted the dearth of such research relating to the UK and the NHS (Lawal 2014). The study was carried out in a PCT in South East England and the target populations were patients and practitioners (see table 3.1 for the research design). A three phase sequential mixed method research was used to investigate the phenomenon from the perspectives of the practitioner and patient populations. Phase 1 used a focus group interview and individual interviews of diabetes educators delivering the sessions. Phase 2 used a questionnaire to survey the opinions of attenders and non-attenders about motivation and barriers to attendance at a Diabetes Education Centre. Phase 3 used individual interviews to explore the barriers to attendance from the perspectives of the referring practitioners within the context of the recent changes to the policy initiative.

9.3. Overview of the results in relation to patient motivation and the identified barriers to attendance

This thesis has discussed various barriers and identified ways of breaking these barriers to improve attendance. The results show that practitioners are challenged by the complexities of the patient and in meeting patient needs. The attrition rate in attendance was influenced by communication barriers between patients and practitioners, and weak collaboration between the practitioners working in surgeries and diabetes education centres. The results also showed that practitioners should not make assumptions or judgements and that they need to be careful about using medical jargon to explain certain things to

patients. The findings also recognised the challenges posed by self-management education funding and government regulations. The psychological effects of diabetes and the impact of organisational structure and ethos were shown to be parts of the barriers identified. Personal perceptions and beliefs constitute a significant part of the problem that contributes to non-attendance. In addition, the barriers associated with non-attendance include bad weather and various personal life problems, such as bereavement and the constraints of a busy life.

These barriers were broadly categorised into three themes: barriers related to patients; barriers related to practitioners; and barriers related to government directives. Results were grouped into five key concepts: healthcare beliefs, bureaucracy, patient-centred care, communication and transcultural care. The measures to overcome these barriers were incorporated and distilled to formulate the proposal for change (Table 8.2) and the overarching framework for the study is presented in Table 9.1.

In all the three phases, the researcher assessed the extent to which the patients' behaviour is determined by each of the components of the Health Belief Model: perceived threat of diabetes, perceived benefits and barriers to compliance, and health motivation (Becker et al 1978). The results showed that individual behaviour is driven by beliefs and perceptions; in addition they demonstrated the importance of both internal and external motivation as a stimulus to attend the sessions. Therefore, from a public health perspective, the timely recognition of

the needs of patients within their current perception of their health is required to supply adequate information to modify negative beliefs, and offer support and appropriate direction to patients.

Another barrier is the impact of government regulations on attendance. Recently, referring newly diagnosed patients with diabetes became part of the quality indicators. Although there has been a shift in policy, the results have not adequately matched the expectations in improvement. Phase 3 of the current study suggested that introduction of Quality Outcome Framework (QOF) incentives has increased the awareness which has led to a change in behaviour of the GPs and practice nurses towards referral but this does not suggest good practice in promoting self-care management. Effective education helps to alter health behaviour and change lifestyle; therefore, successful implementation of the policy relies on the attendance rate not the referral rate. Gallagher et al (2015) argue that although QOF targets are influencing primary care practice, little is known about their effectiveness in improving diabetes care. Nonetheless, the influence of government regulation and control on healthcare delivery is increasingly becoming a topic for debate nowadays.

The findings in all the three phases have shown that patients may not be able to attend because of personal difficulties; therefore, implementing a patient-centred approach may be helpful. This is important to provide services that will be tailored to the needs of the patient by considering their personal circumstances,

needs, beliefs and values. Patient-centred care is expected to shift emphasis from task-oriented practice to acknowledging and responding to their choices and preferences appropriately (Palzang 2010). However, delivering patient-centred care was a bit difficult to implement in the current study due to the presence of organisational protocols, inappropriate work culture and lack of time.

Communication is a vital aspect of therapeutic interaction taking place in both the referral and invitation process. Although this requires time and empathy, it is important to meet the communication needs of the patient by giving accurate and comprehensive information, whilst building a therapeutic relationship that could aid attendance at Diabetes Education Centres. The study indicated that practitioners need to use appropriate terminology to minimise misunderstandings (Webb 2011; Stiles 2011; Sully and Dallas 2010) and avoid giving information in a rush. This entails using effective communication and listening skills to focus on patients' problems, to support patients to set a realistic goal, to respect their beliefs, and involve families in the education to motivate them to engage with the care regimen. Communication is also vital to develop a good relationship between different practitioners working as a team. This study has suggested the need to bridge the referral-invitation gap; therefore, the practitioners need to work in a more collaborative way.

Non-attendance was influenced by barriers such as patients' beliefs, culture, social norms and family influence; therefore, transcultural care could be helpful,

as discussed in chapter 7. Patient resistance may also be due to lack of readiness to take responsibility for their own health and this appeared to have been influenced by their background. Thus, a poor balance between a patient's rights and responsibilities represents one of the barriers. The patients have some responsibilities to achieve and maintain their good health; nevertheless, the state has a legitimate role to influence the people to choose healthy lifestyles (Baggott 2010). DH (2012b) and DH (2007) emphasise performance accountability and greater citizen participation by re-establishing links between rights and responsibilities. Adler and Stewart (2009) proposed an idea of "behavioural justice" on this contentious issue. They argued that individuals are responsible for engaging in health-promoting behaviours, therefore, they could be held accountable for failing to do so in the presence of adequate resources. However, the practitioners are required to take psychological approaches to effect a change in behaviour. This entails the need to consider the patient's perception, motivation, learning capacity, skills, values and social learning preferences.

DH (2009) document titled 'High Quality Care for All: Our journey so far' states that empowering people to take greater control in managing their medical condition is central to achieving high quality care in this modern age. However, motivation is not straight forward and labelling some patients as unmotivated may be perceived as being judgemental. There was a suggestion on whether sanctions could improve a positive health outcome and the evidence suggests that any punitive measure may further fuel non-attendance. Lawson (2005)

argues that most models of health related behaviours focus on understanding the perceived health risk, therefore, the use of sanctions to promote self-care may have a negative impact on compliance.

On the whole, barriers are multifactorial so interventions need to vary and be diverse. Consequently, it is apparent from the current study that positive self-care belief, effective communication, minimising the bureaucratic approach, being sensitive to various cultural beliefs, and offering flexible referral and delivery of the sessions may be helpful in overcoming some of the barriers.

9.4. Implications of this study towards establishing a Framework for Clinical Practice

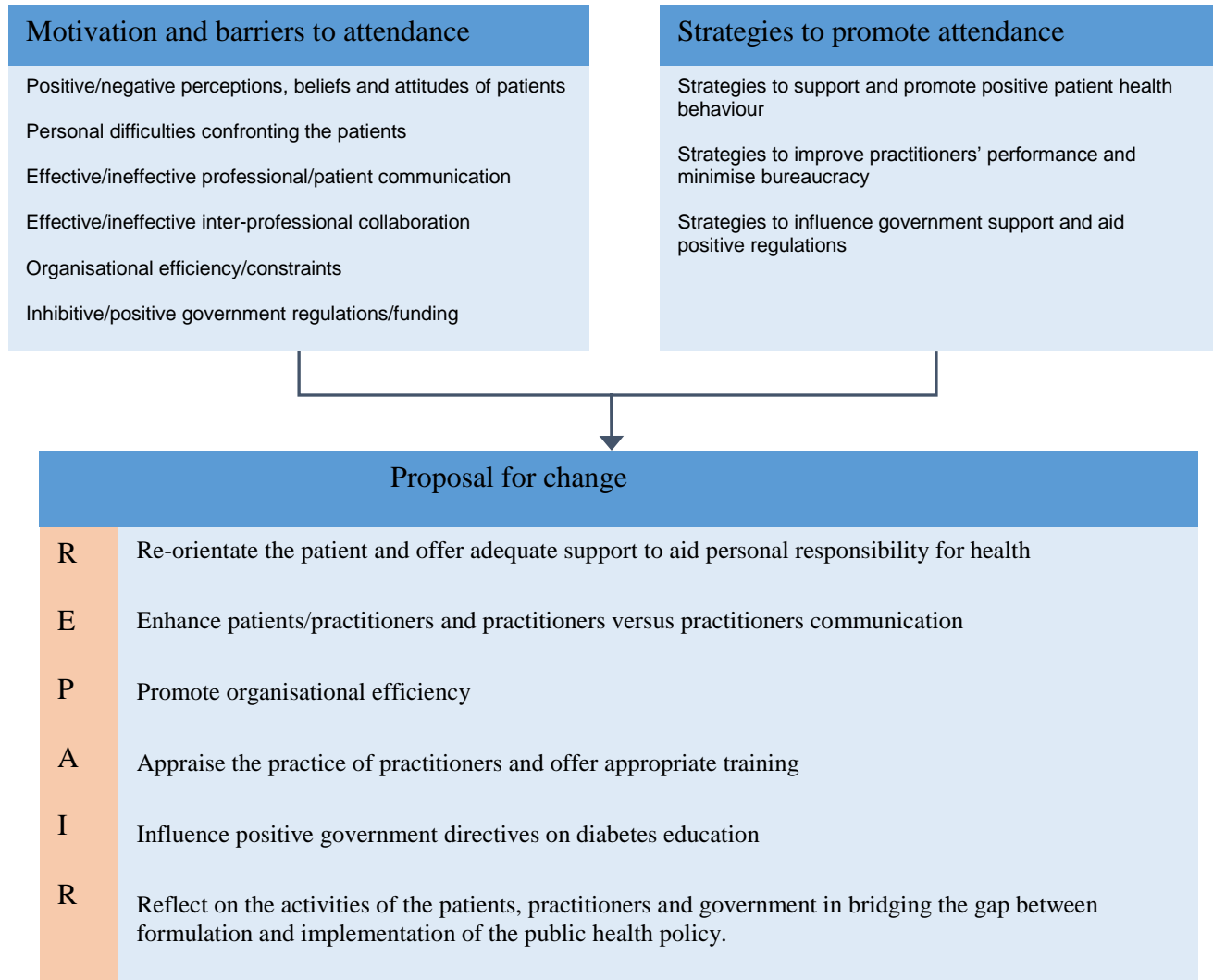
Although the NHS has an established history of improving the health of patients, the absence of simple and quick solutions for longstanding, intractable diseases such as diabetes calls for a new approach towards maintaining the health of the public (DH 2006). The current policy decisions and NICE guidelines on diabetes self-management education seem realistic (NICE 2009); however, healthcare practitioners need to improve the current practice. Patient non-compliance is often associated with personal qualities such as lack of willpower or discipline coupled with personal circumstances which may make it difficult for the patient to follow health advice (NICE 2009). The overarching framework for practice incorporates both the fundamental problems to be considered and the strategies that have been identified to overcome the obstacles.

Although there is no apparent quick-fix to the problem of non-attendance, this study has identified some solutions to enhance attendance. Based upon the discussion and analysis undertaken in the previous chapters, the problem needs to be tackled at both a micro and macro level. Thus, strategies need to be developed to deal with all the stakeholders involved in formulating the policy and implementing it with the target population. Brocklehurst (2004) emphasised that collective responsibilities amongst the individual, community, professionals and government are key aspects of public health improvement. Consequently, the aim is to devise patient, practitioner, organisation and government interventions. Having discussed the barriers and strategies in chapters 4 through 8, the framework for clinical practice is presented below (Figure 9.1). This framework is underpinned by the key findings discussed in chapter 7 (Table 7.1) and chapter 8 (Table 8.1) in respect of strategies to improve attendance.

Regardless of the criticism of the Health and Social Care Bill (DH 2011), the Coalition government argued that the NHS cannot survive without reforms and innovations. Thus, prevention is the best way to deal with type 2 diabetes and education occupies a central position in this strategy. To achieve this goal, structured patient education requires an aggregated effort of all the key stakeholders and the strategies to influence all the major themes that have previously been identified can be summed up with the acronym “REPAIR” as shown in the proposal for change (Figure 9.1). This framework for practice underpins recommendations for clinical practice made at the end of this thesis

and therefore proposes the possibility of exploring the use of flexible and diverse approaches to the delivery of education.

Figure 9.1 – Framework for clinical practice



9.5. Recommendations of this research for clinical practice

The importance of empowerment in managing long-term conditions such as diabetes has been heavily emphasised by different international and national health authorities such as the World Health Organization and the Department of Health in the UK (WHO 2009; DH 2007b). The National Service Framework and National Institute of Health and Care Excellence set out a vision of empowering patients with diabetes through health education geared towards self-care management (DH 2001a; NICE 2003, NICE 2009). Nonetheless, there have been limited studies on this issue (Lawal 2014, Ngwenya et al 2009); therefore, the challenge of how to motivate attendance requires further research. These recommendations are based on the emergent themes that arose from the findings of this study and evidence gathered from previous research that establishes similar or slightly different findings on this phenomenon. Thus, it is recommended that there is a need to consider alternative approaches because broad approaches will capture a wide range of patients.

- Based on the findings, it is recommended that the session should be delivered within the community setting and possibly through an online method in addition to offering a face-to-face sessions. This will address the barriers associated with distance, accessibility, financial cost of travelling and fear that may be associated with hospital attendance.
- The findings suggest the need to consider sending a letter, a text message or a telephone call to remind patients about their appointments. This reminder needs to incorporate adequate information on when, where

- and what to expect during the session. Although adding another layer of communication implies additional cost, compared to the cost of treating complications and re-admissions, it may be a cheaper option. This has the potential to address barriers associated with information delivery, long wait times and various life intervening circumstances confronting the patients.
- Realising the barriers that are linked to organisational constraints, an appointment and referral system that is tailored to the needs of individual patients is suggested. This requires offering flexible time appointments to suit individual needs. To further address the problems associated with the appointment system, a mobile network appointment, and a website to pick preferred date is suggested to complement the current system. As this may not suit some patients who are elderly, the individual's computer knowledge will need to be taken into account. By considering patients who may be working and living in a different town, the options may include writing a letter of invitation offering three sites and possibly offering two different dates. The appointment system can also be improved by providing a free digital answerphone for booking and cancellation, regardless of its limitation.
 - Also, there is a need for the practitioners to work more collaboratively to achieve the common goal and a shared vision of providing structured patient education for the entire population of patients newly diagnosed with diabetes. Therefore, enhancing the interaction between the GP surgeries and the diabetes centres may be helpful, for example, making

- the list of referred patients accessible online to the practice staff, follow-up of cases, instantly accessible data concerning attendees, organising periodic inter-professional meetings and possibly offering the session in the GP surgery.
- The bureaucratic burden which appears to be driven by government regulations and incentives systems needs to be addressed to reduce the barriers between different providers leading to organisational complexities, fragmentation and inefficiency.
 - Offering appropriate development training to the staff in areas such as collaborative practice, patient-centred care approach, effective referral process, consultation process, and ways to assess and influence motivation, cultural awareness and tracking of referred patients could be helpful. This may include regular workshops on how to bridge the gap between referral and attendance.
 - Another recommendation is to consider the education as a prescription rather than a mere referral. It is thought that if the GP prescribes education in a way that is similar to a drug, this may enhance attendance. Although there is no empirical evidence to support this recommendation, there is an assumption that patients take it more seriously when it is prescribed by a doctor.
 - The findings suggest that it may be necessary to target the school education curriculum as children need to understand the value of health promotion. This is based on the assumption that when a subject is taught

in a school environment, it becomes more attractive. Health behaviours result from certain beliefs; therefore, this has the potential to raise awareness of the importance of diabetes education in self-management, and influence positive health beliefs.

- The final recommendation for practice development is to maximise the use of health activists or volunteers by considering linguistic and cultural differences. A suggestion is to introduce a form of administrative back-up support service to assist with various tasks such as ringing patients and attending to paperwork to minimise administrative errors, and this could be supported through a voluntary system. This can be achieved by advertising locally for people who are willing to commit some hours for this charitable cause. This recommendation may help to overcome some of the barriers associated with personal difficulties of patients and minimise administrative oversights. Although it is recognised that the need to reduce healthcare costs should not affect the quality of care given to patients, the volunteer system could save some money and address some of the barriers associated with culture and health beliefs.

In summary, the recommendations suggest that no single educational strategy or appointment system will suit all patients, therefore, individual needs and preferences would need to be taken into account for future clinical practice in order to provide patient-centred care.

9.6. Significance of the current research

The findings of this thesis are important due to a lack of primary research in this area within the UK. The systematic review of the phenomenon of non-attendance at Diabetes Education Centres supports this stance. This research has revealed the role of the social, cultural and physical barriers that prevent some patients from attending the Diabetes Education Centre. The research has also identified the challenges faced by practitioners in terms of organisational constraints. It has highlighted areas that require improvement within the context of the findings and this has informed the recommendations.

The findings concerning issues of bureaucracy add new information to the current literature and future research direction in this area. The patients affected by diabetes receive care from different health and social care providers from the time of diagnosis to the onset of complications and it is recognised that fragmented healthcare delivery can result in duplications, inefficiency and poor patient experiences (Butcher 2000; Huzynski and Buchanan 2001; Hatch and Cunliff 2006). The Health and Social Care Act (2012) acknowledged the importance of further integrating health and social care services. Diabetes UK (2013) also emphasised the need to provide better integrated care by removing the cultural divide between different healthcare providers. Within the context of the emerging NHS, promoting organisational cost improvement and service redesign is fundamental to cost effectiveness. In line with this goal, the findings of the current research are significant because they have the potential to aid

practice development to promote attendance at Diabetes Education Centres and consequently lead to a better use of resources due to reduced bureaucratic processes.

The underlying assumption of the Health Belief Model (HBM) (Becker et al 1978), which is based upon the premise that behaviours are determined by individual beliefs, was applied to relevant aspects of the data. The findings of the study showed a consistent relationship between certain beliefs and motivation for attendance. Therefore, this study adds to the evidence regarding the ability of HBM to explain variance in patient behaviour within the existing critique of the model.

The current research has demonstrated the complexities and prospects of capturing the group of patients who are non-attenders. It has also made a step forward by using sequential mixed methods within this project. Therefore, this has helped to extend the current knowledge on how to gain information from hard to reach groups in order to understand their health needs and plan the required intervention. By targeting non-attenders and undertaking a multi-phase study, the research has contributed to new knowledge, at least in the UK, and will impact on the national understanding of the phenomenon and this is essential for the implementation of government policy.

Another contribution of this research programme is the outputs generated through the peer-reviewed publications and public presentations (Appendix 18). This has allowed the knowledge to be made accessible to patients, practitioners, other researchers and policy-makers.

Finally, the implementation of the findings of this study may translate into clinical benefits as improved attendance could aid self-care ability, prevent diabetes complications and enhance patients' quality of life despite the presence of a life-long medical problem. In addition to benefits to the patients, it could also be beneficial to the public and the government through a more efficient use of funding due to better use of diabetes clinic time, and reduction in the rate of diabetes complications that may result from better knowledge and self-management skills.

9.7. Constraints of the current research

In conducting research of this nature, methodological complexities and access to participants can pose serious difficulties. Therefore, it is important to consider the results of the current research in light of the limitations outlined below.

One difficulty encountered was in the recruitment of suitable participants and managing attrition due to reasons beyond the control of the researcher. Ajay and Rubin (2003) stated that it may be difficult to access non-attenders for research purposes. Furthermore, recruiting the practitioners for the study was influenced

by current changes within the NHS Trust, e.g. re-organisation/re-structuring, retirement, transfer and maternity leave. Also, time constraints were a major problem when considering the busy schedules of the practitioners.

The sample size for this study could be considered small, but it added to the evidence nonetheless. Triangulation of data (qualitative and quantitative) and using different localities have strengthened the relevance of the results. Also, the significant change within local health services has given the opportunity to observe the effects of these changes on patient referral practice over time. Also, this study explored multiple centres and targeted non-attenders, attenders and practitioners.

As discussed in chapter 3, a further limitation could be not using an existing validated questionnaire to survey the views of the patients. There was a need to use a questionnaire that had response appeal with 'hard to reach' participants such as the non-attenders. Nonetheless, the self-developed questionnaire with a small number of items was carefully designed by considering the issues of ecological validity and reliability as discussed in chapter 3 and it has helped to reveal the barriers and enablers to attendance and thus has key implications for clinical practice. In addition, being a self-report questionnaire, there may be some element of bias associated with self-reported measures of behaviours (Asimakopoulou and Hampson 2005).

In summary, whilst the current research might be considered to be limited by the above constraints, the results have contributed to and strengthened the evidence base in respect of the problem of non-attendance (Benoit et al 2004; Gucciardi et al 2008b). This is particularly relevant in respect of research relating to the UK which is acknowledged as being scarce.

9.8. Directions for future research

Although the three phases of the study have explored the research questions and therefore contributed to the evidence base on this phenomenon, non-attendance in multi-disciplinary education centres is a complex area of enquiry that requires further research to ascertain ways to motivate attendance (Lawal 2014; Gucciardi et al 2012; Temple and Epp 2009). As this issue remains relevant with broad appeal to the government and practitioners working with people affected by diabetes and long-term conditions in general, there is a need for further research targeting the non-attenders regardless of the difficulty in reaching them. Testing the strategies identified earlier is beyond the objectives and scope of this study, hence future research is needed to pilot and evaluate these strategies before implementation. Therefore, this thesis proposes that strategies such as the prescription of diabetes education by GPs, provision of an online interactive learning package, the use of a volunteer system for follow-up of patients, community-based diabetes education and modified operational procedures such as offering flexible appointments and choosing an appointment date from the website need to be tested. Finally, further research studies

expanding on this phenomenon can build on the methodological limitations identified by this study, for example, by using a larger sample size and multi-settings with bigger geographical locations.

9.9. CONCLUSION

The problem of non-attendance in clinical practice is a complex and recognised phenomenon (Graber et al 1992; Benoit et al 2004; Lawal 2011). However, until the current research programme no study in the UK had explored the reasons for non-attendance in Diabetes Education Centres. In relation to diabetes education policy, previous research in the UK has focused on developing new and existing education programmes (Chaney et al 2012; Savage, Dabkowski and Dunning 2009), identifying the demographic characteristics of non-attenders (Masding et al 2010) and investigating the effects of education on biomedical measurements (Davies et al 2008) to the detriment of assessing patients' motivation for attendance. Therefore, this area of study is important in the UK considering the prevalence of type 2 diabetes and the need to empower patients throughout the disease trajectory. The increasing focus on preventive health interventions globally (WHO 2008) and in the UK (DH 2008) denote that exploring barriers to attendance at Diabetes Education Centres is crucial (Lawal 2014b; Gillibrand 2010a; Zailinawati et al 2006).

Furthermore, there is no previous study examining the barriers and enablers to attendance in diabetes education programmes that has used a three phase

sequential multiple method involving focus group, individual interviews and questionnaire surveys. Similarly, no single study has explored the views of diabetes educators, referring practitioners, attending and non-attending patients. In addition, most studies on this phenomenon have failed to explicitly investigate ways of developing strategies to overcome the barriers (Ngwenya, Van Zyl and Webb 2009; Temple and Epp 2009). The strength of the current research lies in its use of multiple methods to identify barriers, motivating factors and strategies to overcome barriers to attendance at a Diabetes Education Centre. As a result of the findings, future practice should not be based upon the current principle of one size fits all. Instead, this thesis proposes a model of delivering structured patient education that incorporates patient-centred approaches to encourage people to attend the sessions, such as influencing patients through information, offering flexible appointments and offering multiple and flexible methods of delivery.

Limited international study has also been undertaken on this phenomenon within the context of the Health Belief Model (HBM) (Becker et al 1978). The current research has assessed patients' perceptions, beliefs and attitudes in all three phases of the study using a sample population in the UK. The results indicate that practitioners need to support the patient and influence positive health beliefs to increase attendance. Thus, the current study highlights the relevance of the HBM in explaining the patients' motivation to attend structured patient education

and therefore serves to extend previous HBM research (Graziani et al 1999; Clarke et al 2000; Hsu and Gallinagh 2001; Bayat et al 2013).

Recent NHS reforms have given incentives for referring newly diagnosed patients with diabetes to Diabetes Education Centres (NHS Employer 2013). Although the government has made some advances in promoting self-care education, it shows that resolving the issue of non-attendance at Diabetes Education Centres is not dependent upon one factor such as provision of incentives. It is therefore suggested that the desired outcomes to be measured should consider the number of referrals that generate attendance, patient satisfaction of the session and willingness to attend future sessions. In addition, the present NHS structure is complex and frequent restructuring will continue to influence clinical practice in the foreseeable future. Therefore, practitioners need to respond positively to these changes to meet the public health needs of people with type 2 diabetes to ensure that patient-centred care is at the heart of what they deliver.

However, the current practice is prone to fuelling non-attendance, hence, understanding the barriers associated with all stakeholders (patients, practitioners and the government) is important for both the practitioners and the government to be able to circumvent these barriers to achieve positive health outcomes. Consequently, this study has demonstrated that strategies have to be implemented at the individual, practitioner, organisation and government levels.

Furthermore, it has demonstrated that practitioners need to be influential in formulating and evaluating public health policy to devise strategies for its success. This is essential because it demonstrates that the current regulation of rewarding referral is not sufficient to enhance attendance.

The research presented in this thesis sought to investigate the challenges, barriers and prospects of implementing the government's policy of education for all patients affected by diabetes in order to offer insight into how to overcome some of the challenges and maximise benefits of diabetes education programmes and increase attendance. The results demonstrate that non-attendance resulted from healthcare beliefs, personal circumstances of the patient, ineffective communication, organisation of care and bureaucratic processes. As a result of these findings, this thesis has proposed a novel framework of clinical practice (REPAIR) and in doing so has added to the body of knowledge on how to engage with hard to reach populations with type 2 diabetes who are at a high risk of developing complications due to a deficit in self-care knowledge.

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Appendices

LIST OF APPENDICES

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Appendix 1

Table 3. Characteristics of the 14 articles included in the systematic review.

Source	Location	Aim	Sample	Design and method	Key findings	Limitations
[#1] Benoit et al (2004)	USA	To investigate factors that are associated with attrition from a diabetes education project	573 in total: 504 people who stayed for at least 6 months and 69 who dropped out	Case-control retrospective study using medical charts	The predictors of drop-out were insurance status, high blood pressure or HbA _{1c} and smoking.	<ul style="list-style-type: none"> Retrospective data analysis Focused on participants' characteristics Failure to assess participants' perceptions, beliefs and other attributes such as distance and work schedules
[#2] Graber et al (1992)	USA	To determine the reasons why patients drop out from ongoing diabetes medical care, education and nutritional counselling	422 people with type 1 and type 2 diabetes	Retrospective survey using medical records	Drop-out rate was influenced by distance of over 100 miles to the education centre, non-insulin treatment and cigarette smoking.	<ul style="list-style-type: none"> Retrospective analysis Limited information about follow-up care Failure to distinguish between the various insurance coverage
[#3] Graziari et al (1999)	USA	To examine the use of diabetes education programmes	Convenience sample of 150 people with type 1 and type 2 diabetes who attended a non-acute clinic	Descriptive survey of one open-ended question	The reasons for non-attendance were lack of time, lack of transportation, low level of education of the participant, stress, being unaware of the programme, low perception of the seriousness of the disease, denial/fear, lack of interest and no perceived benefits of the session. Another contributory factor for non-attendance was the perceived cost caused by a lack of awareness that insurance premiums covered the session.	<ul style="list-style-type: none"> Small sample size with convenience sampling technique Sample population was largely African-American (females from a university-based family practice (limited generalisation))
[#4] Cuccardi et al (2007)	Canada	To assess utilisation pattern and identify factors that are associated with attrition in diabetes self-management education	536 people with type 2 diabetes who attended a diabetes education centre for the first time	Retrospective study using medical charts of first-time visitors	Factors associated with attrition from recommended education programme were over 65 years of age, working full or part time and primarily speaking English.	<ul style="list-style-type: none"> Retrospective analysis Difficult to conclude what factors are responsible for the outcomes Possibilities of incomplete data on clinical and contextual factors Limited generalisation
[#5] Cuccardi (2008)	Several countries	To examine the factors that are responsible for attrition in either diabetes clinics or diabetes education centres	14 research studies	Systematic review comprising 1704 people with diabetes	Reasons for defaulting were feeling unwell, inability to take time off from work, being too busy, having a family physician, not being interested, forgetting the appointment, being unable to contact the clinic, family problems, finance, transportation, distance and the programme not providing new information.	<ul style="list-style-type: none"> Thirteen of the 14 studies were conducted retrospectively Most studies related to clinic appointment as opposed to diabetes education Most studies surveyed the opinion of people after they had attended an initial visit to the centre Focus of most studies was on socio-demographic and clinical factors, with limited attention to psychosocial and contextual reasons Most studies performed descriptive analysis Studies using diverse methodologies with small sample sizes
[#6] Cuccardi et al (2008a)	Canada	To determine whether men and women with type 2 diabetes have different behavioural, psychosocial and clinical characteristics during first contact with diabetes education centre	275 men and women with type 2 diabetes attending first appointment	Cross-sectional study using medical charts and questionnaires	Men and women have different psychosocial and behavioural characteristics that can affect attitudes and behaviours towards diabetes education. These include differences in previous exposure to diabetes education and expectations of the benefits.	<ul style="list-style-type: none"> Participants were users of diabetes education centres The differences between both sexes were observed at a single point
[#7] Cuccardi et al (2008b)	Canada	To examine the factors that are associated with attrition behaviour in diabetes self-management programmes	267 people with type 2 diabetes who attended a diabetes education centre: 118 who dropped out	Retrospective, cross-sectional study consisting of a review of medical charts and a telephone interview	Factors contributing to attrition behaviour in the study were full or part time work, aged over 65 years, fewer diabetes symptoms, confidence in knowledge and ability to self-manage, regular physician consultation, low perceived seriousness of diabetes and lack of familiarity with the centre and services.	<ul style="list-style-type: none"> A single open-ended question was asked Quantitative data were collected retrospectively

Table 3 (continued). Characteristics of the 14 articles included in the systematic review.

Source	Location	Aim	Sample	Design and method	Key findings	Limitations
[#8] Cuccardi et al (2009)	Canada	To identify factors associated with attrition in diabetes self-management education services	268 people with type 2 diabetes who attended a diabetes education management centre	Descriptive prospective study using a questionnaire	Failure to attend the sessions was due to inability to adhere to weight loss, recent diagnosis of diabetes, male gender and smoking.	<ul style="list-style-type: none"> Items focused on psychosocial and behavioural measurement as opposed to assessing the barriers to attendance Analysis was based on the number of contacts made in the hospital
[#9] Cuccardi et al (2012)	Canada	To explore participants' utilisation of diabetes education centres and the barriers to attendance	221 people with prediabetes, type 1 or type 2 diabetes in total; 159 attenders and 62 non-attenders	Internet survey and hard copy or type 2 diabetes in questionnaire	Failure to attend the sessions included the condition not being considered as serious, diabetes education not being a priority, perceived futility of the service, insensitive interaction with the professionals and inconvenient timing and location. Other factors included parking issues, language problems and illness.	<ul style="list-style-type: none"> Small sample size Convenience sampling technique Lack of qualitative data to provide comprehensive information
[#10] Rhee et al (2005)	USA	To explore patients' perceptions of barriers to diabetes education	605 people (95% with type 2 and 5% with type 1 diabetes) who attended a diabetes clinic for an initial visit	Cross-sectional survey using a questionnaire	The potential barriers reported were poor vision, inability to read well, problems with hearing, English language problems, older age, employment status and low level of education.	<ul style="list-style-type: none"> Self-developed questionnaire A cross-sectional study that reported anticipated barriers
[#11] Schafer et al (2013)	Germany	To describe the reasons for non-participation in type 2 diabetes education programmes	297 people with type 2 diabetes: 165 attenders and 132 non-attenders	Cross-sectional observational study using results from a postal survey and a medical chart review	Factors influencing non-participation were a belief of sufficient knowledge of diabetes; a feeling that the physician is responsible for diabetes management, the purpose of diabetes education not being clear and negative feelings about the course and groups of people. Barriers were also due to distance and travel expenses, physical and excessive demands of the education (e.g. difficult contents, occupation-related time pressure or working schedule, family-related time pressure and problems with vision and hearing).	<ul style="list-style-type: none"> Small sample size Retrospective data collected through medical chart Inclusion of self-developed instrument
[#12] Sprague et al (1999)	USA	To assess the perspectives of diabetes educators on potential barriers to successful diabetes education	1996 members of the Washington Association of Diabetes Educators were invited to participate; 143 practitioners responded	Descriptive study using a mailed questionnaire	Barriers to attendance relate to lack of understanding of the nature of diabetes and the need for educational support, unaffordable follow-up care and lack of insurance cover for education.	<ul style="list-style-type: none"> Self-developed questionnaire Responses are perceptions of practitioners, which may not directly represent patient views
[#13] Temple and Fpp (2009)	Canada	To evaluate the characteristics of attendees and non-attendees for non-attendance at diabetes/heart health education programmes	A convenience sample of 124 people with type 1 and type 2 diabetes (62 attendees and 62 non-attendees)	Cross-sectional descriptive study using a telephone questionnaire	Barriers to attendance were due to participants being busy; transportation, work-related problems and other health issues that were more important. Other barriers included forgetting, needing the doctor to manage their disease, the participant not needing help or never having heard of the service.	<ul style="list-style-type: none"> Self-developed questionnaire Low response rate due to futile repeated phone calls Low sample size with convenience sampling technique
[#14] Uluwral et al (2005)	Turkey	To assess the association between patient characteristics and compliance	45 people with type 1 or type 2 diabetes who attended a diabetes education session	Controlled experimental study consisting of interviews	The characteristics of participants that influenced attrition from the education facilities were having diabetes for over 5 years and relatively poor knowledge of the seriousness of diabetes.	<ul style="list-style-type: none"> Small sample size

Appendix 2

THAMES VALLEY UNIVERSITY
Faculty of Health and Human Sciences
Faculty Research Ethics Committee
The Annexe, Block H, Paragon Site,
Brentford, TW8 9 GB
Tel: + 44 (0) 208 209 4110
Fax: + 44 (0) 208 209 4143
E-mail: heather.loveday@tvu.ac.uk
www.richardwellsresearch.com

18 March 2008

Mr Muili Lawal
FHHS
TVU

Dear Muili

Re: Application for Ethical Approval No. FREC54/Jun07

Thank you for your email correspondence in respect of your revised ethics application and the changes you were making to the initial application. The clarification you have provided regarding these changes offers sufficient information for me to confirm the approval of the Research Review Committee and enable you to proceed with your project.

The Committee must be informed of any changes to the research proposal and methods as this may entail the need for additional review. A report on the progress/completion of the research is required in 12 months or on completion of the research, whichever is the sooner. The Committee wish you well with the research and look forward to your report.

Yours sincerely

Appendix 3

16 June 2008

Mr M.O Lawal

Thames Valley University
Faculty of Health and Human Sciences, Room C34
Wellington Street, Slough
SL1 1YG

Dear Mr Lawal

Full title of study: Barriers associated with uptake of group education:
Innovative approach to diabetic health education and
self-management.

REC reference number: 08/H0505/73

Thank you for your letter of 28 May 2008, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

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 at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	1	16 April 2008
Investigator CV	1	16 April 2008
Protocol	1	16 April 2008
Covering Letter		10 April 2008
Summary/Synopsis	1	16 April 2008
Letter from Sponsor		
Questionnaire: Appendix 5b	2	30 May 2008
Questionnaire: Appendix 5a	2	30 May 2008
Letter of invitation to participant	1	16 April 2008
Participant Information Sheet: Practitioner	2	28 May 2008
Participant Information Sheet: Patient	2	28 May 2008
Participant Consent Form: Practitioner	2	28 May 2008
Participant Consent Form: Patient	2	28 May 2008
Response to Request for Further Information		28 May 2008
TVU Ethics Approval letter		18 March 2008
Research Degree Registration		04 July 2007
Berkshire East PCT R&D Letter		07 April 2008
Marsh UK Insurance		25 September 2003
CV: J Magill-Cuerden	1	16 April 2008
Sponsor signature page	1	25 March 2008
Section 6 of SSA Form: Site Name	1	17 April 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix 4

Date: 1st July 2008

Mr O Lawal

West of England
Wessex Valley University
Faculty of Health & Human Sciences, Room C34
Bristolington Street
Bristol
BS1 1YG

Dear Mr Lawal

I am pleased to tell you that your project has received approval from Berkshire East

and you now have permission for this research project to proceed in
**Priority areas associated with uptake of group education: Innovative approach to
genetic health education and self-management'**.

We would be grateful if you could let me know when the project has finished and send
a copy of the final report.

If there are any serious adverse events associated with this study, you must send a
copy of the reports to the Clinical Development Unit as well as to the relevant Ethics
Committee.

We will be monitoring the project and would like to have bi-annual updates on the
progress of the study.

Routine auditing of a sample of Research projects will also take place.

Yours sincerely

Clinical Audit and Research Manager

Appendix 5

Muili Lawal

Subject: FW: 6079 WAM Diabetes Project

From: FOIresponse (NHS W
Sent: 05 February 2015 13:40
To: Muili Lawal
Subject: RE: 6079 WAM Diabetes Project

Dear Muili,

Further to our previous emails, and with apologies for the delay in replying, I can advise that NHS [redacted] CCG give permission for you to undertake this follow up to a study and would be pleased to receive a copy upon completion as this would be of interest to the CCG.

Yours sincerely

C
B
K
E
[redacted] **Communications and Fol Coordinator**

[redacted] **NHS**

Clinical Commissioning Group

[redacted] **NHS**

Clinical Commissioning Group

[redacted] **NHS**

Clinical Commissioning Group

The information in this email may be confidential and is intended solely for the named addressee(s). If you are not the intended recipient, any disclosure, copying or distribution is prohibited and may be unlawful. Please note that the information contained in this email /attachment(s) may be subject to Public disclosure under the Freedom of Information Act 2000.

From: Queries HRA (HEALTH RESEARCH AUTHORITY) [mailto:hra.queries@nhs.net]
Sent: 23 December 2014 15:26
To: Muili Lawal
Subject: RE: Inquiry

Dear Mukli

Thank you for your enquiry.

Is your project research? / Does it require ethical review?

If your project will be taking place within the NHS, you should seek the advice of your local R&D office in the first instance. Contact details for NHS R&D offices are available on the [NHS R&D Forum website](#).

The Health Research Authority (HRA) provides two linked, online decision tools to assist you in determining whether your project is classified as research and whether it requires ethical review by a NHS REC. These tools are available at:

- **Is it research?**
- **Do I need NHS REC review?**

These tools are based upon the information contained in the following HRA guidance:

- **"Defining Research"**. This provides more detailed information to help you decide if a project is research, or whether it is some other activity such as audit, service evaluation or public health surveillance.
- **Does my project require review by a Research Ethics Committee?** This leads you through the requirements for ethical review under both the policy of the UK Health Departments and legislation applying to the UK as a whole, or to particular countries of the UK. The **Supplementary notes** section outlines the types of research that do not normally require review by a NHS REC.


Provided that the information you have entered is correct the outcome delivered by the decision tools may be taken as an authoritative decision. You do not need to seek further confirmation.

However, if after using the decision tools, you disagree with the outcome or are unsure of whether you have answered the questions appropriately, further clarification can be obtained by contacting the Queries Line (hra.queries@nhs.net). If you are requesting further advice your email should include the following information:


- Project title
- IRAS Project ID (if available)
- An A4 summary outlining your proposed project (one side only: 1,000 words max)
- A PDF or screenshot of the results page of the decision tool(s)
- An explanation of which questions you have difficulty in answering and why and/or
- An explanation of why you disagree with the outcome of the decision tool(s)

We will be unable to process your further enquiry if you do not provide the information requested above. Please note: responsibility for determining if an activity is research (and whether the research requires review, including ethics approval within the Research Governance Framework) sits ultimately with the sponsor and investigator.

~~Go straight to content.~~



Health Research Authority



Medical
Research
Council

Do I need NHS REC approval?

This decision tool suggests that you do not need NHS REC approval, however, you may still require another type of ethics committee review, e.g. Higher Education Institutions (HEIs) ethical approval.

Researchers in HEIs are advised to check whether, under their institution's policy and internal arrangements, ethical review is required by their HEI research ethics committee.

Exceptionally, the Research Ethics Service may accept an application for review of research at the request of the **sponsor, chief investigator** or host organisation, where it agrees that the proposal raises material ethical issues. Agreement should be sought from the responsible operational manager for the local REC centre prior to submission of the application.

Requests should be sent by email, including a summary of the research proposal (maximum one page) and explanation of why the project raises significant issues which cannot be managed routinely in accordance with established guidelines and good practice, and requires ethical consideration and advice from an NHS REC. Contact points for operational managers can be found on the **HRA website**.

Researchers requiring further advice (e.g. those not confident with the outcome of this tool) should contact their R&D office or sponsor in the first instance, or the HRA to discuss your study. If contacting the HRA for advice, do this by sending an outline of the project (maximum one page), summarising its purpose, methodology, type of participant and planned location as well as a copy of the previous results page and a summary of the aspects of the decision(s) that you need further advice on to the HRA Queries Line at **HRA.Queries@nhs.net**.

Follow this link to start again.

- **About this tool**
- **Feedback**
- **Contact**
- **Glossary**

~~Go straight to content.~~



Health Research Authority

Medical
Research
Council

Do I need NHS REC approval?

1 To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

Exploring barriers associated with uptake of Structured Patient Education: examining policy implementation for patients with type 2 diabetes

IRAS Project ID (if available):

171793

Your answers to the following questions indicate that you do not need NHS REC approval for sites in England. However, you may need other approvals.

You have answered 'YES' to: Is your study research?

You answered 'NO' to all of these questions:

Question Set 1

- Is your study a clinical trial of an investigational medicinal product?
- Is your study one or more of the following: A non-CE marked medical device, or a device which has been modified or is being used outside of its CE mark intended purpose, and the study is conducted by or with the support of the manufacturer or another commercial company (including university spin-out company) to provide data for CE marking purposes?
- Does your study involve exposure to any ionising radiation?
- Does your study involve the processing of disclosable protected information on the Register of the Human Fertilisation and Embryology Authority by researchers, without consent?
- Is your study a clinical trial involving the participation of practising midwives?

Question Set 2

Appendix 6

Thames Valley University/
PCT

Focus Group Discussion

You are invited to a one off meeting to discuss:

Title: Barriers associated with uptake of patient education

The challenges of a fairly large proportion of DNA for diabetes group education will be the aim of our discussion. Your role is to contribute your views about issues surrounding non-attendance. This first phase of the three stage study will inform the development of patient questionnaire survey and a further one to one patient interview.

Moderators: Muili Lawal/Dr -----, TVU

Date: Monday 24th November 08

Time: 15:00 to 16:00 hrs

Venue: Diabetes Centre
England

For further details, please contact ----- by email-----
@berkshire.nhs.uk or phone 00000000000.

We look forward to seeing you there!

Refreshments will be served.





Thames Valley University
London Reading Slough

Participant Information Sheet for Practitioner

A study to explore barriers associated with uptake of group education.

There is a worldwide increase of diabetes and the economic cost of diabetes continues to rise. Type 2 diabetes accounts for the majority of cases and group education currently form an important aspect of type 2 diabetic management. Therefore, you are being invited to take part in a study to explore why people attend or do not attend patient education designed to aid positive self-care behaviour. Before you decide to participate in this study, it is vital to understand why the study is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information.

Thank you for reading this.

Who am I?

I am a Senior Lecturer in the Faculty of Health and Human Sciences of Thames Valley University and a Doctoral student in Public health. I have a specific interest in the care of people with diabetes.

What is the purpose of the study?

The aim of the study is to explore ways of improving uptake of group education offered to type 2 diabetic patients. Therefore, specific attention would be paid to:

1. The social, cultural and psychological factors associated with failures of patients to attend group education as a way to promote self-care.
2. Things that could be done to enhance attendance.

Do I have to take part?

Participation is entirely voluntary. However, your opinion is important to us and will directly affect the outcome of the study. However, if you decide to take part you will be required to sign the consent form. If you decide to take part you are still free to withdraw at any time without giving a reason.

Why have I been chosen?

You have been chosen because you are either involved in referring patient to education clinic or offering group education to the patient for the purpose of developing their diabetic self-management skills. This study seeks to explore your views and perceptions of problems associated with attendance.

What will you have to do if you decide to take part?

You will be asked to take part in a focus group interview. The interview will last for 1-2 hours and there will be 6 - 8 participants in the group. Your responses will be recorded on the flip chart by a moderator. Also, the interview will be tape recorded because it is important to keep accurate responses.

How do we protect your identity?

If you agree to take part, your consent form and recorded responses from the focus group interview will be kept in a locked cabinet within the University premises. All the information you give will be stored on a password protected computer and used to improve the health education provided.

What will happen to the information supplied?

The results of this study will identify ways to improve attendance rate of group health education for patients in relation to type 2 diabetes. It is also thought that findings from this research will inform the development of an appropriate training programme that will meet the needs of educators in promoting patient motivation in group education designed to promote patient self care. Also, the results will be shared with all the participants and the intention is to present it in appropriate conferences and publish it in a peer review journal.

Who has reviewed the study?

As a Doctoral student, the study is being supervised by senior members of staff. My supervisors are Dr Julia Magill-Cuerden, Dr Tony Olden and Dr Dave Sookhoo.

What do you do now?

If you are willing to participate in the research, please sign the consent form.

Contact for further information.

If you would like any further information please feel free to contact any of the following people by phone or email

Mulli Lawal, Senior Lecturer, Thames Valley University, Faculty of Health & Human Sciences, Room C34, Wellington street, Slough. SL1 1YG

Tel: 01753697025

Email: Mulli.lawal@tvu.ac.uk

Appendix 7



Thames Valley University
London Reading Slough

CONSENT FORM

Title of Project: A study to explore barriers associated with uptake of group education.

Name of Lead Investigator: Muili Lawal

Please tick the box

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

I confirm that I understand that my participation is voluntary and I can withdraw at any time without given any reason.

I agree to take part in the above study *by filling the questionnaire.*

I wish to be contacted for the interview

I give consent for the interview to be recorded

I give consent for anonymous quotations to be used.

Name of Participant

Signature

Date

Researcher

Signature

Date

Please return to Muili Lawal, Thames Valley University, Faculty of Health & Human Sciences, Room C34, Wellington Street, Slough. SL1 1YG

Attendance sheet

DNA focus group held at Diabetes Center, England on the 24th November 2008.

In signing this register I declare that I will openly discuss my views.

Name	Designation	Signature

Appendix 8

Research questions guide
Ask questions in a conversational style (Clarification and probing).

The following questions will be used to guide the focus group discussion.

- (1) There is evidence to suggest that education helps to alter people's behaviour and the Government has education policy for diabetes patients. What is your view about the Government recommending education for all the newly diagnosed patients with diabetes?
- (2) Based on your experience; tell me some of the factors you feel might hinder patient attendance?
- (3) Do you think they have got genuine reasons for not attending or not?
- (4) Can you explain ways you have used in the past to motivate patients to attend?
- (5) Can you explore some of the challenges confronting you in promoting attendance?
- (6) What do you think can be done to reduce non-attendance?
- (7) What might help you to enhance attendance?

Appendix 9

FOCUS GROUP MEETING
Stage 1 coding

Q1. Please can you tell me why you think patients are not attending?

J: Because they do not have a perception that it is important and the G.P.'s don't always have a perception that diabetes education is important.

Comment [fa1]: G P & patient have negative perception about the importance of diabetes education

Q2. ...And you think the G.P's are not emphasising the importance?

J: In my personal view yes, I think some G.P's don't emphasise the importance of attending.

Comment [fa2]: G P's don't emphasise the importance of attendance

V: They are quite vague in referring patients to King Edward. The patients don't know why...

Comment [fa3]: G P & PracticeNurses are vague in referring patients

J: They don't actually know what they are coming to, I don't think people understand fully what a structured patient group education (SGE) is and also a lot of health care professionals don't understand. I think that's what part of our problem is and why they don't.

Comment [fa4]: Poor understanding of SPE among patients and health professionals

S: The frightening thing is that sometimes patients aren't even aware that they have diabetes. Another thing is how important it is to attend the actual structured education I think that is not emphasised enough by all of the staff either, whether it is the practitioners or whether it is the G.P's themselves.

Comment [fa5]: GP & Practice nurse don't stress the importance of SPE

B: I think there's also a perception as well that diabetes is very much around eating a healthy diet and keeping active and people probably feel quite defensive and maybe think that they are actually doing those things already and don't want to come and perhaps feel that they are being told off.

Comment [fa6]: Poor understanding of the nature & care of diabetes among the patients

C: I think that a lot of patients don't recognise diabetes as a serious condition and I think that their actual awareness is still that especially in type II diabetes, that it's still a mild condition.

Comment [fa7]: Some patients think diabetes is a mild condition

H: I think there's terminology as well because people are used to being sent an appointment to attend a clinic and when they see the word education they may not attach as much importance to that. Or again whatever wording you use in the letter patients often come with the misconception about why they are actually here.

Comment [fa8]: Practitioners use of technical terms may lead to misconception

A: It's not held at suitable times for instance we don't offer weekends, lunch time, evenings so that potentially means people taking time out of work. They may not have told their employer that they have diabetes or they may not want anyone to know. So

Comment [fa9]: Unsuitable timing of the education session

Comment [fa10]: Some patient keep their diabetes as a secret

B: Even the cost of parking or cost of transfer from Slough to Windsor maybe, for a lot of patients seems to be a long journey. They may not have any transport.

Comment [fa11]: Cost of parking

Comment [fa12]: Distance

V: I think the appointment system isn't great but it is improving depending on the different localities, Maidenhead is quite good because they use a different system to what we use over here.

Comment [fa13]: Lack of personal transport

Comment [fa14]: Appointment system is not great in some localities

Q3. What are they using in Maidenhead?

H: They would send the patient a letter asking them to ring to make an appointment. To book onto the session they'd just send a letter saying you've been booked.

Comment [fa15]: Give responsibility to book for education session to patients

Some localities they had a choice so it was really put on the patient to ring and say yes they would go to the clinic and attend the education on a particular day, whereas in other localities they were just sent a letter to say attend at a day/time.

Comment [fa16]: Offering choice of time to patients

Q4. If the patient is given freedom to choose when to attend education you think this would improve attendance - sending a letter to pick a date and time?

J: At least you also know they've rung in and are likely to attend. Is there any back up for people who didn't ring; has anyone followed up who didn't receive the letter?

Comment [fa17]: Follow up letter of invitation and telephone calls

H: Not that I'm aware of.

A: I think there is a lot of fear attached because it is based at a hospital and I think that plays quite a large role, the fact that they come to hospital for education.

Comment [fa18]: Offering education in the hospital creates some fear

S: I think it is best to start when the G.P. is referring and assess the patient what they are like and their understanding and making sure why it is important for them to go and where it is been held, and as I've said it can work both ways especially in the Slough locality the patients perception is that if I'm going to a specialist clinic/hospital they would attend the appointments because they've been called along to a specialist clinic. But it could work the other way as Hayley was saying that if they've been referred to a specialist they might be fearful of going to the hospital. So it can work both ways but I think the primary aim is really to inform the patient why they are going, what they are going for, what they are going to learn from there and what they are going to achieve from there.

Comment [fa19]: Referring GP to inform the patients about where, why and what to expect

Q5. With what I am gathering, it seems if the people referring them are offering a choice you think that would enhance the attendance?

S: Definitely. Yes definitely I mean if somebody gives you a little letter saying here you are you've got diabetes now you've got to go there, what for? As I've said so when they come to see us their perception is that they have to have a blood test done, an ECG done this and that done, you know really they are not aware they are coming for an education session. They need to be informed how we can look after you, that is not relayed to the patient they are just give a piece of letter saying, you know, go and see....

Comment [fa20]: Inadequate information given during referral

J: When the surgeries who were doing the pilot did it, they have all those letters and they still failed to give those to the patients, so one of the problems is the fact that there needs to be more education for the practices; because even when they had more information even with the pilot quite a big letter went out similar to the choice letter covering ten points of what was covered and expected. I'm not sure anybody turned up or learnt anymore during those three months ---- did they?

Comment [fa21]: The need to provide education for GP practices about the importance of SPE

V: Moving on from that as well you've got to look at the wider scale what G.P's are actually being targeted against and providing type II education is not high on the agenda at the moment whereas a quick fix to get the HbA1c levels is going to be much higher on their priority list. So it may not even be the G.P's, it needs to go back a step further for the government to be promoting how important this is and attaching some value to it. They don't get any remuneration for it at the moment, that's my understanding.

Comment [fa22]: Government target for GP does not reward provision of education

H: I think a group session can sometimes be a little intimidating or they think so initially. I'm not even sure they are aware sometimes that they are coming to a group session....And I think sometimes the time three hours, I've got to sit for three hours.

Comment [fa23]: Group education may be intimidating

Comment [fa24]: 3 hours session may be too long for some patient

B: They're not given any information are they of what to expect when they do arrive, because I know in another place they actually send out a load of information on diabetes, what it is and a questionnaire and they bring that along to their session.

Comment [fa25]: Not giving enough information on what to expect

C: I think it stems down to the general public as a whole are not informed of the seriousness of the condition. If there were shocking pictures and posters and complications related to diabetes, if they knew relatives or friends who had an amputation or suffered a devastating condition then they would relate it to themselves. At the moment I feel our society is too....

Comment [fa26]: Painting frightening pictures of diabetes to emphasize its seriousness

J: Sometimes it can have the opposite effect.

Comment [fa27]: Frightening pictures may have negative effects

H: Should we tell them what we learnt this week three deaths per minute from diabetes related complications?

C: If patients had to pay for their health maybe they would take more effort to look after themselves.

Comment [fa28]: Introducing payments to motivate patients

J: No. having seen countries where it's neglected even more

S: I was just thinking about Kenya where we have to pay for our services, there was a lot of people who did not want to access the service because they had to pay, they could not afford it, those are the patients probably who get more complications and ended up in hospital.

Comment [fa29]: Payment may demotivate some patient

B: It's definitely educational and it is the G.P's and practice nurses pushing and stressing the importance of educating themselves.

J: It's down to us to market what we are providing.

A: Definitely the people who know what they are coming for get more out of the session. They've got their questions, they know exactly what to expect and what they want to be having at the end of that session. So the people who are aware get more from the sessions.

Comment [fa30]: Awareness of what to expect in SPE promote its benefits

B: ...And for the patient wanting to come to the sessions not saying you've got to go...well you get people who just turn up because they've been given a letter to come and they spend the three hours asleep we get them up all the time.

J: I know we get the ones who come in to sleep but we generally we get the ones that are going to take part that's why they turn up. What we are trying to address are why the other percentage...in Slough it's a 40% rate why is that I can't believe that's down to....

Comment [fa31]: Some attend the session but sleep most of the time

Comment [fa32]: Too high non-attendance of up to 40% In some area is unacceptable

V: I think it's interesting, I've seen a difference over the years in that ten years ago people felt more unwell when they had been diagnosed because they were not picked up as early as they are now. When they actually had the symptoms they would be more inclined to access help, whereas now often they feel perfectly well and fine and perhaps don't understand the implications.

Comment [fa33]: Patients' don't see the value of education when they are well

Q6. With your experience you said the people who are motivated to come tend to participate well/better with the education...

J: We see most of the motivated ones aren't we then the few that come because they've been told by their G.P to come. The other bits we are more concerned about are the ones who are not motivated and why, with the ones who sleep hopefully something might have gone in.

Comment [fa34]: Patient who come to sleep are more motivated than those who do not attend

V: I do think the appointment system has a big role to play if you look at Maidenhead they generally have better attendance than we do....

Comment [fa35]: Appointment system has a role to play

...But Maidenhead is still part of this Trust

V: Oh yes it's the same education that's provided its just a different environment and it was set up as a different way of offering the appointments it was perhaps a more personal touch to it.

Comment [fa36]: Appointment system with more personal touch do help

How did they do it?

J: They were allowed to ring in, the actual onus was put on the patient to ring...yes because they had a dietetic secretary who would ring up and negotiate the appointments...at that point of call they got further information as well as what it is.

Comment [fa37]: Giving patients responsibility to ring and negotiate appointments do help

Normally the G.P would refer them to you, so you are now thinking if the secretary from these places now sends a letter offering them to call might help ...

A: ...But isn't that what is happening now, isn't that what she is doing?

J: I mean at the moment we're trying to catch up, because we actually have somebody coordinating the appointments for everybody and that's in the middle of being sorted out so that everything goes to one single person. I think in the future I think we will have I don't think she is ringing every single patient at the moment but...

Comment [fa38]: Adding personal touch to the appointment system involve additional personnel and time

But is she sending the letters out...

V: Yes she does send the letters out but at the moment she is not ringing anybody and realistically I'm not sure whether she would have the time to take that number of telephone calls we were talking about 50 odd a month.

Comment [fa39]: Ringing about 50 patients every month seems impossible now

J: Oh so she's just sending a letter out saying you've been booked for this date and time...If its not convenient ring me and there are other sessions you can go to in Berkshire East and at different times etc. or days of the week, but there is no way she could contact 50 people.

H: Could she maybe like send a letter and say please confirm....but even then she would not have the time available to do that.

Comment [fa40]: Follow up requires time

J: Again in the future you could delegate it but we are in the middle of changing over from what it was.

C: And that still doesn't really address why yes you may get those motivated enough to make the appointment but what about those who ignore the letter or how do we even know they've even got the letter.

Comment [fa41]: Some patients ignore the letter and some don't get the letter

Q. What would be the best way to improve the system here?

J: That's your job isn't it? That's why we're doing this - I thought you were going to tell us. To improve the system. A better appointments system and more resources to support a coordinated effort.

Comment [fa42]: A better appointment system

Comment [fa43]: More resources is required

Q. So you think if the government can provide more money or more staff...?

J: We don't get any money to provide education for the Trust. As such do we apart from obviously our time and the venues but we don't get any other money at the present moment to provide the education.

Comment [fa44]: Money is an issue

Q. So you think more resources could help you perform better, maybe three secretaries.

J: Yes. A website for different sessions we've talked about this before as sort of being our ideal wish, list that people could actually look on the system and choose when they wanted to come.

Comment [fa45]: Our aim is to design a website where patient can choose their appointment

V: Again that would only meet the needs of a certain percentage of the population. Some people wouldn't even go on the web, they don't know what a website is so I think you have to look at the other side.

Comment [fa46]: We need to consider the ability of the patient to use computer

B: I think there might be a role here because Sat had some health activists working with her in the Slough area people perhaps who may have diabetes themselves or who have an interest in chronic long term conditions, who may actually be able to act as an advocate and maybe they would have the time to ring up and speak to the person saying I understand you have been recently diagnosed - this is what's happening, this can help.

Comment [fa47]: The use of health activist to contact patient may help

S: Its certainly improved our uptake of attendance because when you use the health activist who wasn't a diabetic herself but she rang them asking why they hadn't attended what was the reason for not attending, would you like another appointment sent to you; and I think its contrary this is again Slough locality, because she spoke the lingo she stressed what the reason was for not attending and stressed what would be discussed at the education and the attendance did improve. So I think in a way we need to be sensitive as well to the culture.

Comment [fa48]: Health activist calling the patient do help

Comment [fa49]: Need to be sensitive to individual culture

Q. Are the health activist part of the staff or patients?

S No, no it's part of the staff health promotion staff which I could tap into to get some help from them but that's not available to me anymore...

V: The funding has gone hasn't it?

Comment [fa50]: Funding is a problem

S: Yes. I mean the other way of influencing people is what Hayley was saying about health promotion, a lot of our work is actually identifying groups of people who are vulnerable to developing diabetes and actually going out and talking in the hopes that if they do develop diabetes they'll then understand the importance of accessing care.

Comment [fa51]: Health promotion in form of talking to vulnerable people before they have diabetes

Q. ..And further you mentioned the issue of culture

S: I was just thinking for example if they've got ceremonies like Ramadan or Divali or some other events going on I think we need to be sensitive not sending the appointments on a particular month or whatever at least the DNA rate would decrease.

Comment [fa52]: Considering ceremonies like Ramadan and Divali

A: Would it be worthwhile looking at the people who are DNA including their background, what social class they come from, what age group are they, what religion etc..to see whether there is a pattern emerging from that.

The more educated higher class they've got more awareness would have more access to education and information are they more likely to attend? When I do the Deal programme I recognised that the people who seem to ask a lot of questions tend to be the people that are more middle class, you get the people who sit there and don't join in you could probably see that they're from a lower....

Comment [fa53]: More educated higher class people are more aware

Q. Do you feel a form of sanction would be a good idea, for example the Dentist do charge for non-attendance?

C: I think it would. I think as long as people have the opportunity to telephone to make some form of contact if they are not able to attend, I think that people should make more of an effort for their health. I think that our society the way we work at the moment we are carrying too much I think people need to make a conscious effort themselves to change their health.

Comment [fa54]: Patient need to take more responsibility for their health

J: ..But if they do not know the importance then that's still our role to...I know yes ultimately as they say you can take a horse to water but you cant make it drink but we do have a responsibility; are they DNA because they don't understand or they don't think it is important so do we just strike them off after one time. I fully agreed with what you said that people need to take responsibility for themselves...

Comment [fa55]: Patient to take responsibility for themselves

S: ...But wouldn't that demonstrate that there is a need to go out into the community to deliver the education.

Comment [fa56]: Going to deliver the education in the community

H: I don't know if waiting time has a role to play. I mean if you are waiting two months for education you going to either not bother or get it somewhere else yourself.

Comment [fa57]: The waiting time between referral and date of education may have a role to play

B: On the other hand if you've got time they can rearrange work I think if you have a couple of months then your are more likely to take the time off to go to the education.

Comment [fa58]: Waiting time may allow the patient to plan for work and other life routine

V: I think there are different needs for different people don't you? Because the way Carin is explaining it I mean if you had the option to do an e-learning course or something because that fitted in with your lifestyle you could access it straight away. Some people might prefer that option whereas some people might prefer to come to a group session and I think we'd limit choice by only having one way of delivering the education.

Comment [fa59]: Different people have different needs

Comment [fa60]: Option of offering education through e-learning

Comment [fa61]: Individual lifestyle

Comment [fa62]: Offering different choice of education

Q. But that is the government recommendation that they should be having a group structure education

J: No the recommendation is that they should be having structured education that doesn't necessarily mean in a group it could be one to one or online. For structured education you need a shared curriculum, lesson plans, it needs to be auditable, you have to have quality assurance for it and it has to be delivered by trained educators or set up by trained educators.

Comment [fa63]: SPE can be in different forms

Q. So we can have one to one but it is cheaper to have group education

J: Plus the fact that people learn from each other and it's nice to think that you're not the only person with diabetes. It's like anything when you're diagnosed with something you feel you're the only one diagnosed so people come here and help each other, I mean we have type I education and they probably learn more from each other than from the facilitators.

Comment [fa64]: Patient can support and learn from each other through group education

Q. ..And we are thinking that probably going out into the community to go and teach them in their local environment may enhance patient attendance, is that what Sat is trying to suggest?

S: Yes it might be, I'm just thinking if they are not coming what is the reason; is it transport? I am thinking of the Slough area they can't drive and they need to bring somebody along with them – whoever is coming along would have to drive them to the hospital they might need time off as well from work.

Comment [fa65]: Transport may be a problem

J: You could say in the local leisure centre they need transport, they need somebody to bring them in...

S: But whether they go to their G.P practices what they could do is contact the practices nearby and say...

J: Practices don't like that they don't like their patients going out.. I don't think it is going to change.

Q. Do you have any association with Diabetes UK at all? In what areas are they helping you with the education?

J: They don't help us with the education. Diabetes UK helps with events, raising awareness in the community but not actually structured education. I don't think there is any help available.

Comment [fa66]: Diabetes UK is helping with raising awareness

V: Having said that there is a member from the group in Bracknell isn't there who attends the local support group that they've set up but they do have somebody who attends the training sessions, not sure if it is always a positive experience for everybody.

Comment [fa67]: Support group may help some people

Q. So far what are the major challenges that are preventing you from delivering the education?

J: Not enough importance being stressed by the G.P.

Comment [fa68]: GP don't stress the importance

V: Lack of resources, the booking system, practice staff need to be emphasising the importance...

Comment [fa69]: Lack of resources
Weak booking system
Practice staff need to stress the importance of education

J: I don't think people understand the importance.

Comment [fa70]: Patient need to understand the importance of education

B: I mean we've tried with the temples and things gone in and did a six week programme its just people recognising how important it is for them to engage with us.

Comment [fa71]: Patient need to understand the importance of education

S: The thing is if you are feeling well as Vanessa was saying, then you don't want to come.

Comment [fa72]: Patient may not come because they are well

A: But people do go to the doctor for their medicines and what have you, the doctor maybe needs to pull them in and say you haven't been you should go and this is what you'll get from it and if they don't attend maybe the doctor should penalise them and that would make sure that they go.

Comment [fa73]: To apply a penalty for non-attendance

S: Its like the asthma patients if they are not having an asthma problem they'd never go for their asthma....

A: But diabetes is very different to asthma.

C: I mean sometimes we are a bit too soft because they say people only make changes to their lives unless they get a diagnosis of cancer or something,

perhaps we should be putting pictures of three deaths per minute or this or that might happen.

Comment [fa74]: Displaying a frightening picture of diabetes

H: In our group education we want to say if you do this, this and this it wont happen and we are a bit softly softly. I've probably changed dramatically in the last five years of how I educate people because ultimately they need to know.

Comment [fa75]: Talking in a tough way to the patient

A: You are quite firm and people just sit there and think I didn't know that all that could happen.

H: I think what's interesting though is that quite a lot of people do come to the education already have a complication, its often when you are going around that's what they actually start talking about.

J: Diabetes UK have done a lot on how important it is Type II is a silent disease.

Comment [fa76]: Diabetes is helpful in raising awareness

S: I mean its like any disease look at the smokers they've been told its going to kill you, give you cancer but I'm still smoking away and I think no matter how much you want yourself to be wanting to do things then you would do it. Otherwise no matter how much you say....

Comment [fa77]: Individual differences should be considered

A: The majority of them say I didn't know all this could happen so the G.P's and the practice nurses who are at the point of diagnosis are obviously not giving them the information that they should and need to be having.

Comment [fa78]: GP and practice nurses need to give more information

J: Because I think the practices its too down to the cough point they are driven by all the targets, they are not driven by patient care. Diabetes is so driven by the targets we've actually forgotten about the rest of it and that very much came over the weekend.....it is all about target.

Comment [fa79]: G.P's are driven by targets but not patient care

S: Its about understanding as well like you were saying do they understand the terminology I'm going to have a problem with my eyes, so what if I have the problem; but if I say you may go blind than put in simple terms then sometimes they do understand. Like cancer they will understand yes its going to cause you to have liver cancer if you don't look after yourself.

Comment [fa80]: Practitioners to talk to patients at appropriate level to avoid misunderstanding

C: But this is the reason why there needs to be some way of getting people to be aware so that they do attend, because we are looking at education it needs to be something on a wider something that gets out to the population.

Comment [fa81]: Creating awareness about the importance of education

H: Whether it should actually be like other education delivered in schools because of growing obesity in children, should this be something that is part of the national curriculum?

Comment [fa82]: Diabetes education can be considered to be part of the national school curriculum

J: Have we looked at how many people have been diagnosed at any given time and how many referrals we've had? What do the results show? How many

diagnosis of diabetes were made in that quarter and how many referrals were made?

V: We have statistics on the number of invitees and the number of attendants but not diagnosis.

J: Unfortunately we also know not all G.P's refer to us so its not really accurate.

A: We need to look at those practices that are referring and address those that aren't as a starting point.

B: When people are diagnosed the G.P would attach that information wouldn't they?

H: Yes, hope so.

J: So it's a big bit of work but you could see who is and who isn't.

C: I think the other thing we are assuming is that the G.P's and healthcare professionals know where and who to refer to but they don't.

Comment [fa83]: Lack of understanding of referral procedure by the GP and other healthcare professionals

V: I have to be honest here if every practice started referring every newly diagnosed patient we would not be able to cope with the capacity.

So there are a lot of misdiagnosis going on. In your present role do you have a link with the G.P?

J: To a degree because we can only go into practices really who invite us in, we built up a relationship perhaps if somebody has phoned up. We haven't got any directive from the PCT to go into a practice demand to see their diabetic clinic, its only by building up a rapport and relationship. We cant actively say we've come in and I'm Jan the diabetes nurse I've come to look at your diabetes clinic or paperwork, diabetes patients or how many people have been diagnoses perhaps over time....

Comment [fa84]: Poor link between the education centre and GP practices

S: You try to go in and explain your role....

J: But there is nothing from the PCT that says you can go in they are individual practices in their own right.

Q. Most people have mentioned the issue of resources do you think the government is not doing enough to fund education?

J: I think it's a fact that there is never going to be enough resources, not enough money and the government is not supporting them...It's the PCT who hold the money.

Comment [fa85]: Lack of enough money and resources

V: It becomes a competition between different disease areas and what the priority is in that local area as to how that money is spent, because there is no actual funding accompanying what the NSF has asked us to deliver. There is no pot to say this is for structured education, this is for retinal screening so you have to find the money yourself.

Comment [fa86]: Lack of sufficient fund from the Government

J: There are guidelines things like that but there is no money attached to it. The criteria says we should be providing education but there is no budget and

Comment [fa87]: No money attached to the policy

V: From our point of view we need to develop business plans and go and knock on the door of the PCT board to build a case why we need the money and unfortunately we haven't got those business skills or necessarily the time to do that.

Comment [fa88]: Seeking money requires business skills which we do not possess

Q. The government are saying we should be providing the structured education but the funding is not there?

J: Are you not aware of that?

No I'm not.

C: But that is the actual basics of all the healthcare in the NHS today that the staffing, the quality and the numbers of staff that we have as resources has greatly reduced, delivering high quality that we all would like to do and strive to do but its actually having the resources to do it.

Comment [fa89]: No enough resources

J: Its because a lot of our education is funded by educational grants from pharmaceutical companies it is not funded by the PCT apart from our time developing tools and educational booklets that all comes from educational grants...and we have to find that money ourselves.

Comment [fa90]: Funding depend largely on educational grants from pharmaceutical companies

S: The other thing is they put their funds in 10 maybe 20 years ago when there was fewer patients and now there are more diagnoses, more resources are needed so they haven't really taken that into consideration either.

Comment [fa91]: More resources are required to cope with the current level of diagnosis

Q. But have you made this known to the....PCT?

V: They do know that's what we were saying, we don't have the skills to spend hours and hours developing business plans, its not just education we have other remits as well and we need to be knocking on the door to say we need money for this, that and the other

Comment [fa92]: The educators lack time and business skills to bid for money

J: I mean a plan has gone in to the PCT at the moment and we are waiting to see but not holding out any.....and we are waiting to see.

Probably at this stage we can be thinking of another way of delivering this education, probably go online?

J: (a) - We haven't got the time and (b) - at the moment we haven't got the time, skills or money.

Comment [fa93]: Lack of time, business skills and money

H: We've been trying to do this for several years now and we feel like we're not moving forward so to be honest it becomes quite de-motivating after a while.

V: The NHS actually runs knowing that there is a DNA percentage because if everyone attended the NHS would grind to a halt. You tend to find that all clinics everything tends to be over booked by a certain percentage..

But is that a good practice if they deliberately over book with intention that people would not come

V: We don't do it – the Consultant's time is more valuable than ours and more expensive

If the staff are de-motivated how can we motivate the patients? What is the best way forward?

J: We are motivated. I think on occasions we get de-motivated because we are healthcare professionals, caring which is why we're doing what we're doing I think it becomes de-motivating, frustrating.

So the government needs to do a little bit more in terms of funding... and providing the skill?

J: I think the thing that I find strange is that there are some PCT's who have got funding for the education, have got it commissioned, have got lots of staff have got their website set up and a lot of their demographics were very similar to ours and they've got all this and I'm not sure why they had and we hadn't. Again going off on a tangent is it because they have someone championing them and that sort of thing...its who knocks on the door loudest up at board level. It can be done because other PCT's have done it so why can we not do it, why are we very different.

Comment [fa94]: Inequalities in distribution of fund

Q. So there are a lot of variations around the country? Is their own DNA better than yours.

J: Not so much DNA's what I mean is they have got the funding they've got it all because we've seen their plans for the future, they have very defined pathways and education pathways for staff, it was all there, wasn't it?

Comment [fa95]: Funding variation within the country

S: It all boiled down that they had somebody at the top and the ground floor was very committed as we are at the moment, we have no one at the top that's why we are falling apart at the moment. That's why we can't deliver what we want to deliver.

Comment [fa96]: There is inequalities in funding

Q. Back to the patient do you think they have a genuine reason or they just don't want to come?

J: The ones with a genuine reason tend to telephone and rearrange. It's the ones that haven't received their letter maybe that we don't get to hear of but otherwise it's perhaps not important. Perhaps English is not their first language, not received the letter but again that all goes back a little bit to the G.P during the initial assessment having making sure that we're aware the person doesn't speak English or doesn't live at the address they say whatever it might be. It ultimately comes back to who is referring.

Comment [fa97]: Patient who has a genuine reason try to rearrange another appointment

Comment [fa98]: Some may not get their letter of appointment

Comment [fa99]: English may not be their first language

Comment [fa100]: Some GP are not sensitive to patient literacy level

S: It comes like culturally again for instance this afternoon I rang somebody up their appointment was at one o'clock I'm still waiting here now it being two o'clock – it was oh I had some friends come along – so is your diabetes appointment more important or your friends? Then the sudden reply is oh well can I come now then? And here's us being flexible saying come up now because you want to see them. If I had been a typical nurse no I don't want to see you, I'll send you another appointment.

Comment [fa101]: There is different cultural perception to health issue

Comment [fa102]: Accommodating flexible time of education

C: I think we need to learn from doctors or dentists if they don't turn up then that's it. I think we are too caring sometimes.

Comment [fa103]: Become tough on them/discharge them if they fail to attend

Q. So you think having a compulsory structured education for patients is a good idea then?

J: Unless they've been provided with the information to make informed choices

So the policy itself is ok?

All: Uhm Uhm Uhm

J: Yes because it's an ongoing progressive disease so they need the education initially and then they need education as they go along

H: But then you could argue that there is those who get all the education and they don't make any changes in their lifestyle...that's their choice...you could also argue are we leaving it too late? If you gave this education at school before

Comment [fa104]: Giving diabetes education to all at secondary school before having diabetes

the disease process even began prevention is better than cure....I'm sure we will in years to come. I mean they're six when they get their sexual education or eight I think it is. Bring back food and nutrition at school that's what I say...root of all evil...and PE competitive sports.

Q. Relatively you have four major sites Windsor, Slough, Maidenhead and Bracknell. Have you got a lot of activity going on in Maidenhead?

J: Once a month, but at the moment it is held here because of venue but next year it will be back in Maidenhead.

OK and they have better attendance rates?

J: Only purely because of the way they do their appointments they could ring in and ask and say they want to come in on a particular day.

So offering appointment choices is a big issue? The calibre of your patient may even be different.

J: Maybe a different socio economic group to Slough, it's changed a bit in Maidenhead but I don't think it's had any effect. I mean we changed the way we did it with Maidenhead because they had to come here and we thought at one point we had less people turning up because of here but it didn't work out like that. It didn't stop people coming we thought initially it had but we had a funny couple of months then that was it.

H: What we're trying to do now is that we've changed the way that healthcare runs patients taking responsibility and should be actively involved in their own care.

S: and of course for lots of people who have the condition they've been born and brought up or come here and been in a culture where they just go to the doctor and get the cure, get the fix, get the tablet. It is changing the whole way that people relate to health.

C: That's why I think education is important...

S: But its getting people involved in the process isn't it...its down to the initial assessment the initial conversation and that is most important.

J: They've obviously gone to the doctor for something in the first place so if they can go to the doctors they can go somewhere else...We are quite friendly people I don't think we are unfriendly when they get there.

A: Could we not do a policy that at the point of diagnosis all patients are given a booklet on group education?

Comment [fa105]: Patient to take greater responsibility backed up with flexible appointments

Comment [fa106]: Each locality has a different socio-economic group

Comment [fa107]: Patient to take more responsibility and be active in their own care

Comment [fa108]: There is difference in the way people relate to health

Comment [fa109]: Initial assessment is important to cover key personal issues

Comment [fa110]: To give a booklet on group education at the point of diagnosis

J: We did put one together for our pilot if we get the go ahead from the PCT about what they want to do then part of the new deal will be literature at diagnosis so they know what they are coming to.

B: But I think with G.P's you got to do things over ten times before it sinks in.

J: It's a benefit for them to refer as they don't have time to give the education...maybe we need to market it in a different way...

V: How can you earn more money, send your patients to....sadly that's how it comes out.

So you need better marketing?

J: The difficulty is if you look at Desmond the results haven't been as good as...Desmond has just reported that in just over a year HbA1c haven't come down the patients feel better but there's not actual benefit ...They are still saying group education is worthwhile.

Comment [fa111]: Group education is worthwhile

So one to one would be a better option?

J: The practice nurses don't have time for one to one I think they were saying, I went to a practice with a new patient and they have 20mins which isn't long enough to tell somebody lifestyle changes.

Comment [fa112]: Practice nurses don't have enough time to spend with the patient

C: It would be nice to try and identify patients who could perhaps deliver some of the education on a one to one basis, but that also would take a lot of time and training.

Do you think lack of robust referral system is due to lack of time?

J: Yes, they haven't got the time.

Comment [fa113]: Lack of enough time is an issue

Do you have any meetings with the practice nurses or any forum to come together?

J: We see them in practice but they are as swamped as we are they've got so many patients they don't know what to do with them its not their fault.

V: Unfortunately we don't have the diabetes network up and running anymore that was a venue for people to come and discuss things like this, we also had for a while a diabetes interest group for nurses working in the Bracknell area that was well attended initially as local priorities grew in other areas then their attendance at the diabetes group lessened until we had two people and then we decided it wasn't worth running anymore.

Comment [fa114]: Diabetes network/interest group for nurses do help to identify issues that are affecting the patient

I don't think it is feasible to attach a diabetes specialist nurse to each GP practice?

J: I went to a surgery last week and they had so many patients they didn't know what to do so we offered perhaps that I would do a group session or I could do some of the clinics whatever but they had no space to put me, no education room, you can offer anything but if they don't have the resources or time, a lot of practice nurses work part time they're not just dealing with diabetes clinics.

Comment [fa115]: The surgery lacks enough time and resources

S: I think if they have an incentive rather than say we're offering education that might make them, you know points given... take for example lower HbA1ca lot of those practice based commissioned things we saw the other day they all had structured group education in them hadn't they? All of them.

Comment [fa116]: Government may try to award points for SPE

Is there anything else you'd like to add to round up?

V: I would like to know the patients' perspective. I would like to contact patients with DNA to find out why they don't attend because we're full of ideas but we don't know whether that actually does marry up.

J: Didn't we use to offer up Saturdays or evenings in Slough but just 1 or 2 people would come so we thought it a waste a time.

What are the type of questions you think I may ask the patient?

J: Open ended questions on the questionnaire.

V: Don't suggest you've not received the letter...just express concern we were expecting you, why were you not able to come.

For example, knowledge of my disease is important by using a scale like agree, disagree or strongly agree. Would this type of question be ok?

H: They probably would see it as a disease not very patient friendly...condition sounds better...what is your understanding etc..

V: May be my awareness or condition.

Taking responsibility for my care is important is another question?

V: I think most people would say yes It sounds good.

I will go and work on the questionnaire, bring it back and get it vetted before it goes to the patient.

J: I think it needs to be very patient friendly...are you going to telephone them or send it out by post and hope that they return it?

It will be by post, but I will be putting a self addressed envelope

V: It will be a very low response, questionnaire is known for low returns.

J: I would say to telephone...this is what I'm going to do, can I ring you at a more convenient time or something...a lot of people feel threatened by filling in a form, the language barrier would not be able to help ...develop a relationship over the telephone to get those answers back.

Comment [fa117]: Language may be a barrier for some patient

V: If they say they don't receive the letter conversation obviously ends, if they say was it the time...I think you just need a set of opening questions...when is a better time for you...it needs a structured conversation.... You need a few opening ones.

J: Then you might want to compare each sample from different areas see what answers come out...five from each or something depending on how big you want the sample size so.

V: If you did them all within the same month or something then that brings the environmental factors down; looking at the postcodes so that you can get the information from different areas.

S: Anne will have those now, she should have Octobers'...or a bit further down the line.

J: Probably best to talk to Anne. I think we need to get a meeting with Anne she's at Slough.

V: We want to do someone similar with the young adolescents who DNA so it might be interesting to see what questions you come up with so that we could use them with other groups as well to see if there is different reasons between different groups.

Definitely a telephone interview would be better?

Yes definitely.

Thank you very much everybody. Thank you for sparing your spare time.

I wish to welcome you and thank you for your presence. First of all, I believe you know me and my name is Muili Lawal and I know your name is ----- . I have sent the information sheet before to explain the purpose of today's meeting.

Ok, ok, ok, ok

Again, the purpose of the interview is explore your views about why patients are not attending diabetes group education that you are offering and what are your thoughts about how to motivate attendance. Maybe we can start by signing the attendance sheet.

(Signed) – Thank you very much

Q – You have been running this education for a long time

Yap

Q – Thank you, please why do you think some patients are not coming for their education appointment?

I think inadequacy of the letters we are sending out. Patients are not sure why they are coming to see us ----- good other reason could be that relative of patients have diabetes -- they may think they know everything already. It could be due to work or study or any other thing that could get in the way because we are offering appointments during the day which could interfere. It could be we are having it in the hospital and they are concern that it is a specialist thing. They may be nervous or concern about coming to the hospital to discuss things ----- they may not know why they are coming to the hospital.

Commented [ML1]: Poor information.

Commented [ML2]: Family influence

Commented [ML3]: Personal circumstances

Commented [ML4]: Location

Q – So you think they have got genuine reasons for not coming sometimes?

I think, work could be a problem and because there is a trend of younger patient coming to the session and they are unable to get out of work – employer may not allow them to leave at that particular time. We have to be flexible about time like morning, afternoon, week-end or evening.

Commented [ML5]: Employment

Commented [ML6]: Flexibility of delivery

Q – Do you think if there is varied period of education sessions, the attendance rate may probably be improved?

It might make a difference or a later start like 6'oclock in the evening so people can go to work and come in the afterwards.

Q – Can I ask whether you think the government policy of offering education to every patient when they are diagnosed is a good thing?

I think it is a good idea that people are offered the education, but not necessarily they would attend it and we have a longer time to deliver it while the GP have shorter time to spend with the patient. Also, in a group setting, it may benefit the patient as questions can be asked by other group members of the group and some patient does not feel comfortable in group setting, may be a bit shy and therefore not a benefit.

Commented [ML7]: Impact of group delivery

Q - So group education has its own benefit apart from one to one education?

I think in terms of a bigger group of people, people don't feel they are on their own.

Q - Apart from been flexible, what other things do you think can be done to encourage patients to come?

We are looking at changing our educational programme at the moment - - - ehm, ehm, what else can we do, ehm --- it is a difficult one. I think we should be offering them one to one education if they don't like group intervention.

Q - Do you think the government can do more to aid attendance?

Certainly in the area that I work, ehm, in podiatry, they are looking at different type of government approach, for example, the Scottish system offers more support in form of leaflets they can give to the patient. Not a group education but leaflets that they can download and free to order --- but in the UK we do not have such education leaflet policy.

Commented [ML8]: Information delivery

Q - So you think providing more information in form of leaflets could help?

Yeah, particularly leaflet education but we need to think about financing this type of project as funding is always an issue.

Q - Some people have been suggesting sanctions, would you support things like discharging patient if they fail to come?

It is still another area ---- like the Dentist if a patient fail to come ---- Ehm, I don't know but if that is the way the NHS is going to move forward that could be an option in the future ---- I don't really know

Q - Do you strongly oppose it?

I believe it is a better incentive to attend than to be worse off if you don't attend. I think I am not for or against it and we have to see how it works in practice (laughing) - I think it may make things worse.

Commented [ML9]:

Q - Do you have other things you would like to say on this subject?

Ehm --- why people don't attend

Q – and what can be done, if you think we have not covered anything.

Oh, oh, one area we are looking at is a flexible approach may be for the newly diagnosed – to have a continuous education in which case patient may come for just one hour to discuss different aspect of care e.g. foot care e.t.c. --- a continuous roll of education that patient can opt in and out and they can come if they need to know anything. But a newly diagnosed, I think they need a lot to start with.

Commented [ML10]: Opt in and out method

Q – In your own view, do you think culture has been playing a part, for example, during Ramadan festival or during Divali – have you observed cultural influence been part of the barrier?

Commented [ML11]: Cultural impact

Well, certainly at Slough, we offer group education in different two languages that is not the case in Maidenhead and Bracknell which are the two areas that I cover. I think we need to think more about culture and diversity of the group and ways to address their needs. We have high Polish group of people in Bracknell.

Q – Do you have so many of them in your session?

No, I don't but that is not to say they are not more . Different languages as well, I think Punjabi is offered in Slough but I don't know of any other languages being offered which could be a major barrier as well ---- language barrier could be one of the reasons why people are not coming.

Commented [ML12]: Language problem

Thank you very much. You have said a lot during this interview and if you haven't got any more information, I think you covered all the questions.

Oh, really, ok

Thank you again for sparing your time and I would be getting in touch. Thank you very much.

Q – Based on your experience, can you tell me some of the factors you feel might hinder patient attendance?

- Inadequacy of letters
- Not sure why they are coming to see us
- Patient relatives with diabetes – may think they know everything already
- Work/studies may prevent them
- Because it is in the hospital – concerned/nervous to discuss in the hospital settings
- Language barriers.

Commented [ML13]: Information delivery

Commented [ML14]: Family history

Commented [ML15]: Personal circumstances

Q – Do you think they have genuine reason for not attending?

- Occasionally, they have genuine reasons:
- Younger patient not coming due to inability to get out of work
- On annual leave and travelled on holiday
- (No weekend/evening around 6pm).

Commented [ML16]: Employment

Commented [ML17]: Holiday

Q – Do you think the policy is a good idea?

- It is a good idea to be offered the opportunity to have more time to deliver the education

Q – Do you think it has to do with group education as opposed to one to one education?

- Both have got its benefits:
- In group – questions may be asked from others
- Staffing benefit – delivery to more than one person at a time
- Interaction among patient may be helpful
- They may not feel they are on their own
- Group setting may not be a benefit for some shy patient.

Commented [ML18]: Advantages and disadvantages of group education

Q – What do you think can be done to reduce non-attendance?

- Consider one to one education if they don't like group
- Flexible approach – continue roll on education with option to opt in and out.
- Try the Scottish approach – more free leaflets to download/order (leaflet policy has got funding issue as well).

Commented [ML19]: Flexible delivery

Q – Would you support the idea of sanction?

- It may be a better incentive to motivate them, but not sure

Thank you very much everybody. Thank you for sparing your spare time.

Appendix 1

Focus Group sitting arrangement

Dr DS

S

B

A

H

C

V

J

Muli

Appendix 10

CODE BOOK – Stage 2

Information from the data	Code	Remarks
G.P & patient have negative perception about the importance of diabetes education	Practitioners attached little importance to education	Inter-professional working
G.P's don't emphasize the importance of attendance	Lack of emphasis on the importance of diabetes education	Inter-professional working
G.P & Practice Nurses are vague in referring patients	Vague information given during referral	Inter-professional working
Poor understanding of SPE among patients and health professionals	Lack of understanding of the programme	Inter-professional working
GP & Practice nurse don't stress the importance of SPE	Lack of emphasis by the practitioners	Inter-professional working
Poor perception of the diseases and been defensive	Poor understanding of the nature & care of diabetes among the patients	Respect for patient's self esteem
Some patients think diabetes is a mild condition	Poor patient knowledge about seriousness of the condition	Perception
Practitioners use of technical terms may lead to misconception	Failure to convey accurate information	Communication
Unsuitable timing of the education session	Timing of the session	Flexibility
Some patient don't want people to know about their diabetes	Some patient keep their diabetes as a secret	Patient's autonomy and socio-cultural background

Cost of parking	Parking cost	Finance
Distance	Travelling time & cost	Lack of motivation
Lack of personal transport	Stress of travelling	Lack of motivation
Appointment system is not great in some localities	Weak appointment system	
Give responsibility to book for education session to patients	Patient to take more responsibility for their health	Ownership
Offering choice of time to patients	Flexible time of education	Flexibility
Follow up letter of invitation and telephone calls	Back-up arrangements	Follow-up
Offering education in the hospital creates some fear	Scary venue of education	
Referring GP to inform the patients about where, why and what to expect	Better information during referral	Information
Inadequate information given during referral	Giving robust information during referral	
The need to provide education for GP practices about the importance of SPE	Provision of education for GP practices	Development
Government target for GP does not reward provision of education	Government to reward GP for promoting education	Incentives
Group education may be intimidating	Some patient may dislike group education	Impact of group

3 hours session may be too long for some patient	Too long session	Convenience
Not giving enough Information on what to expect	Inadequate information during referral	
Painting frightening pictures of diabetes to emphasize its seriousness	Scary information to motivate patient	Sanction
Frightening pictures may have negative effects	Scary picture may demotivate patient	
Introducing payments to motivate patients	Encourage patient by charging them	
Payment may demotivate some patient	Charging may increase non-attendance	
Awareness of what to expect in SPE promote its benefits	Adequate understanding of SPE aid participation	
Some attend the session but sleep most of the time	Some patient come to sleep in the session	Motivation
Too high non-attendance of up to 40% in some area is unacceptable	High non-attendance rate must be reduced	
Patients' don't see the value of education when they are well	Some patient don't attend because they are not sick	Perception
Patient who come to sleep are more motivated than those who do not attend	Sleeping patient are better than non-attenders	

Appointment system has a role to play	Method of appointment is important	Organisation
Appointment system with more personal touch do help	Following up appointment is helpful	
Giving patients responsibility to ring and negotiate appointments do help	Flexible appointment system	Ownership
Adding personal touch to the appointment system involve additional personnel and time	Follow up of appointment increase personnel and time cost	
Ring about 50 patients every month seems impossible now	It is impossible to ring all patients	
Follow up requires time	Follow up is time consuming	
Some patients ignore the letter and some don't get the letter	Patient have genuine and ingenuine reason for not coming	
A better appointment system	Improving the appointment system	
More resources is required	Additional resources	
Money is an issue	Lack of adequate fund	
Our aim is to design a website where patient can choose their appointment	Designing a website for patient to choose preferred date	

We need to consider the ability of the patient to use computer	Consider computer literacy level of patient	
The use of health activist to contact patient may help	Use health activist to follow up patients	
Employ health activist calling the patient do help	Increase fund for follow up	
Need to be sensitive to individual culture	Different cultural values	
Funding is a problem	Insufficient fund	
Health promotion in form of talking to vulnerable people before they have diabetes	Giving education to vulnerable people	
Considering ceremonies like Ramadan and Diwali	Consider religious ceremonies	
More educated higher class people are more aware	Level of education and standard of living improves awareness	
Patient need to take more responsibility for their health	Patient to show more effort in their wellbeing	
Patient to take responsibility for themselves	Patient to take more control of their health	
Going to deliver the education in the community	Offer alternative venue	

The waiting time between referral and date of education may have a role to play	Long waiting time may be detrimental	
Waiting time may allow the patient to plan for work and other life routine	Long waiting time may be beneficial	
Different people have different needs	Patient have different needs	
Option of offering education through e-learning	Offer other method of learning	
Consider individual lifestyle	Individual lifestyle	
Offering different choice of education	Offer different method of education	
SPE can be in different forms	SPE can be varied	
Patient can support and learn from each other through group education	Group education aid individual support	
Transport may be a problem	Transport problem	
Diabetes UK is helping with raising awareness	Diabetes UK is helpful	Voluntary agencies
Support group may help some people	Joining support group	Voluntary agencies
GP don't stress the importance	GP failure to stress importance of education	Inter-professional relationship

Lack of resources Weak booking system Practice staff need to stress the importance of education	Limited resources Poor booking system Practice staff to stress importance	
Patient need to understand the importance of education	Poor understanding of benefits of SPE	
Patient need to understand the importance of education Patient may not come because they are well	Poor understanding Lack of symptoms	
To apply a penalty for non-attendance	Apply punishment	Patient's right
Displaying a frightening picture of diabetes	Scaring patient	
Talking in a tough way to the patient	Discipline	Patient's dignity
Diabetes UK is helpful in raising awareness	Diabetes UK is helpful	
Individual differences should be considered	Uniqueness of individual	
GP and practice nurses need to give more information	Practitioners to give better information	Information
G.P's are driven by targets but not patient care	Negative government approach	Targets
Practitioners to talk to patients at appropriate level to avoid	Communication gap	

misunderstanding		
Creating awareness about the importance of education	Improve awareness of education	
Diabetes education can be considered to be part of the national school curriculum	Offer diabetes education as part of school programme	Influence policy
Lack of understanding of referral procedure by the GP and other healthcare professionals	Poor professionals' knowledge	Development
Poor link between the education centre and GP practices	Weak interpersonal link	Collaboration
Lack of enough money and resources	Limited resources	
Lack of sufficient fund from the Government	Limited fund	Funding
No money attached to the policy	Limited money	
Seeking money requires business skills which we do not possess	Lack of business skills to secure funding	Training and Development
No enough resources	Lack of resources	
Funding depend largely on educational grants from pharmaceutical companies	Limited resources from government	
More resources are required to cope with the current level of	More resources Required for high incidence of diabetes	Resources

diagnosis		
The educators lack time and business skills to bid for money	Lack of time and business skills	Availability of time
Lack of time, business skills and money	Insufficient time and business skills	
Inequalities in distribution of fund	Funding inequalities	
Funding variation within the country	Funding variation	
There is inequalities in funding	Inequalities in funding	
Patient who has a genuine reason try to rearrange another appointment	Patient with genuine reason tend to show effort	
Some may not get their letter of appointment	Some patients don't get their letters	
English may not be their first language	English as a second language	Language
Some GP are not sensitive to patient literacy level There is different cultural perception to health issue	Patient literacy level Cultural perception to health	Language and culture
Accommodating flexible time of education	Flexible session	
Become tough on them/discharge them if they fail to attend	Discipline	Sanction
Giving diabetes education to all at secondary school before having diabetes	Diabetes education for all in school	
Patient to take greater responsibility backed up with flexible appointments	Greater responsibility for patients Flexible appointments	
Each locality has a	Socio-economic difference	Diversity

different socio-economic group		
Patient to take more responsibility and be active in their own care	Patient to take active role in their care	
There is difference in the way people relate to health	Individual uniqueness	
Initial assessment is important to cover key personal issues	Tough initial assessment	
To give a booklet on group education at the point of diagnosis	Offer group education pamphlets on diagnosis	
Group education is worthwhile	Group education is good	
Practice nurses don't have enough time to spend with the patient	Lack of time	
Lack of enough time is an issue	Lack of enough time	
Diabetes network/interest group for nurses do help to identify issues that are affecting the patient	Diabetes network/interest group is beneficial	
The surgery lacks enough time and resources	Lack of time and resources	
Government may try to award points for SPE	Government incentive	
Language may be a barrier for some patient	Language problem	Language

Appendix 11

Stage 3
Grouping / clustering of codes into categories

Codes	Sub-themes
<ul style="list-style-type: none"> - Practitioners attached little importance to education. - Lack of emphasis on the importance of education. - Lack of understanding of the programme. - Lack of emphasis by the practitioners. - Provision of education for GP practices. - GP failure to stress importance of education. - Practice staff to stress importance. - Poor understanding of benefits of SPE. - Poor understanding. - Failure to convey accurate information. - Practitioners to give better information - Communication gap. - Poor professionals' knowledge. 	<p>Perception and attitude of practitioners to education</p>
<ul style="list-style-type: none"> - Vague information given during referral. - Weak appointment system. - Better information during referral. - Giving robust information during referral. - Inadequate information during referral. - Method of appointment is important. - Improving the appointment system. - Poor booking system 	<p>Referral system/Appointment system</p>
<ul style="list-style-type: none"> - Lack of symptoms. - Some patient keep their diabetes as a secret. - Scary venue of education. - Adequate understanding of SPE 	<p>Perceptions and belief of patients</p>

<p>aid participation.</p> <ul style="list-style-type: none"> - Some patient come to sleep in the session. - Patient have genuine and in-genuine reason for not coming. - Patient to show more effort in their wellbeing. - Patient to take more control of their health. - Greater responsibility for patients - Patient to take active role in their care. - Poor understanding of the nature and care of diabetes among the patients. <ul style="list-style-type: none"> - Poor patient knowledge about seriousness of the condition. 	
-	
<ul style="list-style-type: none"> - Some patient don't attend because they are not sick. - -Language problem - Work - School - Parking cost - Travelling time & cost - Stress of travelling. - Long waiting time may be detrimental. - Long waiting time may be beneficial. - Transport problem. - Patient with genuine reason tend to show effort. - Patient have different needs. - Individual lifestyle. - Uniqueness of individual. - Individual uniqueness 	<p>Circumstances</p> <ul style="list-style-type: none"> -Holiday -Employment/Education -Sickness -Language
<ul style="list-style-type: none"> - Patient to take more responsibility for their health. - Scary information to motivate patient. - Scary picture may demotivate patient. - Encourage patient by charging them. - Charging may increase non- 	<p>Sanctions/penalties</p>

<ul style="list-style-type: none"> attendance. - Scaring patient. - Discipline. - Discipline 	
<ul style="list-style-type: none"> - Back-up arrangements. - Following up appointment is helpful. - Follow up of appointment increase personnel and time cost. - It is impossible to ring all patients. - Follow up is time consuming. - Additional resources. - Lack of adequate fund. - Use health activist to follow up patients. - Increase fund for follow up. - Insufficient fund. - Limited resources - Limited resources. - Limited fund - Limited money - Lack of business skills to secure Funding (business capacity) - Lack of resources - Limited resources from goverment - More resources required for high incidence of diabetes - Lack of time and business skills - Insufficient time and business skills - Funding inequalities - Funding variation - Inequalities in funding. - 	<p>Use of health activist (Resources)</p>
<ul style="list-style-type: none"> - Government to reward GP for promoting education. - Negative government approach - Government incentive - 	<p>Government incentives</p>
<ul style="list-style-type: none"> - Targets - Lack of time 	<p>Targets</p>

<ul style="list-style-type: none"> - Lack of enough time - Lack of time and resources 	
<ul style="list-style-type: none"> - Some patient may dislike group education. - Group education aid individual support. - Group education is good 	Preference for group education
<ul style="list-style-type: none"> - Parking cost - Travelling time & cost. - Consider computer literacy level of patient. - Different cultural values. - Consider religious ceremonies. - Level of education and standard of living improves awareness. - English as a second language. - Patient literacy level. - Cultural perception to health. - Socio-economic difference. - Language problem 	Patient socio-cultural background
-	
<ul style="list-style-type: none"> - Too long session. - Designing a website for patient to choose preferred date. - Offer alternative venue. - Some patients don't get their letters. - SPE can be varied. - Weak interpersonal link. - Thorough initial assessment. - Timing of the session. - 	Adaptive official protocol
<ul style="list-style-type: none"> - Flexible time of education. - Flexible appointment system. - Flexible session. - Flexible appointments - Offer other method of learning. - Offer different method of education. - 	Flexible delivery
<ul style="list-style-type: none"> - Diabetes UK is helpful. - Joining support group. - Diabetes UK is helpful. - Improve awareness of education. - Offer diabetes education as part 	Raising awareness

<p>of school programme.</p> <ul style="list-style-type: none">- Diabetes education for all in school.- Offer group education pamphlets on diagnosis.- Diabetes network/interest group is beneficial.- Giving education to vulnerable people.	

Appendix 12

Stage 4

Developing sub-themes to major themes

Perception and attitude of patients to education	(1)
Referral system	(2)
Targets	(3)
Sanction	(3)
Employment/Education	
Language problem	(4)
Government incentives	(2,5)
Attitude of practitioner	(3)
Patient socio-cultural background	(1, 3)
Official protocol/barrier	(2,5)
Raising awareness	(3)
Nature of diabetes	(1, 3)
Use of health activist	(2,5)
Flexible delivery	(2, 5)

Findings: Five main themes emerged:

- (1) Perceptions and attitudes of patients to diabetes education
- (2) Official protocol and self-management education resources
- (3) Perceptions and attitudes of practitioners to diabetes education
- (4) Personal circumstances
- (5) Strategies to improve attendance

Appendix 13

Thames Valley University/BE PCT

Dear Respondent,

This questionnaire is aimed at obtaining information on your opinion about self-care management. There are no right or wrong answers. The information you give will be strictly used for research and academic purposes. However, anonymity is guaranteed and your cooperation will be highly appreciated. The research has been approved by the Berkshire Research Ethics Committee (**Approval No 08/H0505/73**). Thank you.

SECTION A – This section seeks to gain your views about health education and benefits of developing ability to manage your condition. **There are no right or wrong answers.**

Please tick (√) your response.

	5	4	3	2	1
Please tick your response.	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. Adequate knowledge about my diet, weight and exercise is important to develop self- management skills.					
2. It is always possible to manage my condition through self- effort.					
3. Attending planned sessions at education centre is important to develop self-care skills.					
4. Using the internet to find out about my medical condition is sufficient to offer adequate information.					

SECTION B – This section is to identify factors that encourage you to attend the teaching session. It is also to gather information on what can be done to enhance your future attendance.

	Yes	No
5. The letter of invitation is clear.	<input type="checkbox"/>	<input type="checkbox"/>
6. There is chance to clarify information from the clinic	<input type="checkbox"/>	<input type="checkbox"/>
7. I know enough about diabetes already	<input type="checkbox"/>	<input type="checkbox"/>
8. Learning in group is a good way to learn about diabetes.	<input type="checkbox"/>	<input type="checkbox"/>
9. I use alternative medicine and therefore do not need the advice of the education Centre.	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you have caring responsibilities for any children under 16 years, an elderly or dependent adult?	<input type="checkbox"/>	<input type="checkbox"/>
11. I was offered flexible time to choose from.	<input type="checkbox"/>	<input type="checkbox"/>
12. The education Centre was easily accessible and near to my house.	<input type="checkbox"/>	<input type="checkbox"/>

Qualitative data

The open ended question generated the following data from the participants:

List the factors that motivate you to attend:

- My partner and practice nurse said so.
- I wanted to find out more about diabetes
- I need to take control of my disease
- I wanted to find out more about diabetes and how to control my diabetic problem
- To take more responsibility for my condition
- Diabetes is new to me and I wanted to find more information

List some factors that would have hindered your attendance:

- Timing of the appointment
- Group learning
- If my diabetes is well controlled
- Improvement in my disease
- Distance
- Language problem

Are there any other issues you would like to share with the health practitioners?

Nothing

Ok for now

Statistics

		The staff told me what to expect	I know enough already
N	Valid	9	8
	Missing	1	2

Frequency Table

Age in Years

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	40 and under	2	20.0	20.0	20.0
	41-65 years	6	60.0	60.0	80.0
	66 and over	2	20.0	20.0	100.0
	Total	10	100.0	100.0	

Sex

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	6	60.0	60.0	60.0
	Female	4	40.0	40.0	100.0
	Total	10	100.0	100.0	

Living Arrangement

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Living alone	2	20.0	20.0	20.0
	Living with partner	7	70.0	70.0	90.0
	Living with family	1	10.0	10.0	100.0
	Total	10	100.0	100.0	

Ethnicity

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	White	4	40.0	44.4	44.4
	Asian/Asian British	3	30.0	33.3	77.8
	Black/Black British	1	10.0	11.1	88.9
	Mixed race	1	10.0	11.1	100.0
	Total	9	90.0	100.0	
Missing	9	1	10.0		
Total		10	100.0		

Occupation

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Employed	3	30.0	42.9	42.9
	Unemployed	4	40.0	57.1	100.0
	Total	7	70.0	100.0	
Missing	9	3	30.0		
Total		10	100.0		

There is history of diabetes in my family

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	7	70.0	70.0	70.0
	Yes	3	30.0	30.0	100.0
Total		10	100.0	100.0	

I can speak

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	English	9	90.0	90.0	90.0
	Punjabi	1	10.0	10.0	100.0
Total		10	100.0	100.0	

I have a learning difficulty

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	10	100.0	100.0	100.0

Adequate knowledge about diet, weight and exercise is important

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Neither agree nor disagree	1	10.0	10.0	10.0
	Agree	2	20.0	20.0	30.0
	Strongly agree	7	70.0	70.0	100.0
Total		10	100.0	100.0	

It is always possible to manage my condition through self-effort

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	1	10.0	10.0	10.0
	Disagree	4	40.0	40.0	50.0
	Neither agree nor disagree	2	20.0	20.0	70.0
	Agree	2	20.0	20.0	90.0
	Strongly agree	1	10.0	10.0	100.0
	Total	10	100.0	100.0	

Attending the session is important

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Disagree	1	10.0	10.0	10.0
	Neither agree nor disagree	1	10.0	10.0	20.0
	Agree	5	50.0	50.0	70.0
	Strongly agree	3	30.0	30.0	100.0
	Total	10	100.0	100.0	

Using the internet to find out is sufficient

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	3	30.0	30.0	30.0
	Disagree	6	60.0	60.0	90.0
	Neither agree nor disagree	1	10.0	10.0	100.0
	Total	10	100.0	100.0	

The letter of invitation is clear

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	2	20.0	20.0	20.0
	Yes	8	80.0	80.0	100.0
	Total	10	100.0	100.0	

There is chance to clarify information from the clinic

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	2	20.0	20.0	20.0
	Yes	8	80.0	80.0	100.0
	Total	10	100.0	100.0	

I know enough about diabetes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	9	90.0	90.0	90.0
	Yes	1	10.0	10.0	100.0
	Total	10	100.0	100.0	

Learning in group is good

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	1	10.0	11.1	11.1
	Yes	8	80.0	88.9	100.0
	Total	9	90.0	100.0	
Missing	9	1	10.0		
Total		10	100.0		

I use alternative medicine and do not need to attend

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	3	30.0	50.0	50.0
	Yes	3	30.0	50.0	100.0
	Total	6	60.0	100.0	
Missing	9	4	40.0		
Total		10	100.0		

Do you have caring responsibility for

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	7	70.0	70.0	70.0
	Yes	3	30.0	30.0	100.0
Total		10	100.0	100.0	

I was offered flexible time to choose from

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	3	30.0	37.5	37.5
	No	5	50.0	62.5	100.0
	Total	8	80.0	100.0	
Missing	9	2	20.0		
Total		10	100.0		

The centre was accesible

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	6	60.0	75.0	75.0
	No	2	20.0	25.0	100.0
	Total	8	80.0	100.0	
Missing	9	2	20.0		
Total		10	100.0		

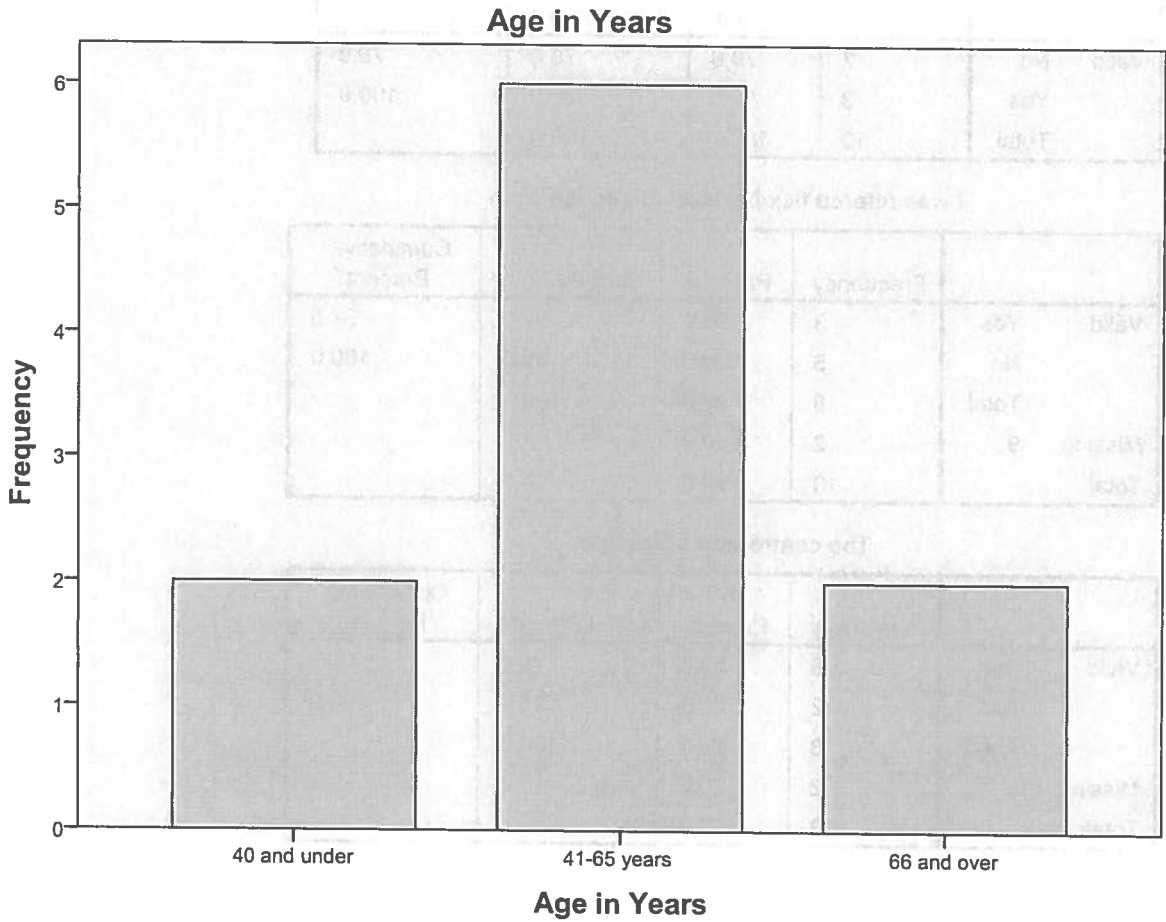
The staff told me what to expect

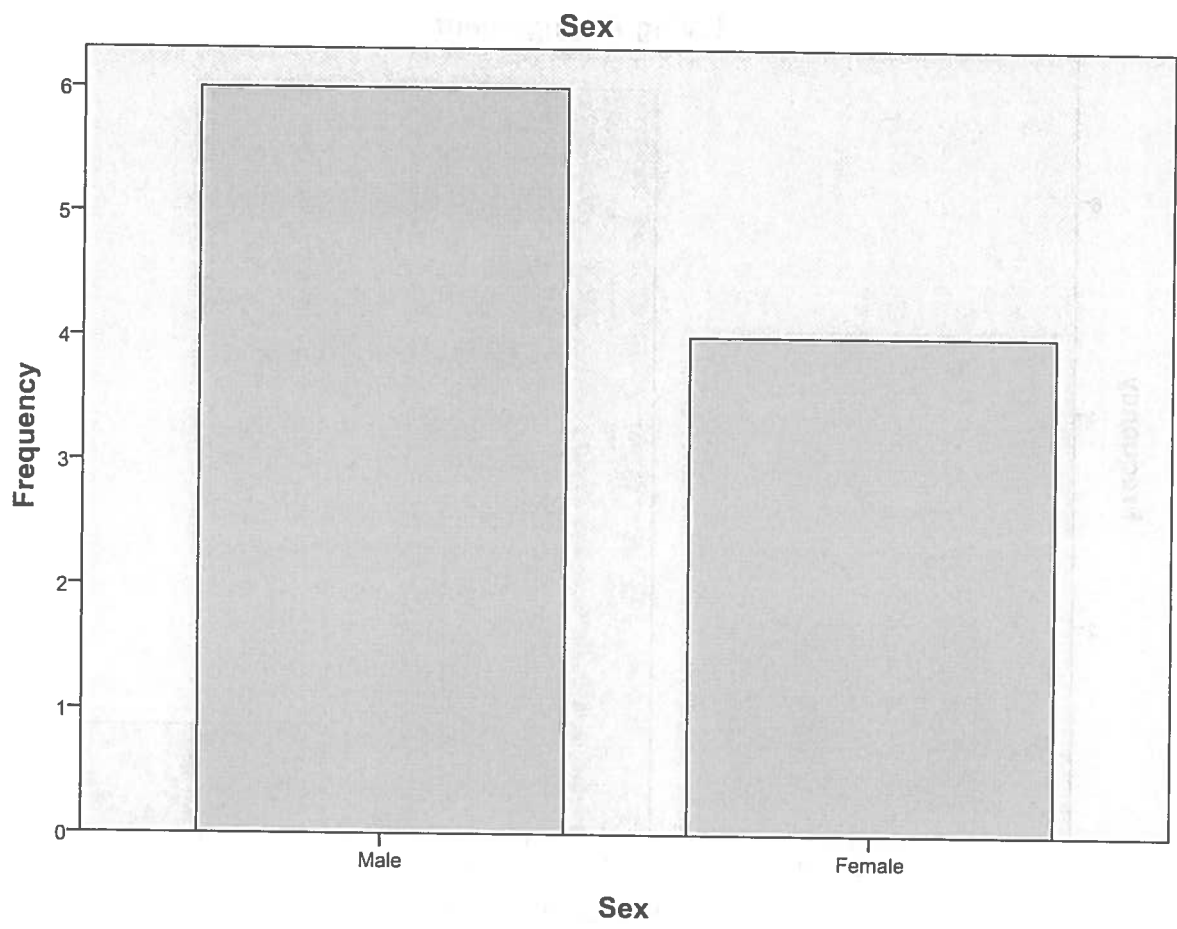
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	8	80.0	88.9	88.9
	No	1	10.0	11.1	100.0
	Total	9	90.0	100.0	
Missing	9	1	10.0		
Total		10	100.0		

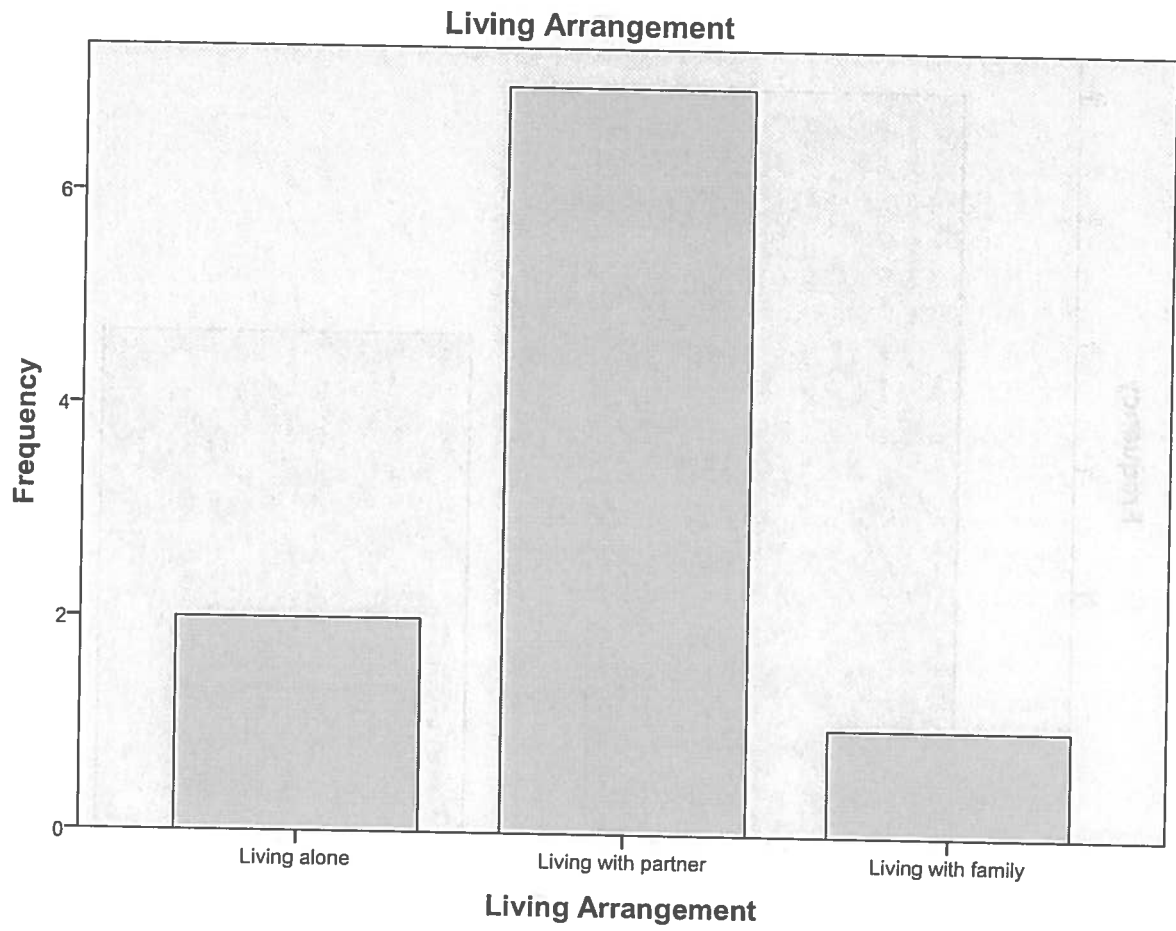
I know enough already

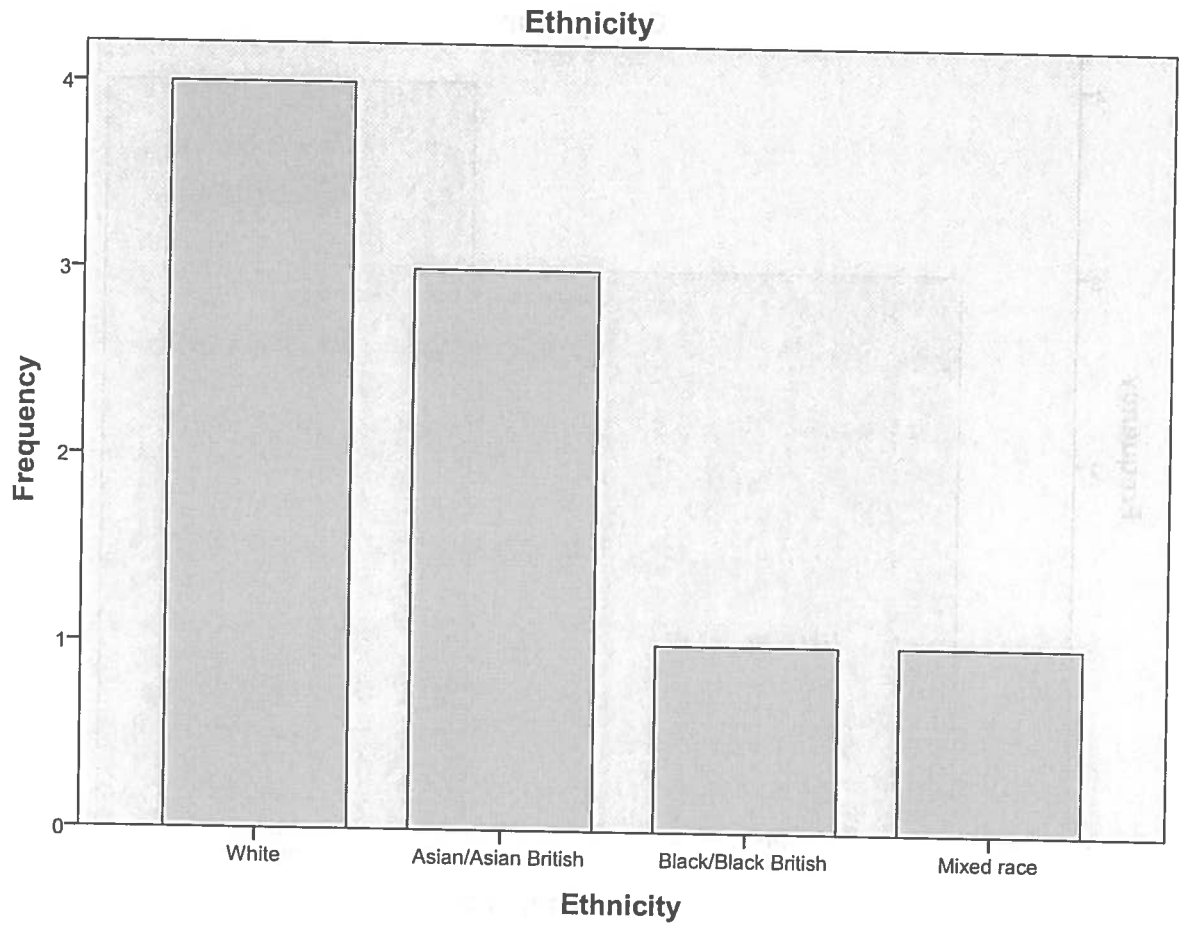
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	1	10.0	12.5	12.5
	No	7	70.0	87.5	100.0
	Total	8	80.0	100.0	
Missing	9	2	20.0		
Total		10	100.0		

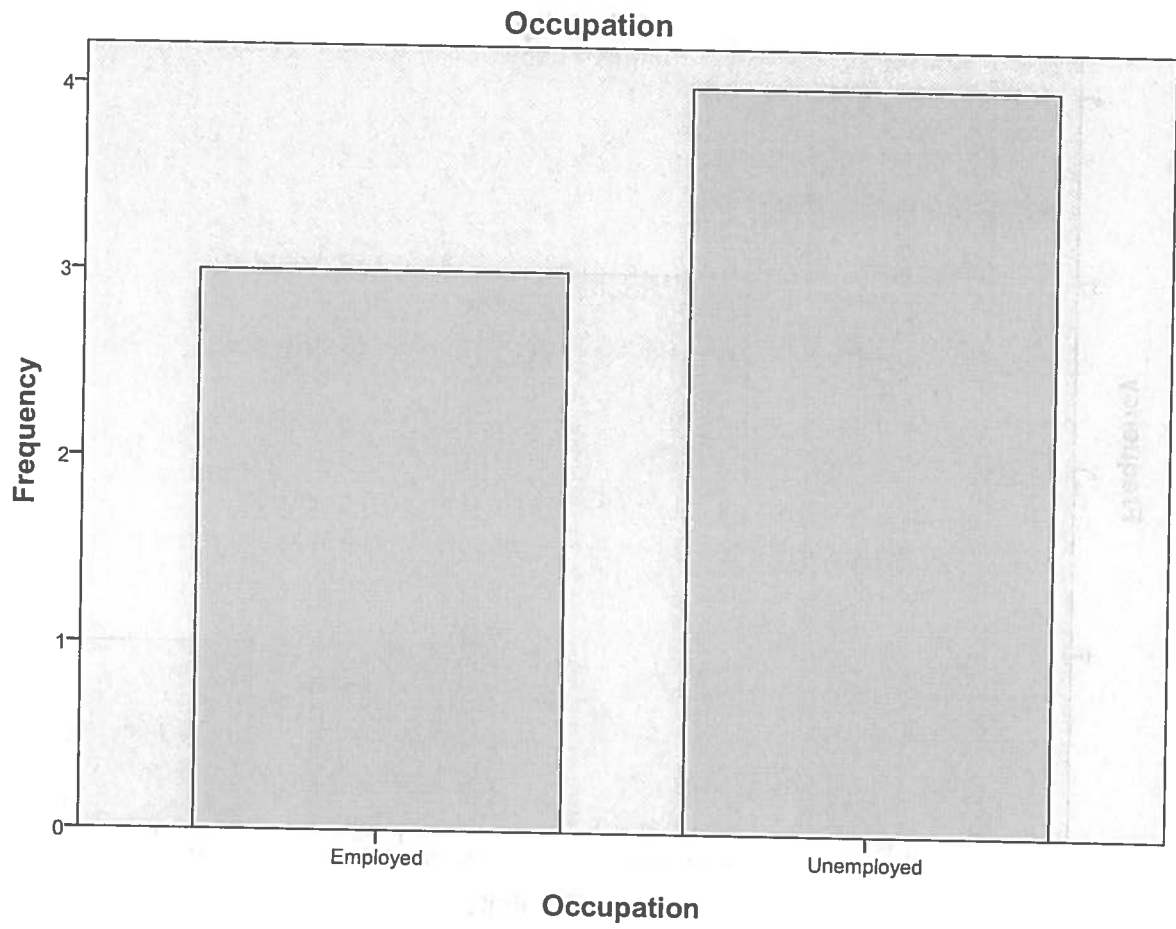
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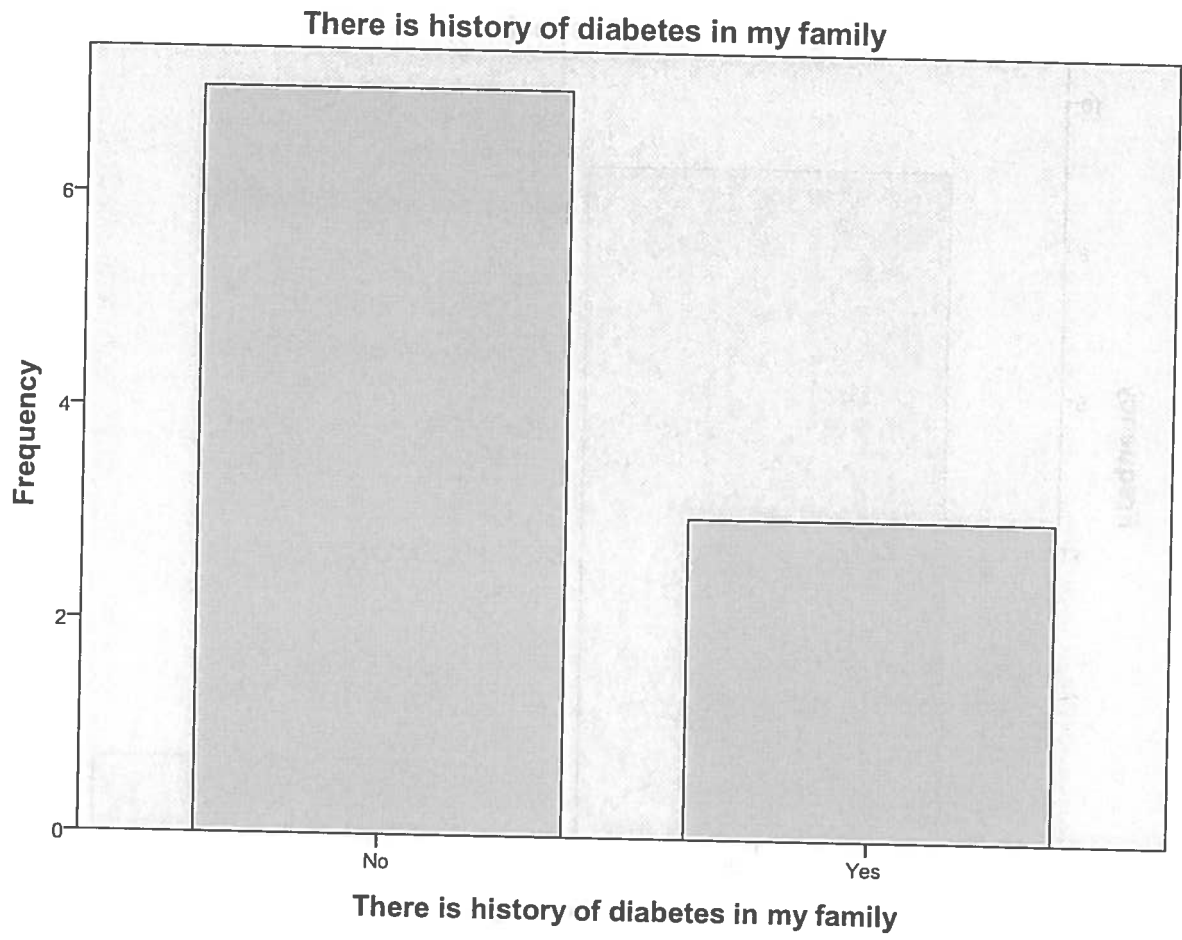


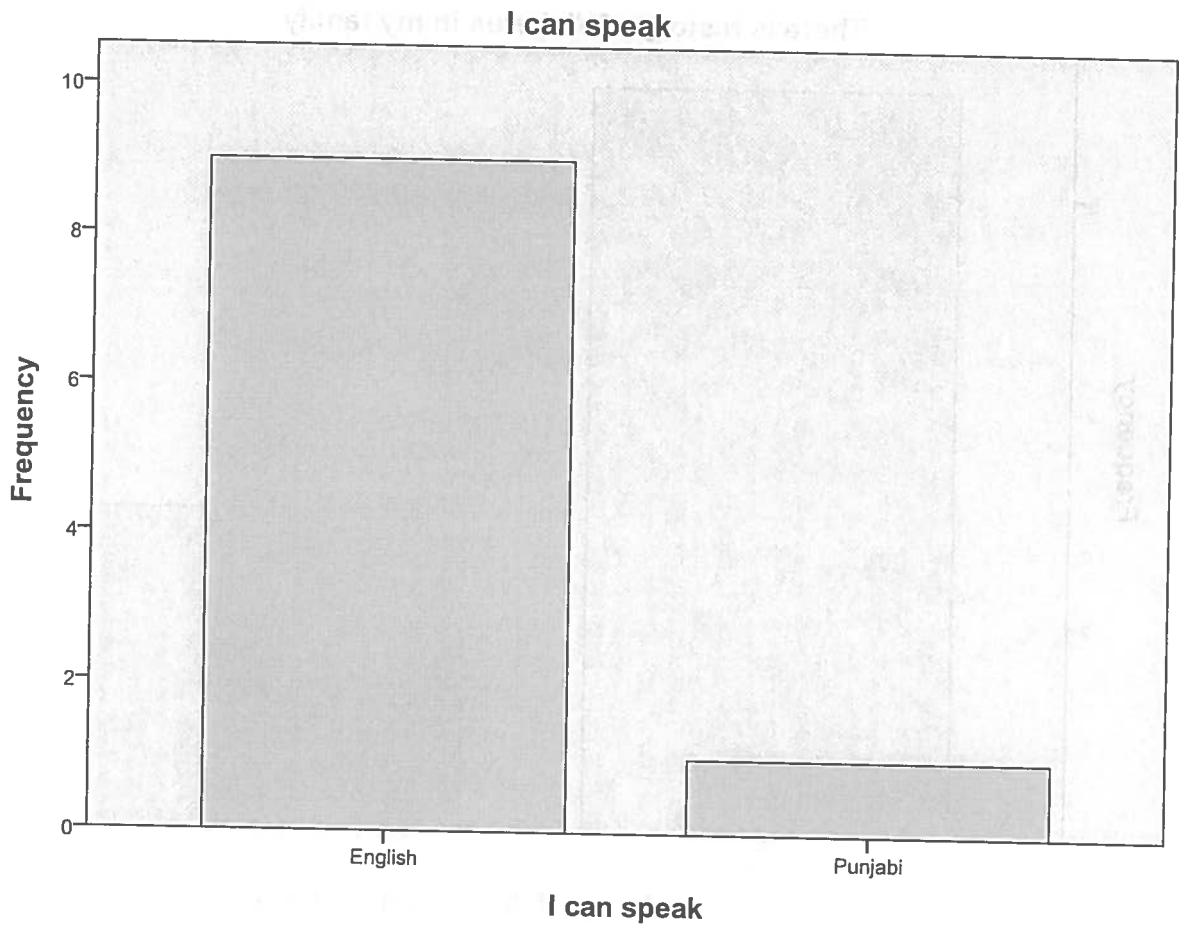


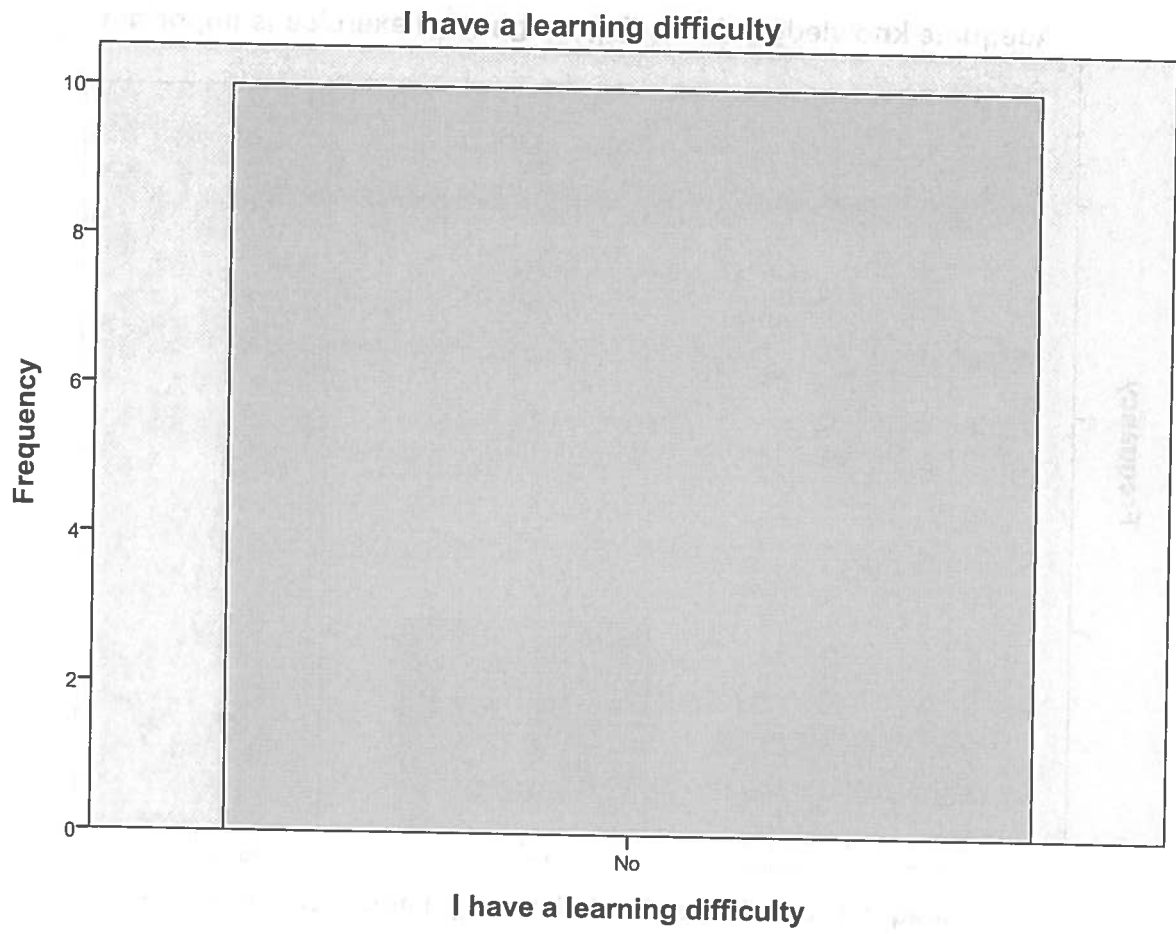




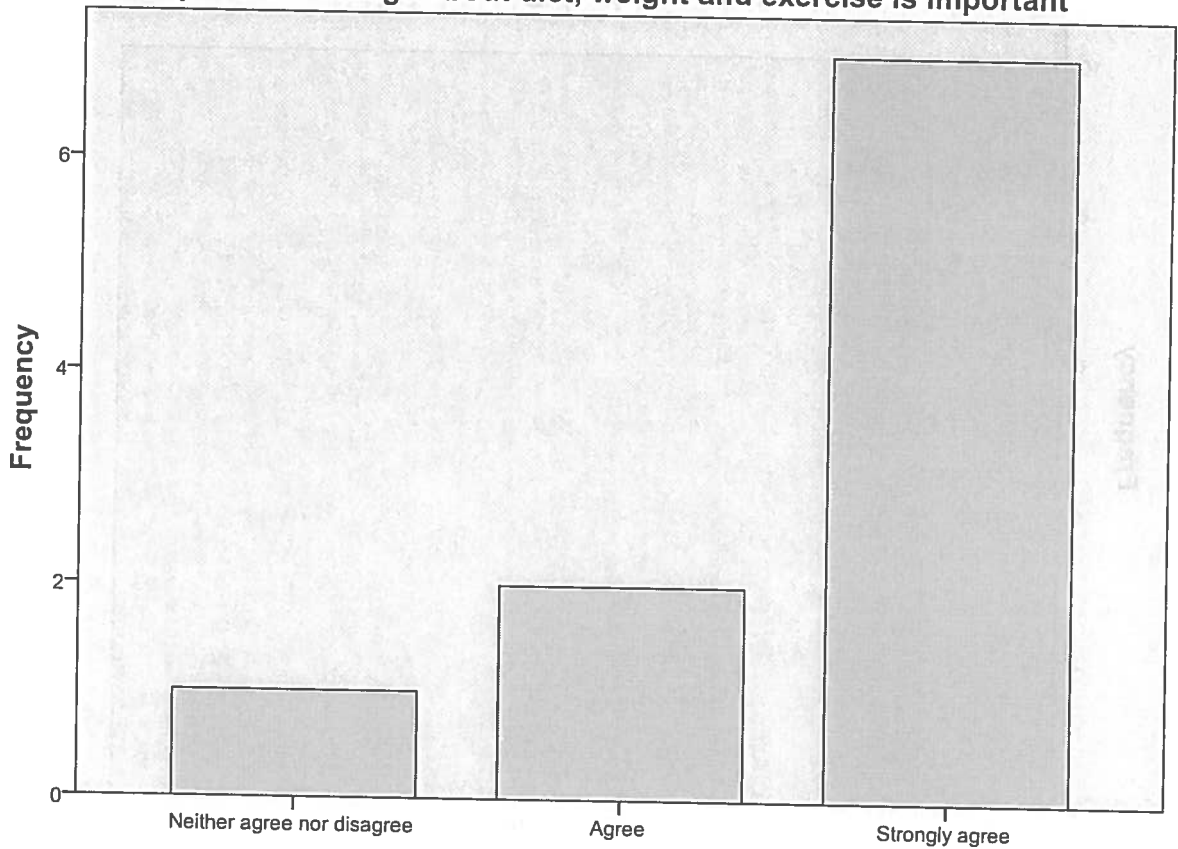




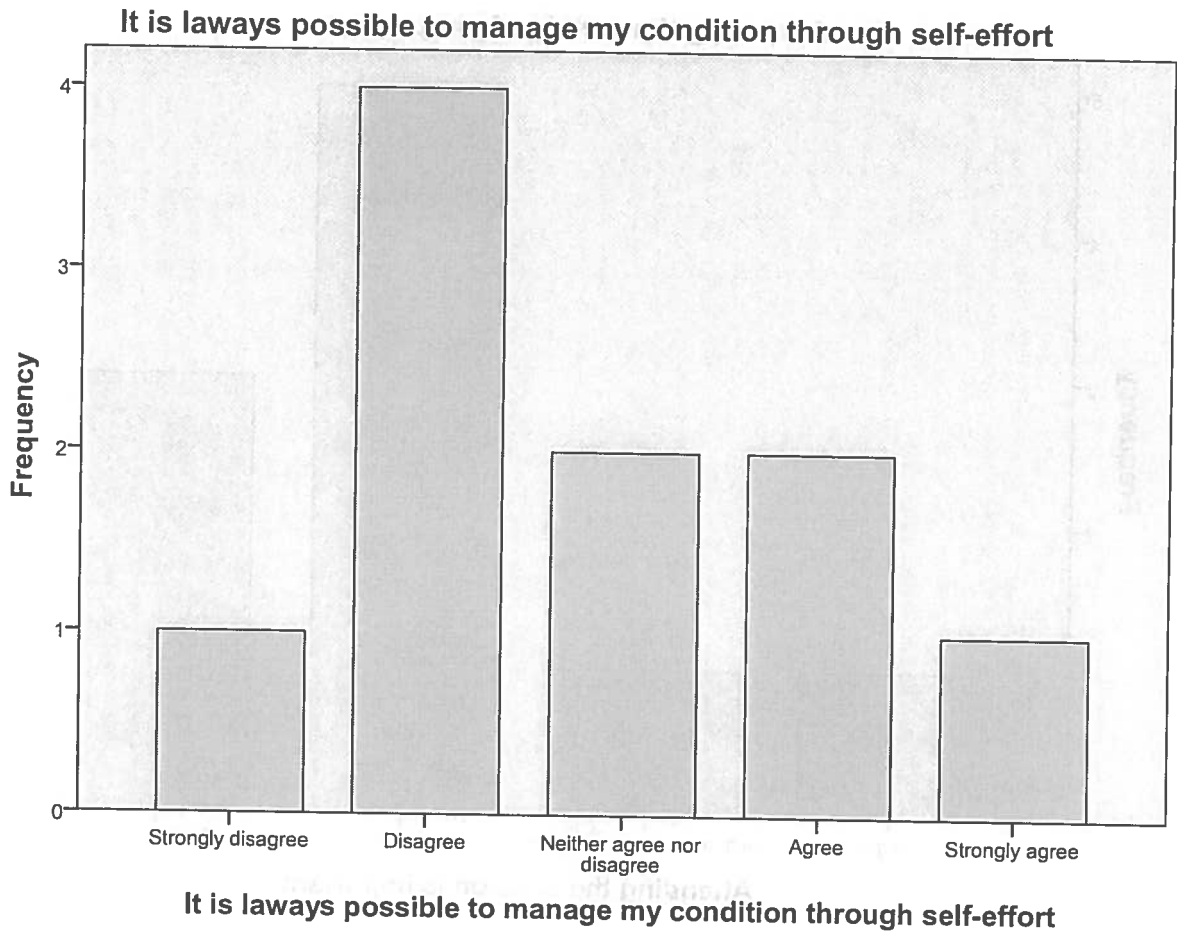


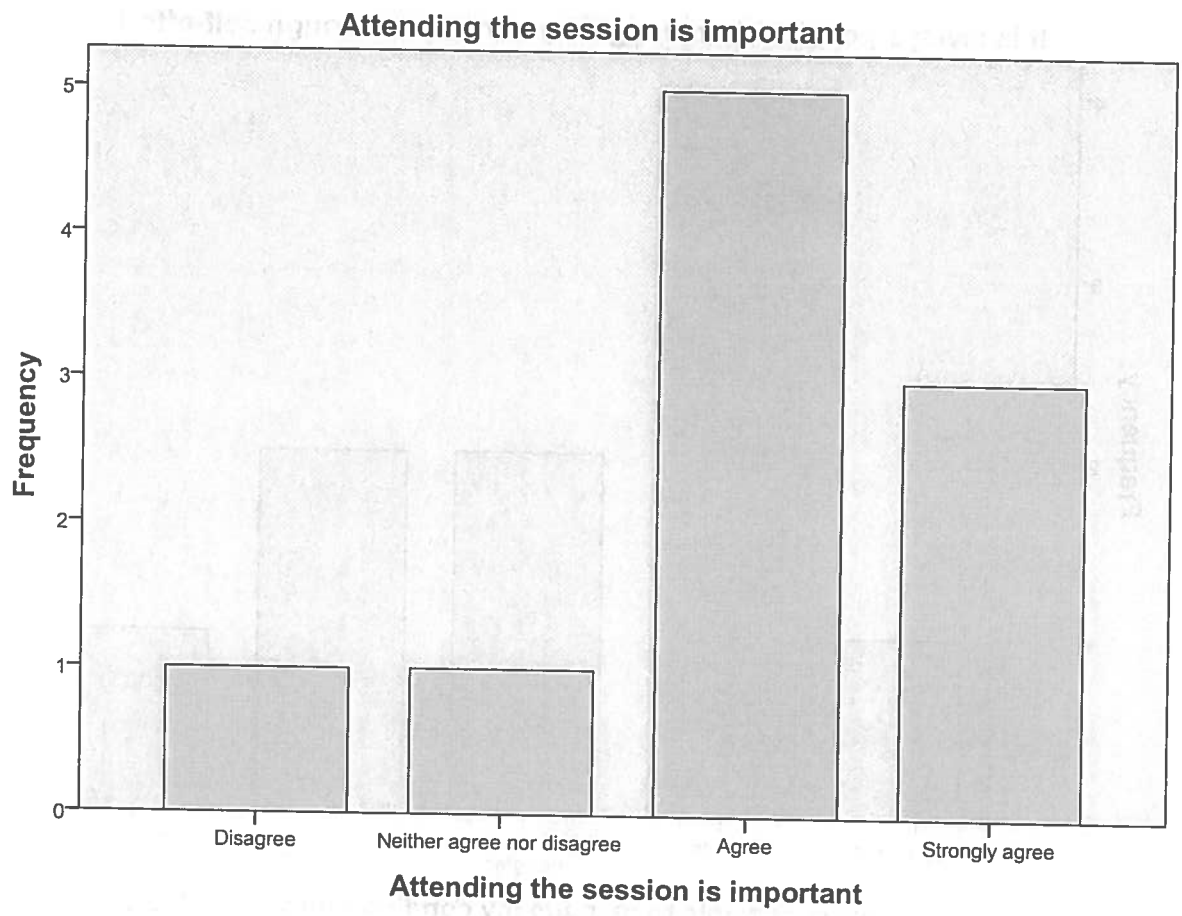


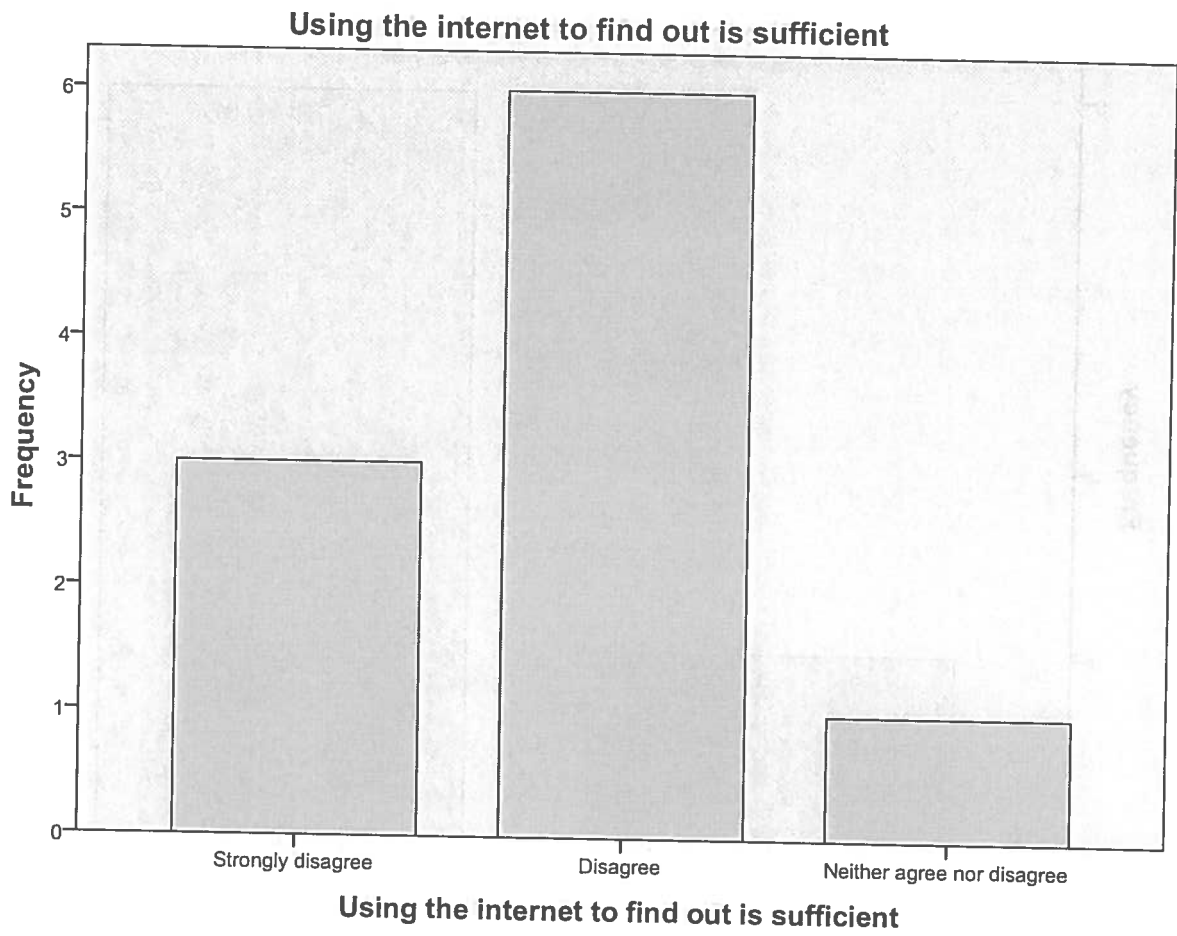
Adequate knowledge about diet, weight and exercise is important

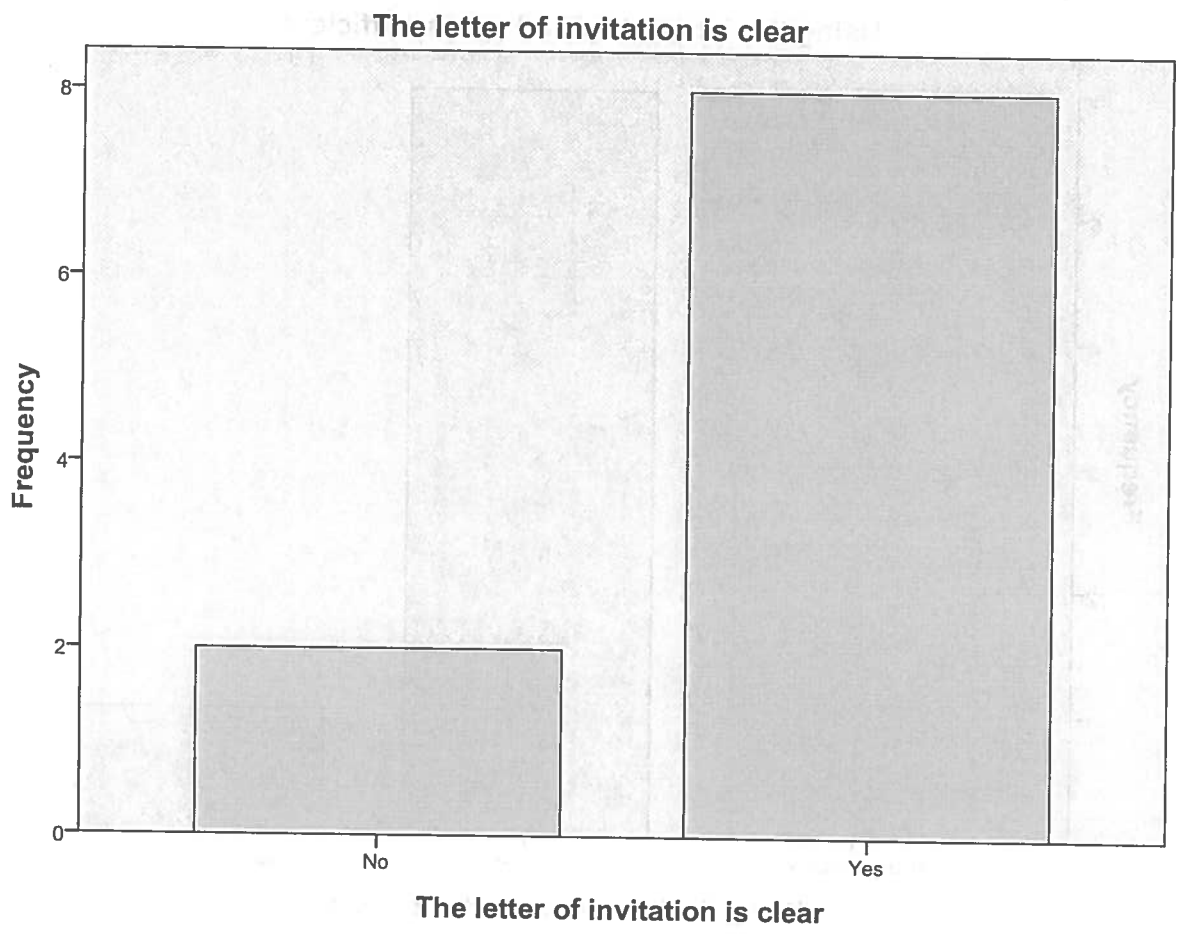


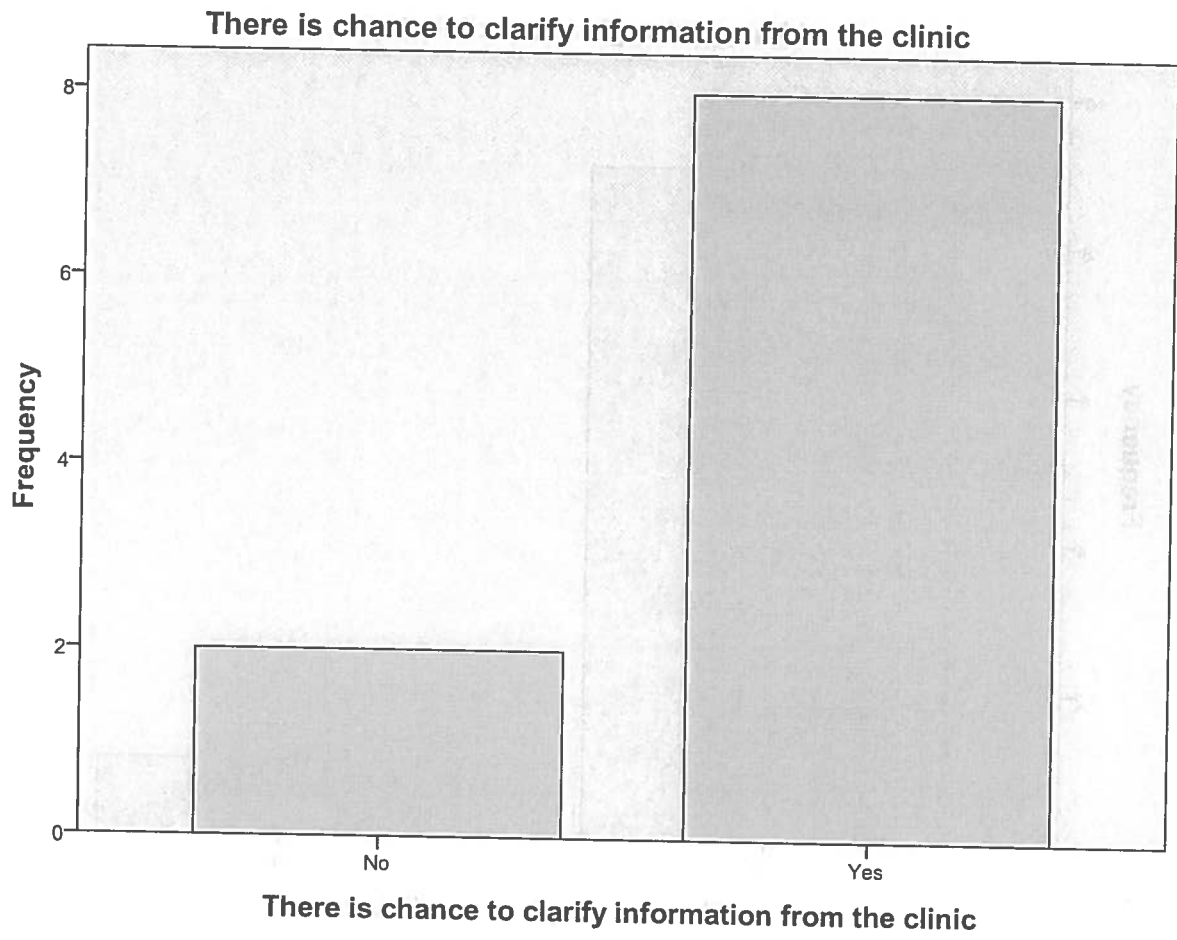
Adequate knowledge about diet, weight and exercise is important

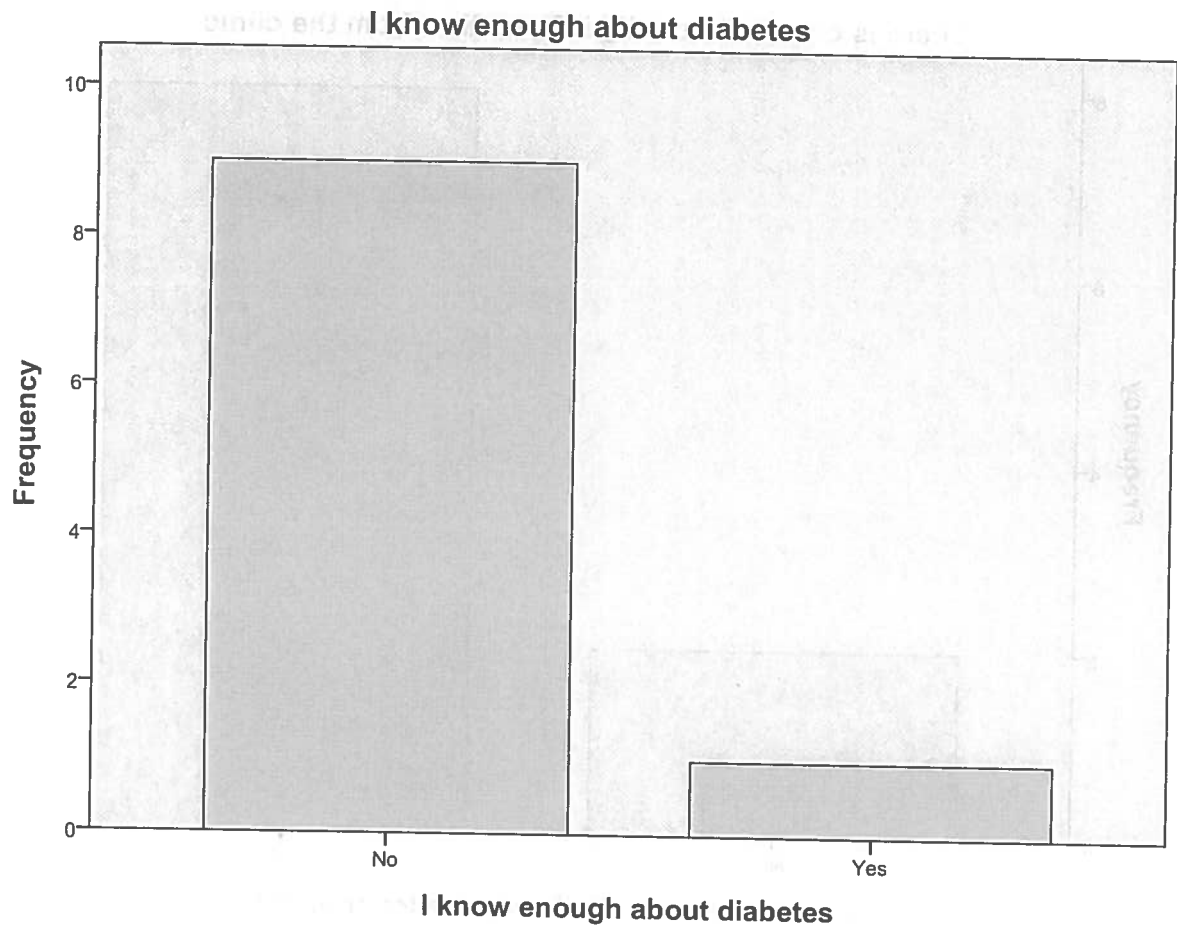


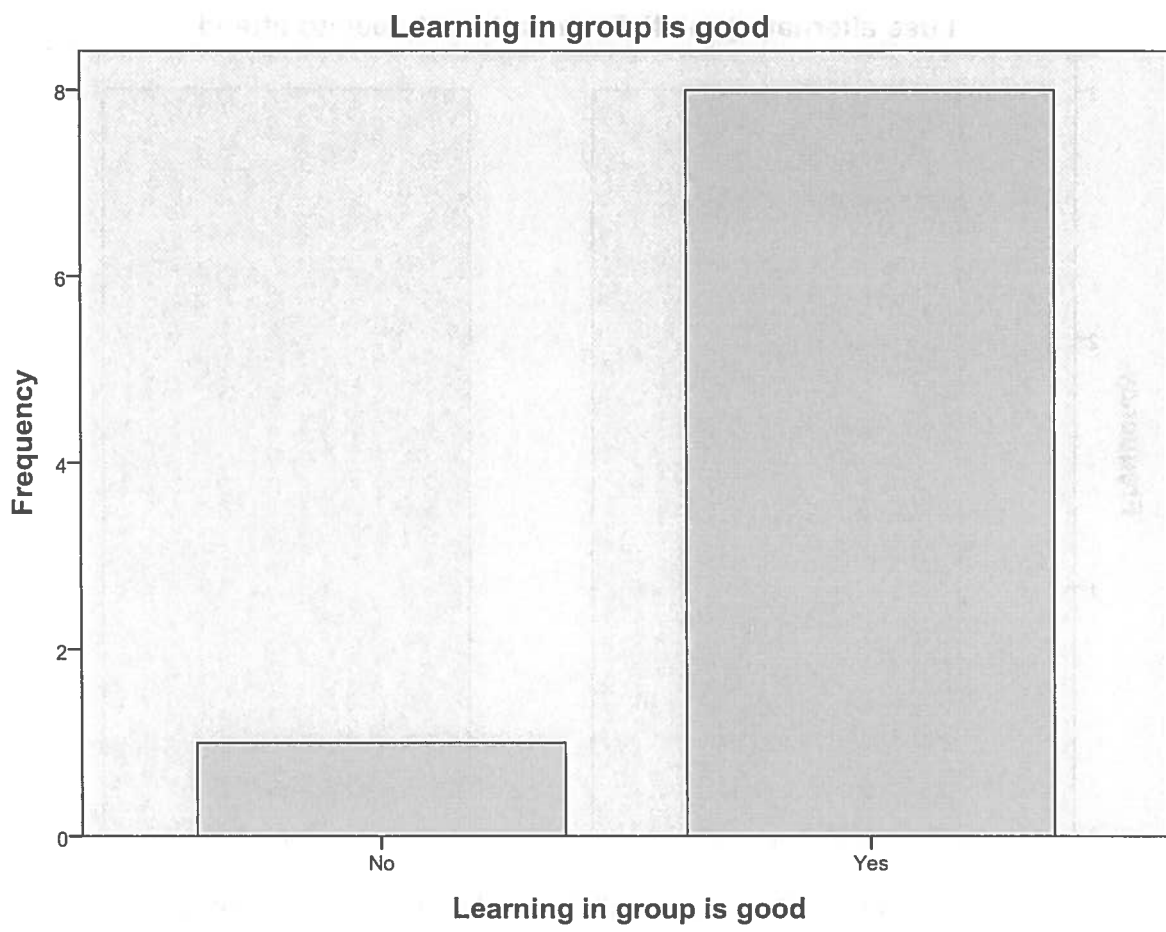


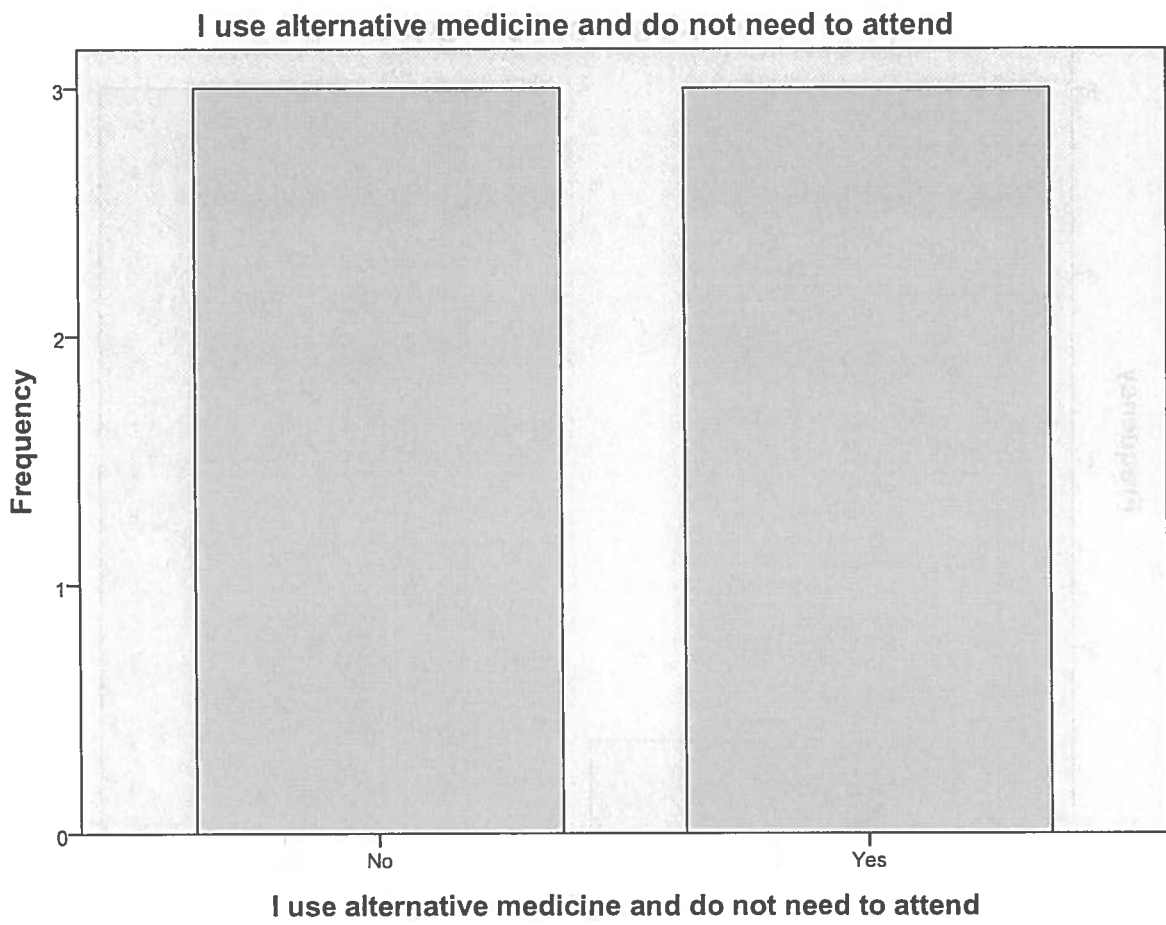




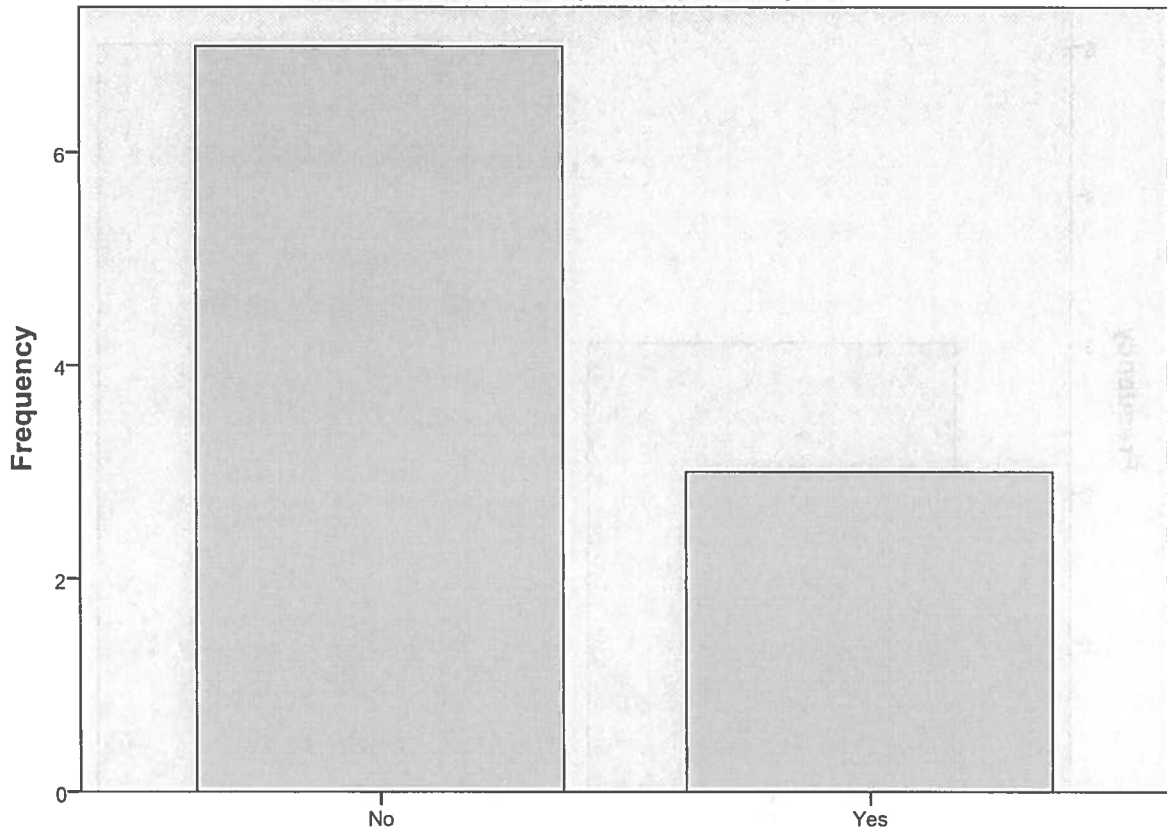




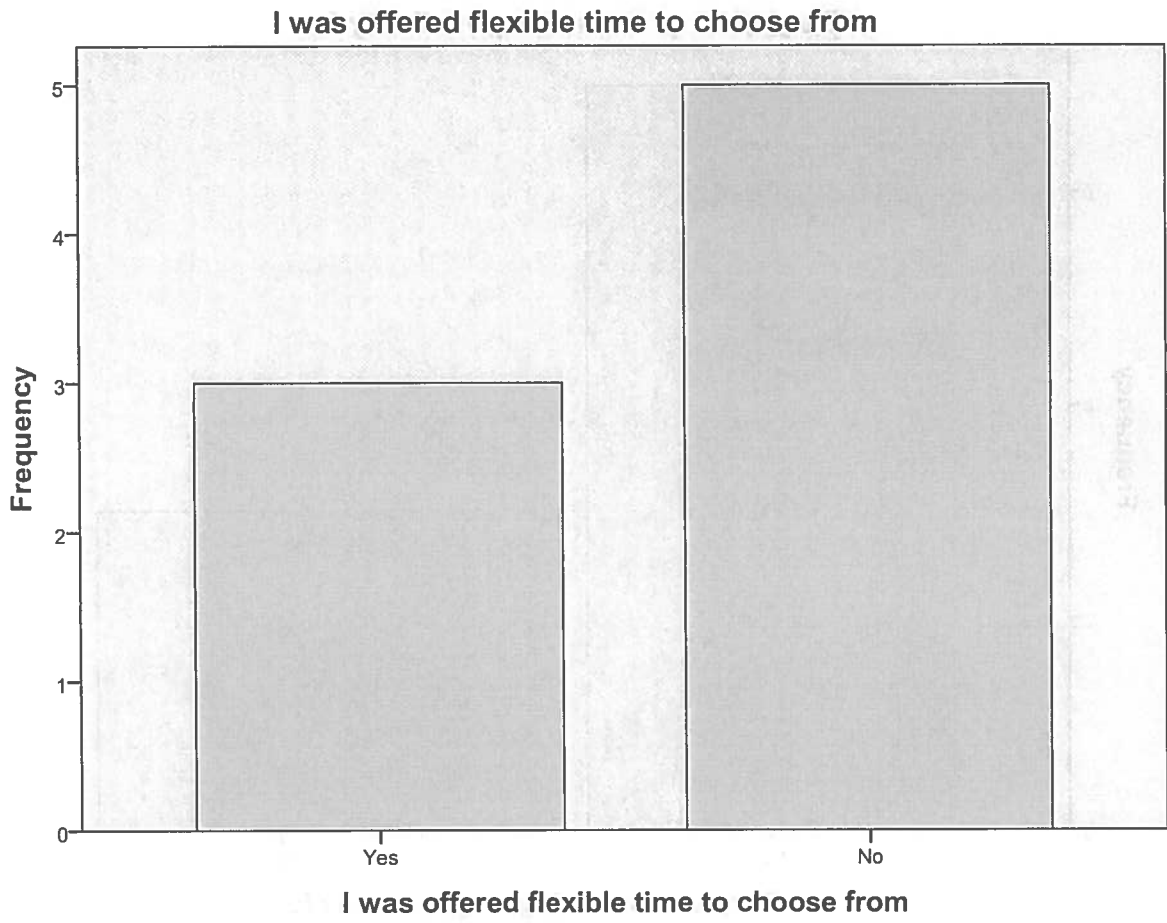


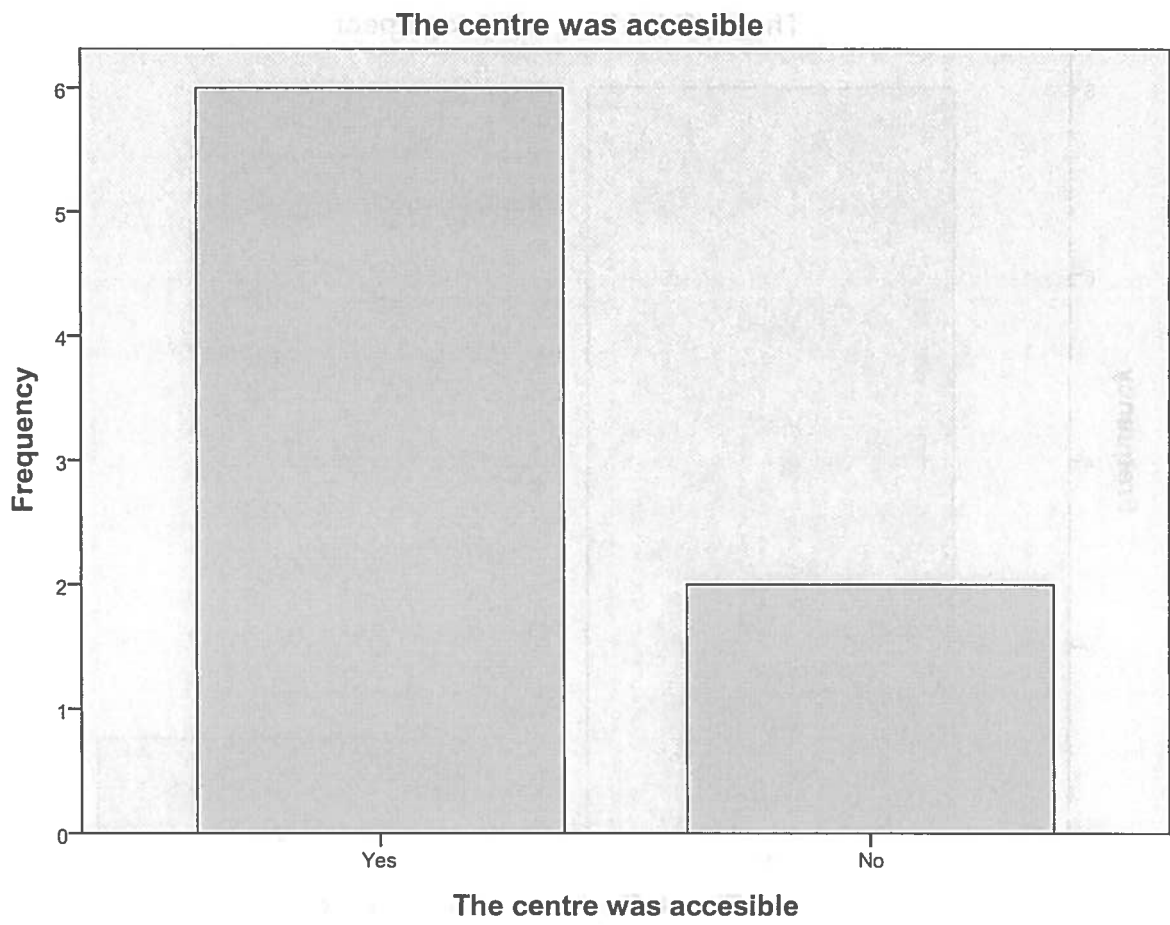


Do you have caring responsibility for

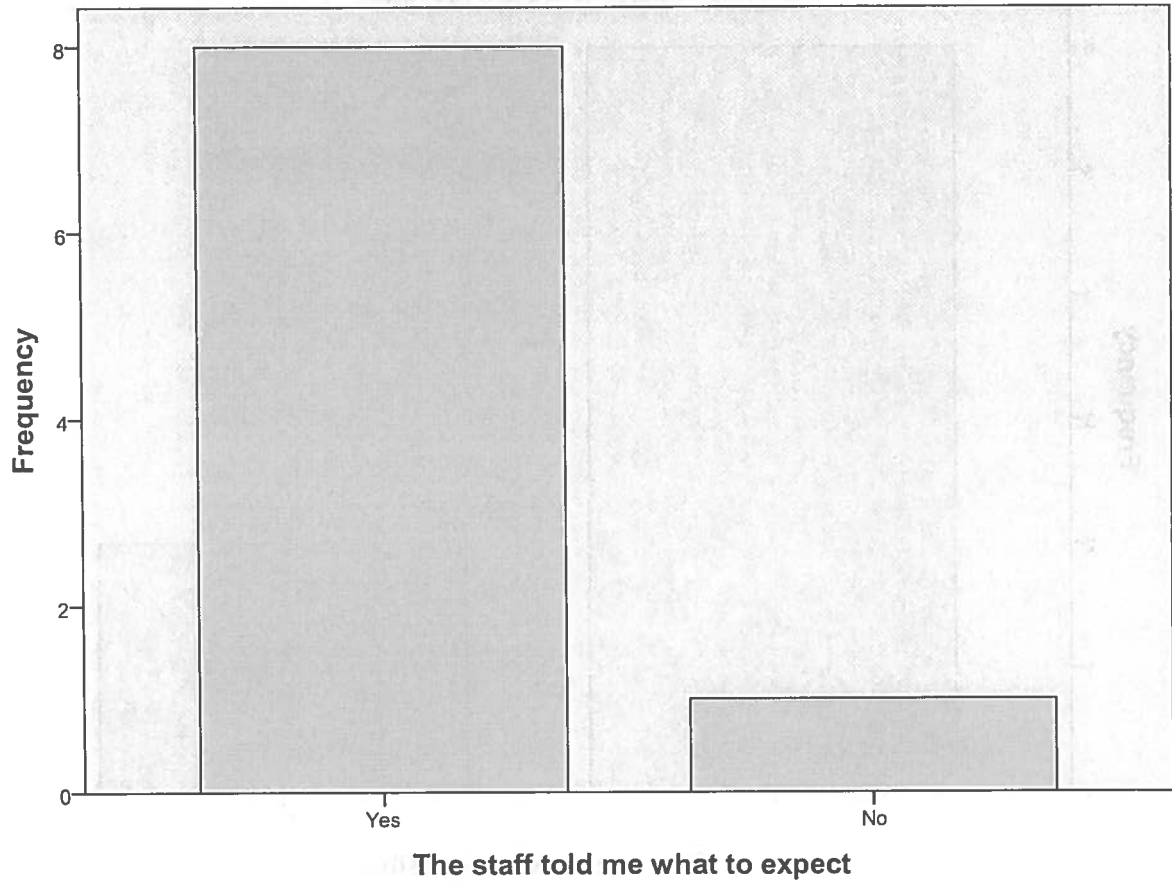


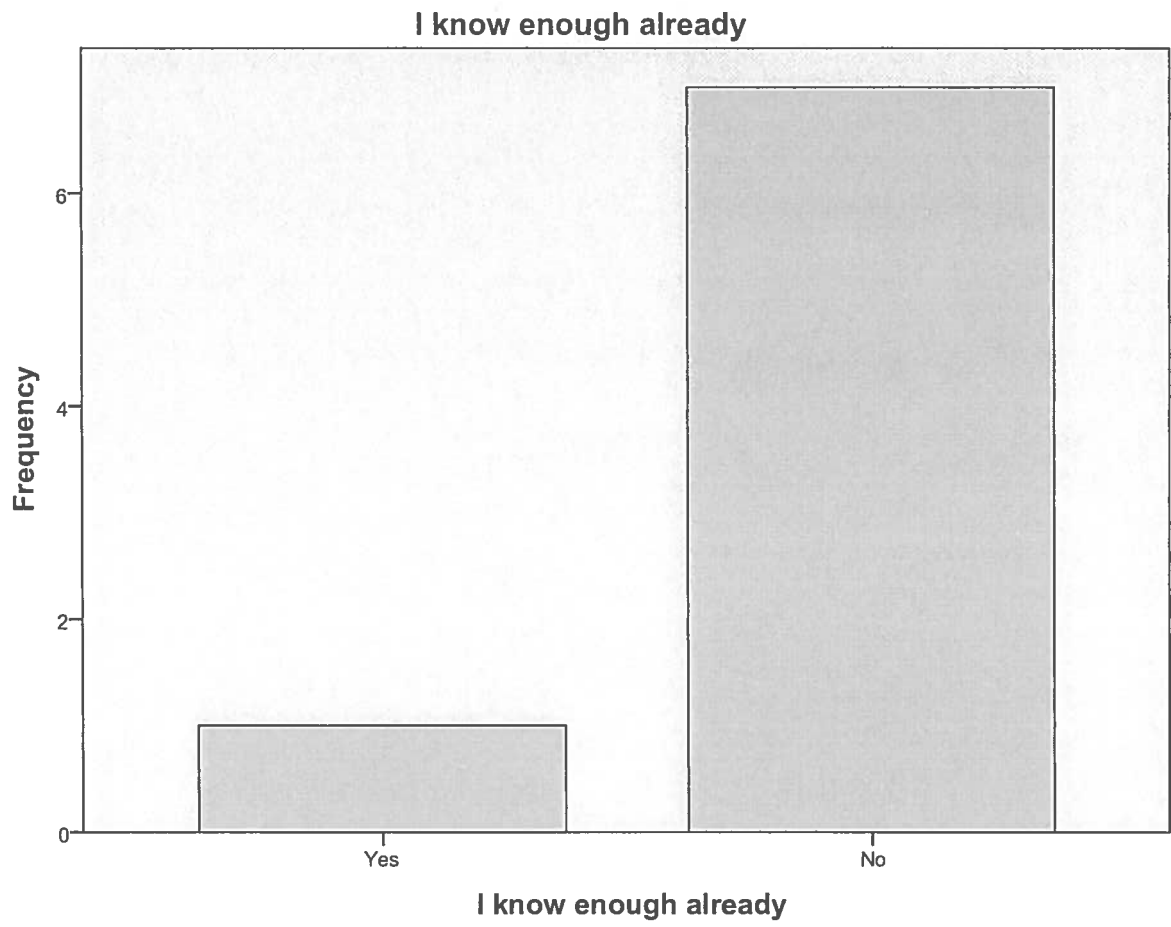
Do you have caring responsibility for





The staff told me what to expect





CROSSTABS

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/COUNT ROUND CELL.
    
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Crosstabs

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Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Age in Years * Sex	10	100.0%	0	0.0%	10	100.0%
Age in Years * Living Arrangement	10	100.0%	0	0.0%	10	100.0%
Age in Years * Ethnicity	9	90.0%	1	10.0%	10	100.0%
Age in Years * I know enough already	8	80.0%	2	20.0%	10	100.0%

Age in Years * Sex Crosstabulation

Count

		Sex		Total
		Male	Female	
Age in Years	40 and under	2	0	2
	41-65 years	3	3	6
	66 and over	1	1	2
Total		6	4	10

Age in Years * Living Arrangement Crosstabulation

Count

		Living Arrangement			Total
		Living alone	Living with partner	Living with family	
Age in Years	40 and under	2	0	0	2
	41-65 years	0	5	1	6
	66 and over	0	2	0	2
Total		2	7	1	10

Age in Years * Ethnicity Crosstabulation

Count

		Ethnicity				Total
		White	Asian/Asian British	Black/Black British	Mixed race	
Age in Years	40 and under	0	2	0	0	2
	41-65 years	3	1	1	0	5
	66 and over	1	0	0	1	2
Total		4	3	1	1	9

Age in Years * I know enough already Crosstabulation

Count

		I know enough already		Total
		Yes	No	
Age in Years	40 and under	0	2	2
	41-65 years	0	5	5
	66 and over	1	0	1
Total		1	7	8

CROSSTABS

/TABLES=Sex BY LivingArrangements Ethnicity FamilyHistory Language Disability Selfcare Selfeffort Attendance Internet Invitation Clarification Diabetesknowledge Groupeducation complimentarytherapy Dependant Flexibility Accessibility Influence Knowledge Occupation

/FORMAT=AVALUE TABLES

/CELLS=COUNT

/COUNT ROUND CELL.

Crosstabs

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Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Sex * Living Arrangement	10	100.0%	0	0.0%	10	100.0%
Sex * Ethnicity	9	90.0%	1	10.0%	10	100.0%
Sex * There is history of diabetes in my family	10	100.0%	0	0.0%	10	100.0%
Sex * I can speak	10	100.0%	0	0.0%	10	100.0%
Sex * I have a learning difficulty	10	100.0%	0	0.0%	10	100.0%
Sex * Adequate knowledge about diet, weight and exercise is important	10	100.0%	0	0.0%	10	100.0%
Sex * It is always possible to manage my condition through self-effort	10	100.0%	0	0.0%	10	100.0%
Sex * Attending the session is important	10	100.0%	0	0.0%	10	100.0%
Sex * Using the internet to find out is sufficient	10	100.0%	0	0.0%	10	100.0%
Sex * The letter of invitation is clear	10	100.0%	0	0.0%	10	100.0%
Sex * There is chance to clarify information from the clinic	10	100.0%	0	0.0%	10	100.0%
Sex * I know enough about diabetes	10	100.0%	0	0.0%	10	100.0%
Sex * Learning in group is good	9	90.0%	1	10.0%	10	100.0%
Sex * I use alternative medicine and do not need to attend	6	60.0%	4	40.0%	10	100.0%

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Sex * Do you have caring responsibility for	10	100.0%	0	0.0%	10	100.0%
Sex * I was offered flexible time to choose from	8	80.0%	2	20.0%	10	100.0%
Sex * The centre was accesible	8	80.0%	2	20.0%	10	100.0%
Sex * The staff told me what to expect	9	90.0%	1	10.0%	10	100.0%
Sex * I know enough already	8	80.0%	2	20.0%	10	100.0%
Sex * Occupation	7	70.0%	3	30.0%	10	100.0%

Sex * Living Arrangement Crosstabulation

Count

		Living Arrangement			Total
		Living alone	Living with partner	Living with family	
Sex	Male	2	4	0	6
	Female	0	3	1	4
Total		2	7	1	10

Sex * Ethnicity Crosstabulation

Count

		Ethnicity				Total
		White	Asian/Asian British	Black/Black British	Mixed race	
Sex	Male	2	2	1	1	6
	Female	2	1	0	0	3
Total		4	3	1	1	9

Sex * There is history of diabetes in my family Crosstabulation

Count

		There is history of diabetes in my family		Total
		No	Yes	
Sex	Male	6	0	6
	Female	1	3	4
Total		7	3	10

CROSSTABS

/TABLES=Ethnicity BY LivingArrangements FamilyHistory Language Disability Selfcare Selfeffort Attendance Internet Invitation Clarification Diabetes knowledge Groupeducation complimentarytherapy Dependant Flexibility Accessibility Influence Knowledge Occupation

/FORMAT=AVALUE TABLES

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/COUNT ROUND CELL.

Crosstabs

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Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Ethnicity * Living Arrangement	9	90.0%	1	10.0%	10	100.0%
Ethnicity * There is history of diabetes in my family	9	90.0%	1	10.0%	10	100.0%
Ethnicity * I can speak	9	90.0%	1	10.0%	10	100.0%
Ethnicity * I have a learning difficulty	9	90.0%	1	10.0%	10	100.0%
Ethnicity * Adequate knowledge about diet, weight and exercise is important	9	90.0%	1	10.0%	10	100.0%
Ethnicity * It is always possible to manage my condition through self-effort	9	90.0%	1	10.0%	10	100.0%
Ethnicity * Attending the session is important	9	90.0%	1	10.0%	10	100.0%
Ethnicity * Using the internet to find out is sufficient	9	90.0%	1	10.0%	10	100.0%
Ethnicity * The letter of invitation is clear	9	90.0%	1	10.0%	10	100.0%
Ethnicity * There is chance to clarify information from the clinic	9	90.0%	1	10.0%	10	100.0%
Ethnicity * I know enough about diabetes	9	90.0%	1	10.0%	10	100.0%
Ethnicity * Learning in group is good	8	80.0%	2	20.0%	10	100.0%
Ethnicity * I use alternative medicine and do not need to attend	5	50.0%	5	50.0%	10	100.0%

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Ethnicity * Do you have caring responsibility for	9	90.0%	1	10.0%	10	100.0%
Ethnicity * I was offered flexible time to choose from	7	70.0%	3	30.0%	10	100.0%
Ethnicity * The centre was accesible	7	70.0%	3	30.0%	10	100.0%
Ethnicity * The staff told me what to expect	8	80.0%	2	20.0%	10	100.0%
Ethnicity * I know enough already	7	70.0%	3	30.0%	10	100.0%
Ethnicity * Occupation	6	60.0%	4	40.0%	10	100.0%

Ethnicity * Living Arrangement Crosstabulation

Count

		Living Arrangement		Total
		Living alone	Living with partner	
Ethnicity	White	0	4	4
	Asian/Asian British	2	1	3
	Black/Black British	0	1	1
	Mixed race	0	1	1
Total		2	7	9

Ethnicity * There is history of diabetes in my family Crosstabulation

Count

		There is history of diabetes in my family		Total
		No	Yes	
Ethnicity	White	2	2	4
	Asian/Asian British	2	1	3
	Black/Black British	1	0	1
	Mixed race	1	0	1
Total		6	3	9

CROSSTABS

/TABLES=Occupation BY LivingArrangements Ethnicity FamilyHistory Language Disability Selfcare Selfeffort Attendance Internet Invitation Clarification Diabetesknowledge Groupeducation complimentarytherapy Dependant Flexibility Accesibility Influence Knowledge

/FORMAT=AVALUE TABLES

/CELLS=COUNT

/COUNT ROUND CELL.

Crosstabs

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Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Occupation * Living Arrangement	7	70.0%	3	30.0%	10	100.0%
Occupation * Ethnicity	6	60.0%	4	40.0%	10	100.0%
Occupation * There is history of diabetes in my family	7	70.0%	3	30.0%	10	100.0%
Occupation * I can speak	7	70.0%	3	30.0%	10	100.0%
Occupation * I have a learning difficulty	7	70.0%	3	30.0%	10	100.0%
Occupation * Adequate knowledge about diet, weight and exercise is important	7	70.0%	3	30.0%	10	100.0%
Occupation * It is always possible to manage my condition through self-effort	7	70.0%	3	30.0%	10	100.0%
Occupation * Attending the session is important	7	70.0%	3	30.0%	10	100.0%
Occupation * Using the internet to find out is sufficient	7	70.0%	3	30.0%	10	100.0%
Occupation * The letter of invitation is clear	7	70.0%	3	30.0%	10	100.0%
Occupation * There is chance to clarify information from the clinic	7	70.0%	3	30.0%	10	100.0%
Occupation * I know enough about diabetes	7	70.0%	3	30.0%	10	100.0%
Occupation * Learning in group is good	7	70.0%	3	30.0%	10	100.0%

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Occupation * I use alternative medicine and do not need to attend	6	60.0%	4	40.0%	10	100.0%
Occupation * Do you have caring responsibility for	7	70.0%	3	30.0%	10	100.0%
Occupation * I was offered flexible time to choose from	6	60.0%	4	40.0%	10	100.0%
Occupation * The centre was accesible	5	50.0%	5	50.0%	10	100.0%
Occupation * The staff told me what to expect	6	60.0%	4	40.0%	10	100.0%
Occupation * I know enough already	5	50.0%	5	50.0%	10	100.0%

Occupation * Living Arrangement Crosstabulation

Count

		Living Arrangement		Total
		Living with partner	Living with family	
Occupation	Employed	3	0	3
	Unemployed	3	1	4
Total		6	1	7

Occupation * Ethnicity Crosstabulation

Count

		Ethnicity				Total
		White	Asian/Asian British	Black/Black British	Mixed race	
Occupation	Employed	2	0	1	0	3
	Unemployed	1	1	0	1	3
Total		3	1	1	1	6

Occupation * There is history of diabetes in my family Crosstabulation

Count

		There is history of diabetes in my family		Total
		No	Yes	
Occupation	Employed	2	1	3
	Unemployed	2	2	4
Total		4	3	7

Appendix 14

Thames Valley University/ BE PCT

Questionnaire Survey

Your perceptions about group diabetes health education

Dear patient,

This questionnaire seeks your views and opinions about diabetes education which your GP has advised and referred you to attend. We are asking your views whether you did or did not attend. It will be really helpful if you respond as this will enable us to assist people like yourself in the future. Anonymity is guaranteed and the information you give will be strictly used for research and academic purposes. The research has been approved by the Berkshire Research Ethics Committee (**Approval No 08/H0505/73**).

Thank you for your time.

PART ONE

SECTION A – This section seeks to gain your views about health education and benefits of developing ability to manage your condition. **There is no right or wrong answers.**

Please tick (✓) your response.

	5	4	3	2	1
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. I believe that taking responsibility to care for myself is an important aspect of my health care.					
2. Attending planned sessions at an education centre is important to develop the ability to care for myself.					
3. Using the internet and talking to other patient to find out about my medical condition is sufficient to offer adequate information.					
4. I believe that my diabetes is well controlled and do not need to attend the teaching session.					

SECTION B – This section is to identify the reasons that encourage you to attend the education session. It is also to gather information on your opinions about group education and what we may provide so that you will be interested in attending the education centre. Please tick (✓) your response.

- | | Yes | No |
|---|--------------------------|--------------------------|
| 5. The Doctor or Practice Nurse told me what to expect during the teaching session. | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. There is opportunity to contact the education centre or GP clinic to clarify information | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I know enough about diabetes before I was referred by my GP to the education centre | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Group education is a good way to learn about diabetes | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. I like to share experience and gain support about my care through group education | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. The letter of invitation is clear | <input type="checkbox"/> | <input type="checkbox"/> |

Thames Valley University/
PCT

Dear Patient,

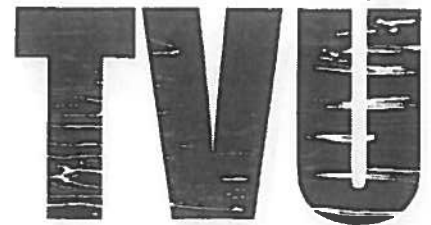
Your views about group diabetes health education

I am doing a survey to find out ways of improving diabetes health education. Your views are very important in improving the service of diabetic patient. You may have received a questionnaire for this survey previously and if you have sent back your questionnaire, I apologise for sending this to you again.

I would be grateful if you could just take a few minutes of your time to complete the enclosed questionnaire which is of great importance to us in obtaining views about diabetic health care education. All the information is made anonymous and treated in confidence.

I have enclosed a stamped addressed envelope for your response and would be grateful if you could respond by the 10th of May.

Thanks.



Thames Valley University
London Reading Slough

Thames Valley University/
PCT

Dear Patient,

Your views about group diabetes health education

I am undertaking a study to improve the education service provided to diabetes patient. I know that I have sent a questionnaire to you before and I hope you don't mind me sending another one to you again.

This study is so important and would help people like you that do not attend the diabetes education session.

I have enclosed a stamped addressed envelope for your reply and shall be grateful if **you could send the completed questionnaire back to me within two weeks.**

I look forward to your contribution in improving the service we may offer you.

Thanks.



Thames Valley University
London Reading Slough

Appendix 15

Thames Valley University/BE PCT

Questionnaire Survey **Your perceptions about group diabetes health education**

Dear patient,

This questionnaire seeks your views and opinions about diabetes education which your GP has advised and referred you to attend. We are asking your views whether you did or did not attend. It will be really helpful if you respond as this will enable us to assist people like yourself in the future. Anonymity is guaranteed and the information you give will be strictly used for research and academic purposes. The research has been approved by the Berkshire Research Ethics Committee (**Approval No 08/H0505/73**). Thank you for your time.

PART ONE

SECTION A – This section seeks to gain your views about health education and benefits of developing ability to manage your condition. **There is no right or wrong answers.**

Please tick (√) your response.

	5	4	3	2	1
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. I believe in taking responsibility to care for myself is an important aspect of my health care.					
2. Attending planned sessions at an education centre is important to develop the ability to care for myself.					
3. Using the internet and talking to other patients to find out about my medical condition is sufficient to offer adequate information.					
4. I believe that my diabetes is well controlled and do not need to attend the teaching session.					

SECTION B – This section is to identify the reasons that encourage you to attend the education session. It is also to gather information on your opinions about group education and what we may provide so that you will be interested in attending the education centre. Please tick (√) your response.

- | | Yes | No |
|---|--------------------------|--------------------------|
| 5. The Doctor or Practice Nurse told me what to expect during the teaching session. | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. There is opportunity to contact the education centre or GP clinic to clarify information | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I know enough about diabetes before I was referred by my GP to the education centre | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Group education is a good way to learn about diabetes | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. I like to share experience and gain support about my care through group education | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. The letter of invitation is clear | <input type="checkbox"/> | <input type="checkbox"/> |

Appendix 16

Question Guide

(1) There is evidence to suggest that education helps to alter people's behavior and the Government has introduced an educational policy for all newly diagnosed patients with diabetes. In your opinion, do you think the policy of recommending education for all is a good idea in the first place?

What is your view about the Government recommending education for all people diagnosed with diabetes?

(2) I believe that you are either responsible for referring or delivering structured patient education to patients with diabetes?

- What is the referral process?
- Who are the people involved in the referral process?
- How do you identify the patients?
- How are they referred?
- How much information was given during the referral process – e.g. where to go and what to expect?
- Do you think the referral process is a contributory factor to non-attendance?
- Do you think professional versus patient interpersonal relationships is partly to blame for this problem?
- In your opinion, do you think there is a good collaboration between the surgery and the education centre?

(3) Did you observe any changes in the attendance rate over the last 2 years/since the implementation of the Social Act 2012/new QOF scheme? What do you think about the difference/what do you think is responsible for these changes? If it hasn't changed, why do you think it is so?

(4) Based on your experience, can you tell me why you think some patients are not attending the group education following referral?

(5) A big issue is how to implement the policy. Judging from your experience, what do you think can be done to improve the attendance rate?

(6) Some people have been talking about sanctions, (take for example, the Dentist occasionally charge the patient for missed appointment or occasionally discharge some patient for not cancelling appointments). What is your view about using any form of sanction or incentive to motivate attendance?

Do you still have more to say on how to motivate patients to attend/any additional comments?

Appendix 17

LEVEL 1 CODING

Interview 1

The aim of this interview is to find out why patients are not attending the Diabetes Education Centre with the intention of finding out ways to improve the attendance rate. Based on your experience as a practice nurse, what do you think contributes to non-attendance at the Diabetes Education Centre?

Mainly, probably that people are not happy to go to wherever it is. I think the hospital I'm not quite sure, they say they can't be bothered to go and to get a bus or haven't got any money or err so it's that but also I think maybe the nurses and doctors don't explain enough what it's about...

So you think probably the referral process is not robust enough?

Yes I would guess so it's just shall we refer you for Diabetes Education yes or no? And the patients always nod as they always do when the doctor or nurse says something! So it's not really explained, what it is and how it would help them.

Why do you think that is happening?

Time, lack of time.

Oh! Ok.

Yes, I mean we know what it's about but trying to explain it to a patient is difficult. I think probably nurses are slightly better than doctors doing that but even so when you are pushed you know you hardly have time to do the referral let alone explain to the patient what it's about and also it's a tick box on the template that comes up.

So it's all about ticking boxes?

It is a tick box referral for diabetes education so you sort of tick the box and say to the patient would you like to learn more about diabetes and they nod but you don't explain where it is or how long it will take or how many sessions it is.

Ok for the diabetes referral a lot of it is about ticking boxes?

It is, it is because there are so many boxes you have to tick now so when you are seeing a diabetic patient you have to check their feet you have to do all sort of normal things like blood pressure and you have to make sure they're referred for their eyes, their feet you know, as well the diabetes education, so it is the tick boxes that come up and if you've only got 10 minutes or a quarter of an hour it's not long to explain all of these things.

So you've got very limited time to spend with these patients?

Yes, and I think with the doctor is worse.

Within this limited time, who does the referral?

The nurses, I think the nurses do most of the referrals but again it is time....

But you have more time than the doctors?

Well I do, I only have half an hour for a new patient. I'm lucky and the doctors have about 10 minutes.

And that is not enough to refer a patient to the DEC?

Well if you are going to give a complete explanation, it is not enough because I mean I'm talking about this particular area **we have language problems so that takes a lot of the time when somebody doesn't speak English and I don't speak Punjabi or anything** you know the others like Hindi and you are trying to explain to the patient about diabetes and trying to get them to understand what it's about. **I do quite a lot of helping them to understand self-care because that's important with diets and things like that and then by the time you get to the sort of tick box which says Diabetes Education, well ok I could refer them but they don't speak English very well, they are not in the right place to be learning** because especially new diabetics you need to tell them gradually over a few session - what it's about. I think bunging them straight into diabetes education is difficult and they wouldn't go if they didn't really understand why they had to go, you see what I mean.

I can see it!

Because when you are told you are diabetic it is frightening and people get really worried so you have to spend a lot of time with them trying to explain that they have to look after themselves and between us we can make sure they are well looked after so we have to get them in the right place to want the education otherwise they won't understand why they have to go.

Does that make sense?

Yes it makes sense, but once you have identified the patients, they need the education to be able to manage themselves?

Yes, they need the education, well all the patients need the education basically all the diabetics but in the past, really up until more or less now the nurses have done the education so we have done it, you know the diet and the exercise and eyes and feet and all the rest of it and driving and all that sort of thing most of us as nurses have done that for a very long time and I would see a new diabetic several times, would have a check list and make sure that each time I see them I would tell them something different like when you are ill what to do or you know if they drive a lorry or whatever you have to tell them about their medication and hypos and things like that so because it's an awful lot to take in when you are newly diabetic so I think the education for most nurses would be over a series of appointments. I know the

Diabetic Education help them to do all of this but as I say **the patients' needs to understand why they need to go and be in the right place.**

Which right place?

The right place mentally. **So you need to prepare them mentally so they know ok... so they can be more receptive and prepare to take it on board.** Exactly yes, they can't go if they don't understand why they have to go.

Can we probably say that education is not high on your agenda compared to other treatments such as drug management?

For the patient, do you mean?

From the practitioners point of view?

Most nurses have done it for so long because we didn't have this facility for having diabetes education then yes maybe it's not very high on our agenda. But now that we have this tick box to say that we have sent the patient to diabetic education then now it's probably higher on the agenda.

Would you say that the referral process has got better within the last 2 years, particularly comparing it with the time before it was part of the Quality Outcome Framework (QOF)?

Yes I think probably more people are being referred, but I know the people that we refer don't go.

So the increase referral rate does not necessarily lead to attendance?

No, it doesn't.

Then we know that there is a problem somewhere and how do you refer them- do you give them a letter or a phone number?

Yes, because it is again, it's not getting it right, we can really say... ok after you have referred them, you've got them, no. We fax their details to the DEC whatever the address that is on the form and we are in the process of changing to an electronic system. I can't remember the address but they would contact the patient.

Ok they are responsible for contacting the patient?

Yes, the education people would contact the patient.

Do you have a good idea about what happens in the process?

No, but I have an idea **it might be part of the thing that you need to educate the practitioner and each nurse or doctor or whatever needs to go to the education to see what it is that is happening.**

Do you follow them up after the referral?

No, we don't have the time to do that.

Does this suggest a lack of adequate collaboration between the referring practitioners and the providing practitioners?

Well no I think it is run by the hospital nurses. So we are in contact with the specialist nurses quite a lot and I use them a lot but maybe it's a two way thing and maybe we need to attend one of the sessions and see what happens maybe they need to tell us a bit more about what is happening maybe that would help so that we can educate the patients. As I said, they can get a letter from diabetic education and its oh! I can't be bothered.

Do you mean the practitioners delivering the structured patient education programme?

They call them structured patient education but there are different types and do you know the expert patient programme.

Yes, it is a popular education programme?

That's right and it used to be for long term conditions – there was asthma training as well for other patients but I know I couldn't get my husband to go and he said he would go to the Diabetes Centre as he is diabetic but when it came to it he didn't want to go as he said he knew more... than they could teach him!

So the barrier could be due to the perceptions of the patient as well, if the patients think he/she knows enough and cannot see the benefits of the education?

Yes definitely. I think that's probably a key part of it actually, the patient perception of what it is because we haven't given them the information, we haven't given them the enthusiasm to go and they don't really understand what it is about so they think it's a waste of time.

So that brings us back to the process of referral. Do you think that lack of follow-up could be part of the problem?

Yes, I appreciate that and I suppose when we see them and we know that the patient has not attended then I might say to the patient you know why didn't you go and usually there is an excuse like they haven't got any money or there is no bus or it was too far.. or I haven't got time or I work you know all these excuses they give so but I wouldn't follow it up anymore, because we have thousands of diabetic patients and you know we would follow them up in an ideal world, we would do a lot of things but the ideal world is not anymore as it used to.

Does the Doctor follow them up either?

Well the GP's in a way have been de-skilled unfortunately because nurses have taken over a lot of this work you know the long term conditions work we monitor the asthmatic and COPD patients and diabetic patients and epileptic patients etc.....

Ok so many things are going on at the same time?

Yes far too many, yeah and we just don't have the time to monitor like we used to. And again you have too many people walking in with all these sick bugs and that seems to be more important anyway because we are being judged and the boxes need to be ticked.

Does this mean that the recent QOF has impacted on your practice?

Exactly, and that is quite right, that is the problem , QOF in a way started as a good idea but there are too many tick boxes and too many things to look at and too many things we have to do to get the money and in a way it's spoilt the way we look after the patients because we don't give them the care anymore and we don't know them and I used to know all my patients who came on a regular basis and I used to call them myself at the Diabetic Clinic I knew them all but now.... I can't now because you've got so many. There are too many things that you need to produce to ensure for that outcome. So the government have set too many goals that we haven't got hope of keeping. And without keeping these goals money will not come in, so you have to find a way of keeping the money coming in which makes sense anyway. But we've got same number of staff that we have always had and there has not been an increase and now we are having trouble finding practice nurses anyway. So patients just get basic care rather than the required level of care.

So more personnel could help?

Yeah personnel very much we just haven't got enough practice nurses we haven't got practice nurses around.

So there's not a lot of training going on?

No there isn't that is the problem, that is being sorted now by the Health Education at last but yeah there aren't enough practice nurses anymore.

What is the role of the practice manager in all of these?

Well the practice manager would organise the administration of the call and recall of the diabetics that's probably all they do.

Not actually initiating or managing the referral?

No they don't see the patients at all. Apart from picking up complaints and things like that but no they don't see the patients so they would do the administration or

make sure the administration was done for the call and the recall so patient needs to be called once or twice a year whatever it is so they would arrange that.

With all what we have been discussing, the practice nurses seems to be central to the issue of non-attendance?

Yes, yes definitely.

So you need to do more?

Yes we do need to do more but you **speak to most practice nurses they just don't have the time and I'm sure they will all tell you that.** They want to, we want to do it and we have been trained to do it.

Some participants have suggested the possibility of using sanctions to motivate attendance. What is your view on imposing any form of sanctions?

Oh no I don't think that is the right way to go at all.... No I can't think that would work err I mean it might work **if the education was near to the patient and at a time they could go because a lot of the patients work so they can't really go in the daytime or I'm sure work won't let them off to go to the diabetes education and I mean that's really almost punishing them for being diabetic to put sanctions that seems really harsh.** So no I don't think that's a good idea at all.

So you don't think that is a good way to go at all?

No I don't.

Ok, it's all about finding ways to make sure that patients attend the sessions?

Yes I know and I appreciate what you are saying, but no, I think, I mean you rather not put sanctions. **The practice nurses can do a lot of the education so it's not as though the patients are not getting any and most of the practice nurses do basic education for them and you know we tell them to look at Diabetes UK website and things like that so they can do a bit of research themselves but again in this area the language barrier is a problem.**

In terms of changes, has the recent NHS Social Act (2012) brought some positive changes to your working practice?

No it hasn't it's a shame but has increased the pressure and it hasn't really increased the attendance.

So there has been more referral which doesn't really translate to attendance because you've got to tick the boxes. Therefore, don't you think that you need to do a bit more?

Well the thing is in this area the attendance is very bad I gather, because I'm on the diabetic steering committee now and it seems the attendance is appalling but I think it is multi factor it's not just one thing you know like we have been saying **its language, it's not having maybe the education at the right time or in the right place, its encouraging the patients to go and making them understand why they have to go so its lots of things.**

In your own view do you think it is a good idea for the government to introduce the policy of education in the first place?

What education?

Structured Patient Education for all patients with diabetes?

Well, yes I suppose it is because I am a great believer in self-care and I think if patients understand why they have to look after themselves and how to look after themselves then it will take some of the burden from us, so yes **the policy is good but maybe it's the way it's been implemented.**

Now that takes us to the issue of implementation. If it is a good policy then we need to try and implement it properly. What ways do you think can be used to improve attendance?

Well, making sure that **it's a time and place where the patient can go to, and are happy to go and being done in different languages**, especially in this area. Yes probably those are the main things aren't they.

Do you think the government could do a little bit more to help you?

No, I think they interfere too much, too much as it is.

So you think they interfere too much?

I think it's probably good to have a general basis of education but I don't know across the county whether they are doing the same sort of education?

Is there a place for different kinds of education, however, regardless of the type of education, the issue is about how to motivate attendance?

They do and in this area we have one practice which does their own education and they run their own sessions for the patients and the patients come because the

practice is running it and they've sorted out exactly what they want to do and they do it and it's done in the practice for the patients and they go.

How did they manage to do that?

Well they just got the enthusiasm it's the doctor and I think there are two doctors who do it and one of the nurses all full of enthusiasm and thought patients aren't going to the structured education and thought we will do it ourselves and they did.

So instead of sending patients to the diabetes education they are doing their own in house education?

Yes, it's structured almost the same, you know you need to teach all diabetics the same things but they do it in house and it's successful.

That does not fall within the regulation, for example, there need to be a Dietician and a Podiatrist in the team?

Absolutely, but they are not doing that?

Does the new structure of the CCG give them the freedom to just decide what they want to do in their Surgery regardless of what is happening in the other GP surgeries?

Yes there is nothing to stop you from doing it and it's very successful.

So you have some degree of flexibility within the organisation?

Well you could say that I suppose yes....

Because I don't think you can do that in the past?

Yes you could absolutely, every practice have done it in the past, I mean the practice I worked in for 23 years that's exactly what we did we had ran the diabetic clinic. I called for all my patients and I knew them all and we used to call them every six months or whatever we had a Dietician who attended the clinic. We have myself, the Doctor and the Dietician and we never actually got the Podiatrist we could refer to the Podiatrist and we used to run the clinic with the Dietician there in the practice. So I mean that is how it always worked so the patient was always getting what they needed and then once QOF came in and the new GP contract, that just went out of the window and just didn't happen anymore.

So one of the solutions could be doing this education in the GP surgery even if it means bringing other practitioners in?

It will probably encourage them and probably solve the problem of things like location because people are more likely to live locally and would have registered there. The only trouble is that you have limited space depending on the size of

practice and you can't do it for one GP or two GP's, really you need or maybe several practices joined together. I think how it would work best is in the practice and then the specialist nurse could come out and talk to the people who are on insulin and that sort of thing and help with all of that.

Do you have that kind of space?

Well I wish we could do it here but we don't have enough rooms at the moment because the Walk-in Centre takes up a lot of space, but we do have a Dietician who comes but she sees people from other practices from around and she's not part of our diabetic clinic but I wish she was.

So going from GP surgery to GP surgery, there seems to be some organisational differences?

Yes but I think that is the ideal solution actually. For us, coming to the patients rather than the patients coming to us to the education. I would love to do that here absolutely, love it, you get all the patients round the table here and I'm sure they would come because they are already familiar with the GP surgery and then seeing an old faces. They can see the nurse that they are used to and they would know, it wouldn't be difficult.

Could this have some resource implications?

Yes, I think you are right. That's right and it would only be once a year, really I mean or maybe twice a year to do sessions and we do have quite a lot of new diabetics but they could have one session every six months sort of thing which other diabetic's wouldn't have. As you said, the resource implication could be an issue; it's a waste of the nurses' time anyway if the patients don't turn up for the education to spend the day in the practice. And these patients end of with complications and it would be everybody's waste of time and money it will affect all of us at the end of the day.

In your observation, are patient's perceptions a major problem?

The patient has got to see why they need to have the education because unless they are told as I say it's a huge shock to be told you are a diabetic as there are all sorts of myths that go round about diabetes you know like how you're going to go blind and you will lose your legs those sort of things so they need to understand why they have got to learn about it.

Do you have any issues motivating patients with family history of diabetes?

For a lot of our patients, their parents will still be living this day if they are alive in Pakistan or wherever but a lot of my patients say to me oh my mother died of diabetes so they have a lot of maybe wrong ideas about how diabetes can be treated, or maybe they don't even know it can be treated you know it's the whole

thing that their mother died of diabetes and they don't understand how maybe the mother could be looked after better and how they can look after themselves better.

Is the process of referral well supported by the GP?

In each practice now we are supposed to have a GP who is interested in diabetes and you can't expect all the GP's to have an intense interest but they do need to know if they see and are referring people what they are referring them to and most of the time now it's the nurses and one GP who is the specialist, a GP with specialist in diabetes that's what they call them.

So you have a GP champion for diabetes?

Yes exactly that's the idea to have one person who everybody would go to for their diabetes and the other doctors would say oh Dr Smith is the one you need to see for your diabetes. We can't all be specialist in everything. Well yes it's new now I mean in the past it hasn't worked but as I say they are starting off again now. Or if you have asthma or COPD you will go and see Dr Jones or epilepsy see Dr.... you know somebody else, especially in a big practice.

And that should work better?

Well yes because it can be so complicated now and I mean in the past it was a lot simpler. You know you treated them with just insulin and that was it and now there is all these you know huge array of treatments so you can't expect people to have the same knowledge that they did and as I said it's deskilling the GP's in a way.

Generally, it seems you're taking a lot more responsibilities now?

Yes we are taking lots more.

Whatever the case, we need to find ways of improving the attendance rate and this area seems to be a little bit more different in terms of its diversity?

Yes definitely and completely different from places like Area B and Area C, you know we do have a very Asian population and Polish but then Polish people seem to understand better. Because **it's a bit tricky to motivate somebody who doesn't believe in taking responsibility for his/her health.**

Exactly.

Yes it's very much the will of our life and **people from this ethnic background can just easily see the benefits of tablets in comparison to education.**

So they don't really see it as a treatment?

No, **it's a sort of side line because they don't see the importance of looking after themselves** because that is the idea of the education isn't it so they should be self-

caring and they understand more about their diet that they should do some exercise and how it helps and if they don't understand that then they are not going to do it are they.

No, I don't think so but we have to find a way of motivating them, are you trying to do something different in the future?

I would love to but I'm going to retire....

I mean within the team, not necessarily you?

Well I would like to get the education here yeah, in the practice because I think that is the way forward as you could motivate the patients and get them together you know and you could have a first session where you could actually sit and ask them about their beliefs and the myths that they have about and diabetes and literally just have a brain storming session you know to try and understand where they are coming from because the way I work in practice is to try and understand the patient first and their beliefs. So you know if you are coming to me, I would try and understand about your diet and what you ate and what your natural diet was, what your beliefs were about diabetes and then try and work round that **because you can't impose things on a patient, it doesn't work** you must not eat sugar and they don't understand that.

So providing the education in the surgery is a good option?

Yes that is right **because round here they will not travel**, they really won't, I mean I had a patient the other day who we wanted him to go to another area I can't remember what it was for I mean the area is just down the road literally and he said I haven't got any money to take the bus the bus is £4 something and he said I haven't got any money and he said if it's a nice day I'll walk and I said well does that mean you won't attend the session if it's raining, he said no I won't.

What can you do for that kind of people? You can't even sanction them?

No you can't as that is punishing them and that is not right at all, **I gave up I couldn't go further because I didn't know what to say and I think I did refer him but I put on the referral this man will not turn up as he doesn't have any money.**

You are not expected to give money to patients?

No!!! I haven't got any money to give. I mean a lot are on benefits you know I can understand and a lot of them smoke and drink so they are spending their money on that but if they genuinely don't have any money then £4.50 for a bus fare to go a mile or two is quite a lot and he said he was happy to walk if it was a nice day unless its pouring with rain.

You cannot guarantee a rain free day because the date would have been fixed already?

Exactly, so I don't know how you would get round that, unless we had it here to which he would come because he lives just round the corner. **I think it seems an obvious way to improve the attendance rate is by offering the service in the local area so people can come together**, thank you very much.

Interview 2

With your experience as a practice nurse, what do you think is a contributory factor to non-attendance following referral to the Diabetes Education Centre?

A: I think there are numerous reasons so if you say you have a patient that are newly diagnosed we go through the basics and we say to them there are advantages if you go to this structured educational programme. We say to them what it involves, it's very visual and it's a traffic light system so **what some patients are concerned about is their educational level.** Will they be able to cope, especially some of the older ones they want to know where it is, who they will be meeting and mixing with and a lot of them don't want to go and they think oh that's too far and I may not feel comfortable mixing with other people and may not understand what they are saying. I can think of numerous examples in my surgery, there are certain demographics, as I can think of an elderly Irish woman and she was not going to go as **she didn't feel comfortable and that she wouldn't be able to cope with what was going to be said, even though I said to her it's very visual and you don't have to be reading a lot or anything because there are so many different groups involved whether it be Asian or whatever group, so it is that group thing perhaps they wouldn't be able to cope.** There's another which is **the working patients** so if you've got a young diagnosed type 2 diabetic I think it has improved but initially there was no evening courses or Saturday courses and **these patients are not going to give up working or they may not be allowed to leave work and if you are going to lose income or your work won't let you go then that is not feasible.**

B: My view about why they don't attend most of the time is that the **education sessions are not suitable for them, very often they are working full time and there needs to be flexibility, for example, Saturday appointments, evening appointments and the other is the venue there needs to be a more varied venue and I think that sometimes there is a fear that they won't understand although we always reiterate that they can have them in another different languages so if English is not their first language that sometimes can be a barrier and there are lots of different people speaking other languages. May be transport and they can't get to the venue we often encourage them to bring a family member or if it's a male, a female who does the shopping is a good idea to bring her with him because she is doing the buying and not always can they organise that. That's it really, that's the negatives why they won't attend.**

A: I think in this area they have started Saturday appointment but that's not clear and **that information needs to come down to us, you know it would be really good for you to go and it's on a Saturday and I could say what time would suit you? Then I could say "well they run it on a Thursday evening" so why don't you go on a Thursday evening something like that so it's time...**

B: For young people it's time and they're not going to go if they can't access it within their off hours so that is one of the main reasons.

Obviously language in my demographics, my practice we have a large Asian community and 7% of our practice are diabetic and that is just growing so a lot of the

Asians if English is not their first language they do not feel comfortable to go out of our area. A lot of the elderly Asian women are not comfortable with bus routes and simple things like that; to go and get two buses to go to a diabetes education centre is not what they would like to do.

A: So we need to have more satellite places. This is a very large practice and maybe we need to think about having more educational sessions with practices around here. We are affiliated to about 7 or 8 practices and I'm the lead practice nurse here and this is something that we need to think about, you know if the education is here whether other practices in my locality would come here rather than go up to the main hospital or go to a very far community centre, patients don't like to travel they like to be in their own area with their own people so that's one of the other main things.

So what are the main barriers?

B: Talking about recapping, so working patients will not go, no matter what you say they will not go. Also if people say what am I going to get out of it, so you have to sell it. What's happened now because it's actually really popular the waiting list has got longer so we've actually promoted it and initially once we knew there was a programme going we were sending patients and when QOF came in, other less proactive GP's said oh there's QOF points here so they were firing off all these referrals for patients that they've never sent so it overwhelmed the system, the system can't cope and it was just a tick box exercise but that's another side of it.

A: GP's just flipping people off so they could get the money for that. It's too long and now it's up to a minimum of 3 months, so if you've got to wait 3 months you have just been diagnosed and the nurse has told you that your blood glucose level is raised and we talk about diet and exercise and if you need to start on medication and then we talk about Diabetes UK and how that organisation can help and try and get them involved with that with the charity and they get the magazines and all the rest of it, but then they have to wait for over 3 months to start a programme, they won't go it has to be immediate.

What do you think about the referral process?

A: In what way?

Do you think you are giving adequate information?

A: I think so, yes we refer them we have a form that we send to them and we try and make sure they understand what we write down. I think the referral process can be improved, the people that organise the programme need to get that information out because as far as I'm aware it's unknown so that information is not good and if that information isn't coming out to me I can't give it to the patient.

B: I like the referral process, we fax the referrals over to the education provider and they telephone the patient and we make sure their mobile and home number is on the form just in case but we have had some comments that they haven't had a phone call in a month, then by that time they are disheartened and they have forgotten about it then when people phone up they're like oh I can't be bothered about it. They are all fired up when they come to see us and we motivate them to do something about their diabetes to try and reduce their blood glucose levels and when

they leave us they are quite motivated or appear to be and if they haven't had a phone call within a week they become quite demotivated and then they make up excuses why they can't attend. **So I think if the phone call is quicker, to put their name down even if you say you cannot come in the next week but just a phone call that you are on our list and we will be writing to you or even fixing a date and time there and then would be ideal and then confirm it in a few week's time.** I think that is the best bet as they do lose momentum and an acknowledgement to invite them to the educational programme quickly could help.

Who are mainly responsible for the referral?

A: It's always the practice nurse as we do their annual review and always check if they have been referred before and if they haven't for whatever reason and they have slipped through the net we then see it as our opportunity to refer them. The Doctors very rarely see them for an annual review because we run the diabetic clinic.

Would you say there is lack of adequate collaboration between you and the education provider?

B: Yeah, definitely. Because at the beginning we were involved, it was a new service in our area and because it was new we went to meetings with them. There was a lot of talk about it and everyone was very excited and any new patient with diabetes should be referred as outcomes would be better and I believe outcomes are better because if you have a good basis and a good understanding then you will improve and do well. **But now the system has become overwhelmed and if you have to wait for over 3 months to be seen then that's not going to help** and I need to know if it's running on Saturdays and **the service provider needs to update us more.**

A: We go out of here, out of our practice area to other places that we can and there are a lot of practices that are not proactive so without a shadow of a doubt those practices are not informing their patients about what they're what they should be doing to help improve their health. It's like mental health you have to wait so long to be referred for CBT – **we have all these brilliant ideas which don't come to fruition because once you've established the service and the service is known the service becomes overwhelmed and then it's not fit for purpose because patients won't go.** If they wait 3 months they won't go because by that time they've come back to us we have done a follow up HbA1c to see what we have spoken to them about and we've given them a lot of written literature but it doesn't take over the fact that if they went to a structured programme they would gain a lot, there would be support from other patients on the programme.

B: One of our nurses was recently diagnosed with diabetes and she attended the programme in a different Borough and in that Borough it was immediate, she was called immediately after her diagnosis into their programme and was mixing with other patients and they didn't know she was a nurse but it was within weeks.

Apart from the problem associated with time gap, how would you describe your relationship with your patients?

A: More or less a professional relationship, is there any issue here?

No, this is just to check how this can aid or hinder attendance?

A: Yes we know the patients and there is a bond and you know **if you have a GP who wants his QOF points and decided to overwhelm the service by just generating maybe 40 referrals in a day** because he has never done it before but it now has QOF points, the system is suddenly overwhelmed by 40 referrals from one practice how can the service survive and **that's the thing because if there is no QOF point then it's not going to get done in practices as there is no payment.**

What is your view on the impact of QOF on the attendance rate?

B: I don't think the patients have got any clue or idea.

I mean what is your view on the role of QOF in relation to non-attendance in Diabetes Education Centres?

B: I think it is fantastic and it ensures that we are selling it better and I think the aim of QOF point is to make us clinically better. I think referring them to the education provider is part of the QOF points as we want the money, **it's just another tick box but it's on the template and it ensures that we ask that question and I think it's a good thing.**

With what you have just said about QOF, do you think just ticking the box is good enough?

B: **I think it's a memory jogger so that when they are in with us and we are going through the template at their diabetic review and have you referred them to the diabetes education Programme pops up that is our trigger.**

A: Oh yes, I think it's a good thing.

So now it's entirely up to them whether they attend or not?

A: Absolutely, **but at least it ensures that we have asked the question because you can lead a horse to water but you can't make it drink** and it's trying to force that horse to drink how do you force it? I'm not sure that sanctions will help.

So in your view, QOF is a contributing factor?

A: **Absolutely it has overwhelmingly added to the problem of the service, every year with diabetes we have so many QOF points.**

Some people have suggested the use of sanctions, what is your view about using sanctions to encourage people to attend?

B: When you say sanctions, you mean holding back on something?

Maybe discharge or fine them?

B: Ahhh!

I mean like the Dentist?

B: I don't... I mean it's not compulsory I do see what you are saying so if they are given an appointment and don't turn up for that appointment. Err that could work couldn't it.

What is your view on this?

B: What is my view err. I think it would be quite a good suggestion. I think sanctions are err yeah I think it'll be a good idea. Once they have confirmed to me that they are interested in attending and I make them fully aware that there is a sanction and if I refer you and if you don't attend there will be a fine. Oh my God, it's like living in a..... I don't know.

It's your view; you don't have to support the idea?

B: I don't think that is a good idea. I'm not sure about that I I'm thinking back as soon as you said Dentist it does throw a different light, doesn't it, because if you don't turn up at the Dentist they can fine you, although they don't always but they can.

So you think it is not a good way to go?

B: No, I don't

A: No, absolutely not because when he did say Dentist he threw into the mix a separate idea. **I don't think that a lot of the patients just DNA, you can't sanction them;** this is the NHS you can send a letter and say you have failed to attend and that's as strong as the letter they should get. You're not going to give them a fine because I tell you they'll all come back and say I actually forgot or I was in hospital with my brother or my husband wasn't very well or I had flu on that day, **there is just no way of going down that route, you'll just be giving yourself a headache so a letter saying if you would like to continue please rebook,** I think where the issue is that we give them the information then the education provider don't contact them quickly and that's when they ignore it.

B: That's what I was saying, that **there is such a huge gap between us referring and the education provider contacting them even if they just give them a phone call to say we have you on our list, we will be contacting you to arrange a convenient time, it will keep that motivation.**

A: Yes, because they need to be contacted saying actually we do apologise but the service is oversubscribed there is a waiting list of 8 weeks or a waiting list of 12 weeks then patients know but you see they don't get that then 3 months down the line they say oh I got a call for my retinal screening because we always say to them these are the two things that are really important, full retinal screening bang bang that appointment is there within 6 weeks – having their retinal screening is a very efficient service.

Why is that?

A: This is **because it's an educational programme and it takes longer time** so it's not going to be as quick as someone being given an appointment to have your eye screening done, but they come back to us and say I've had my eyes done but I've never been contacted by that programme you used to talk about so they lose faith in that.

B: And if there is no manpower to make this phone call then just generate a letter saying you are on the waiting list we have your details and it's that momentum. Like I was saying, they are all fired up when they leave here oh yeah we are going to change everything then **a month later they have forgotten that they've even been to**

us. You know that and **these people also lead such busy lives**. So what sanctions would you give to a patient?

Okay.

A: You see its different when you go to the Dentist well it shouldn't be, but the mind-set is that if you miss that appointment with the Dentist or you miss it with the physiotherapy, like my husband sees a Chiropractor regularly for his back and he's been seeing him for about 10 years and his back is no better but he still goes. But if he DNA at an appointment as sometimes he just forgets because he pays £35, that's the cost £35 but it's a private service. I think it's different if you've made the commitment of an appointment if you've made that commitment and you said yes I'm going to attend this appointment and then you don't go then that person sitting over there has then missed it and could've gone to that appointment, so yeah there is a case for fining missing committed appointments but I don't think you can say...

If they have DNA you can send them a letter and you say this appointment could have been offered to somebody else, because **they do that at the hospital also**. **Would you then say you've DNA and if you do it again you won't get your referral for your hip, your back, your leg, or your arm?** All what you can do is to send a strong letter

Do you think there are different beliefs and perceptions when it comes to diabetes education in comparison to other treatments?

A: Absolutely 100% (both). **We don't have that mind set yet that this is preventive care, what they are going for when they've got their appointment with a Consultant is therapy – in this case they are sometimes in a very bad state of health. For the education, they don't feel any different at this stage** unless your HbA1C is very raised, you know the likelihood is because we actively routinely screen patients who have first degree relative for diabetes, those patients that complained of symptoms suggesting diabetes and we pick them up very early and that's what it is. **And they say to us well I don't feel ill... I haven't got diabetes as I don't feel ill**. That is an on-going thing with the health service full stop, because we are over medicalised as you've got patients like we talked about the other day, patients in their 60's, 70's, 80's, 90's on 15-16 tablets a day, they need to get back to the point and let's talk about health and do you want to be on that statin or do you want to look at exercise, do you want to be on that statin for the rest of your life? Or do you want to look at your diet? We haven't got it, **it's a public health issue here that we want a tablet to cure all disease and we don't think education will change it so it's a mind-set isn't it and it's a very ignorant mind set and it's cultural we want something to fix it but we don't want to do anything about it**. You need to be proactive and you have to walk to work, I'm overweight, I'm going to start to walk to work I've got a coat to do it – that's it.

B: It has to come from Public Health, we need more bicycle tracks... anything to improve exercise and if we exercise more and if our lifestyle allowed it we wouldn't be popping pills, I mean how many people take tablets in this practice, all staff and GP are all on a prescription tablet but not me.

A: But the other thing that I will say is that erm there are not enough programmes in place because a lot of my diabetic patients go on a walk here, an hour walk on a

Saturday morning, they meet at 10am outside the surgery, all gathered together and then go off on a walk. It needs somebody to organise this, the person who organised this has now left. It's about having structured things in place that we can say this thing happens every week now come on it.

Does it mean a new person hasn't taken up that role?

A: No, because you know why – **its voluntary and it was an ex nurse who worked here that organised it on her own** and it went on for a little while then she had to stop due to health issues and now nobody does it.

But if you identify something that has worked in the past and now deliberately stopped it, could it be due to lack of resources?

A: Resources...resources, but it is erm, I don't know.

So volunteers could really contribute something to your services in term of resources?

B: Oh gosh yeah. But I spent a lot of time and effort contacting the organiser of the walks saying please can you start from our practice as it was really beneficial and well attended and is going on in other localities and there was a lot of communication from me and this other parties but they couldn't offer it here because they had no one to come and lead the walks because it has to be a registered walker.

Why?

A: It has to be someone responsible so if anyone got chest pain or whatever then they could act, you know we couldn't just say you know go off and have a walk.

Again, it is education and we don't see the health benefits from education immediately, but we see health benefits from a tablet and the other programmes like eye screening. These life adverts on the television are brilliant, these adverts that the government are running you know.... Keep fit about the play oh people... yes! They're brilliant but we just need much more... these adverts are only on twice a week. Yes it was a very good campaign but it's on less. **We need campaigns, we need posters, and people need adverts on education.**

You can afford that because as a GP practice, you own the money, it is GP commissioning now within the NHS?

A: What, are they going to pay £10,000 for an advert on the television?

They won't pay that?

B: Well it has to come from the errr. so at the moment you have a lot of new initiative coming through from the Federation which is... so you've got the CCG and then the Federation network so you've got GP's that are in charge of the budgets and that's a new thing going on err. That's where we need to hit them ... that's where we need to put our requests in for more money for education.

Who is going to do that - so the new NHS structure has made some changes to your clinical practice?

A: We will see, **it is brand new, it has not established itself yet, it's barely off the ground.** You've got lots of new initiatives coming through but at the moment I don't want to go down that route because they are not dealing with the educational bit and resourcing for that, that's from the CCG, the Federation is dealing with out of

hospital services so at the moment they are looking in the new year they would have bid for out of hospital services, **there's a lot of money coming through diabetes but it's not about diabetes education it's about diabetes management and insulin** because there's a lot of money coming through so you can generate income from that.

Is that not a problem, if the education is not taken seriously?

A: Yeah it's just going to get worse.

But that's one of your roles as a practice nurse?

A: Well we do, don't drop the sort of damp on us as we started the nurses forum and we were very proactive, **we get paid shit money, absolutely rubbish money to do this and you get to the point when you think to yourself actually I don't have any more left in my reserves to keep giving** and I would like something back and you know that sounds very mercenary but that is the reality.

B: We are paid terribly... I mean I don't know what you pay on your lecturer's fee and all the rest of it but I'll give you an example. The GP's will earn a band 8A or a band 8B for insulin initiation...ok my colleagues and myself initiate insulin and we are paid on band 6.

Why is that?

A: So you look at the difference, you do the maths, we do the forum, I'm the treasurer, everything is all for the practice, now education has to come from Public Health. Public Health England need to be involved and in control of this because ultimately they have the responsibility to get that information down to all of these people, it's not down to nursing, it's down to Public Health informing them, all of these Federations and all these networks that education needs to be top of your list and if we do not tackle the problem of education we can over medicalise, we can issue tablets, we are getting fatter we are getting unhealthier and we are issuing more flipping tablets!!!

B: Yeah we can initiate insulin over and over and over and over and over again that's not curing the problem the problem is right at the very beginning before these people get diabetes and that's where we need to get them when they are impaired fasting, that stage just before they flip into diabetes we need to get in the stage before, so they don't become diabetic.

But the government has made diabetes education a QOF point now and it should make some changes?

B: It should do.

I would think so?

B: **I think it's a great thing that the government have made this a QOF point because they want to earn a little bit of money, they might wake up and things may change, oh gosh we have to actually get this.**

A: **But it is one thing ticking that box and referring them and it's another thing making that patient get of that chair and going to the appointment and that is what you have to try and change.**

So the issue now is that there is increasing number of referrals due to the new QOF points system?

A: Do you know what they were telling me.... the girls who work at the education centre came here and they hold a diabetic clinic once a week chatting away and she said **we are absolutely struggling and inundated with referrals because it has now become QOF points**. One GP in one day sent about 250 referrals to her, he just whacked off fax after fax after fax, did he see those over 200 people in that day of course he didn't. Do they know they're being seen? No of course they don't.

How can that be possible?

A: That's what he did in one day so if that one GP in this one network did that, how many others are doing it and then how many others in all the other wards are doing it.

B: You see I didn't believe that because how could he have over 200 because how many newly diagnosed diabetics do they have, because on average I get between 5 and 7 newly diagnosed diabetics a week so that's a large amount so I was thinking how could there have been over 200.

A: But apparently it was so, the fact is if a QOF point says refer to structured educational programme the referral programme goes up so we can't meet the criteria and meet the demand.

So QOF could be a disadvantage?

A: No I don't think it should be, but it can only be an advantage if it's done properly.

But NICE guideline has recommended structured patient education for the past six to seven years?

A: If you are a good practice like we are and we love diabetes and we thrive on it and we work really well on it we are used to it, it's those people like that GP. One man band, I'm not saying they're bad of course they're not but you always get some few cases like this.

But you're in the same building so you should know what is happening?

A: Oh it's not a GP that works here I can tell you that, he does not work here that GP.

Who does the referral?

A: Yes we do, the practice nurses, GP's don't do the referrals here, my colleague and I do.

As you do all the referrals, what are your views on how to improve the attendance rate?

B: By contacting them sooner. For a start **it has to come from the education provider office by keeping up the momentum going and keeping the enthusiasm of what we have told them**, keep the memory alive in their heads and that is how they are losing patients.

Can you think of any other ways to aid attendance?

A: The location has to be local, near their GP practices, more sessions on Saturdays possibly even Sundays - why not? We have to work on Sundays! We want weekends, we want evenings **so you want a wider mix of time** because type 2 diabetes is not waiting for everyone over 65 years, we are getting younger and younger diabetics so we need to get people out of work.

B: Locality, **more sessions need to be available, the timing of the sessions** because a different locality which isn't far from us, they see their patients within a shorter period, ours are now overwhelmed and we don't see them until 3 or 4 months it doesn't work.. they need a contact letter or a phone call.

Do you see providing the education session in the GP surgery as an option?

A: How many rooms have we got upstairs that we could rent to them; we could rent rooms to the education providers.

It sounds sensible and it could it be helpful?

A: Yes, they can come out to this area and do it.

It's just a matter of referral and attendance taking place in the same surgery?

A: Yes, I mean you've seen those waiting rooms on a Saturday, Sunday, and in the afternoon they are available and it will reduce the waiting list. We've got to change the mind-set of the patients in the first place because what we do is say to them you know when they come in and they are newly diagnosed they've got to start tablets, no let's look at your lifestyle first so automatically it's a different kettle of fish but we will say you know... your HbA1c today is 10 and if you can lose 10% of your body weight, only 10% that's all we are talking, and you can do that easily by stopping that cappuccino, very little tasks and you give them little achievable tasks you get off the bus stop earlier, stop drinking your fruit juice and you get off the bus two stops before your destination. We had a lady in today she has lost weight she said I've done nothing differently, we said well you have because you've lost 4 cm off your waist circumference, but I've eaten the same. It turns out that her husband was ill at home and she has just had cardio surgery and she's up and down those stairs like a flipping yo yo see..... What has happened? It is about you have got impaired fasting glucose, the blood test has just been done this morning but we are not anticipating that you have gone over into diabetes stage so you are showing them that education and exercise are important, by losing that 10% is all empowering.

B: When we see them for their first diabetic review and they get a blood test taken they are with us for half an hour, it's the longest appointment ever because it's all chatting and education, giving them leaflets and then we might check their blood pressure, we might do a weight on them and we do refer patients who have also been diagnosed for several years to the education provider because you would actually benefit from this because you talk to them and they haven't got a flipping clue on what a carbohydrate is and **you think how can you be diabetic for 7 years and not understand what a carbohydrate is and what is a simple sugar, we are not talking that they should have a degree, we expect them to understand that a plate of rice with that japatee or that pasta with that garlic bread is going to bump up your glucose level because you have two carbohydrates.**

A: We have told them this, but of course 3 or 4 years down the line they have forgotten about it. So it's that education and that on-going education it needs to be reinforced every time they come and see us for their annual review.

You've got more time than the GP's because I think they have fewer minutes per patient?

B: Yes they have 10 minutes to see a patient. But GP's don't see the diabetics at all in this practice – which is good they don't need to and we manage the diabetes and their medication – we run the diabetic clinic full stop they're there to sign the prescription and of course when they do start a new medication we have to run it by them so they are part of the discussion.

Ok.

A: We love diabetes here.

Thank you for that.

A & B: Thank you.

Interview 3

Thank you very much for agreeing for this interview, what do you think contributes to non-attendance at the Diabetes Education Centre among patients with type 2 diabetes?

I think there may be a lot of factors, for the type 2 diabetes, it is two sessions of about 3 hours in the middle of the day, therefore, **it could be work commitments** and or the problem of actually getting to the venue. **Sometimes its health issues because they just don't feel well enough to attend. Some may believe that God brought the disease and the GP has nothing to do with it.** A lot of people are very busy and they may not see it as something that they are entitled to go and attend. **It could be language problem, being in school** or they may have access problem. I think those are the main issues.

What do you mean by access problem sir?

The venue and time may not be convenient. However, we do generate problems for ourselves because we tell them when to come and we do make them to wait. Also, the patients may think they want more freedom of choice.

Please can you think of any other barriers to attendance?

Another issue is poor data collection, not knowing the number that has turned up within a reasonable space of time. Sometimes the patient's say they rang the education centre and there was no reply.

Is that possible?

Occasionally, the computer phone does go off and patient might not be able to make contact with them during the intermittent disruption.

What do you think about your referral process?

The actual process is fairly straight forward and helpful.

That's sound great, but there is still evidence to suggest that non-attendance is an issue in this region?

I think there is slightly over 50% take up for patients that attend both sessions.

Is that good enough?

No, it is not good but it is still comparable with other regions across the country.

Would you agree that the referral could be part of the problem?

Not really. **With gestational diabetes, the attendance is significantly different and the process is the same**, probably because they are worried about the baby and could easily realise the impact of gestational diabetes. Also, the type 1 diabetes patients are more engaging. But with the type 1 diabetes patients, we are seeing them regularly and the Practice Nurses normally tell them what to do.

What is the reason for the massive difference?

I think with the type 2 diabetes, **they don't realise the impact that diabetes would have on their lives**, they just don't have the awareness. It's like when you are 18 and you start smoking you don't realise the impact that it will have on you later or the inevitability as well.

What do you mean by inevitability?

Some patients may have a strong family history and say oh well I knew I would get it at some point.

Do you think there is an increase in the referral rate?

Well probably it has increased but I have to look at the actual figures, I don't know it at the top of my head.

Could the increase be due to the newly introduced QOF points which give incentives for referral?

I think it's hard to see a change quickly but definitely we are monitoring things and examining what the patients tell us.

Some responses suggested that QOF has led to a quick referral just to tick a box? What is your view on that?

I have a completely different view on that. We have looked at all of the processes across all the referrals to try and see how we can maximise the benefits of our service. I think it must have increased because we keep adjusting the system to meet the needs of the patient and it is all around trying to get people to attend.

You seem to be convinced that the QOF indicators hasn't impacted on your referral rate?

Yes, and **attendance at a DEC is a process measure.**

Please can you clarify that?

I mean it is a process measure but not an outcome measure.

Meaning what sir?

Sometimes it doesn't change anything. Occasionally they go to the sessions and they are sitting there with their arms folded and they say I was told I had to come and they rarely know anything different. **We need to determine the outcome measure and should everybody be referred?** Some patients don't want to be medicalised. Also, I think we don't always take the opportunity to sell it well because **people are not always receptive to lifestyle changes**, so we need to sell the lifestyle changes very well.

Do you think resources could be part of the problem?

In terms of referral you mean? I suppose you could say you would never have enough resources but it is not an issue because we do refer all the newly diagnosed patients.

Are you involved in the referral process?

Very rarely, but we have experience practice nurses in the surgery who does the referral. GP might refer them but that is very sporadic across the whole CCG.

Sanctions have been suggested in the previous responses, what is your view regarding imposing sanctions on patients that have failed to attend?

Well it makes me feel a bit uncomfortable, because it's like anything else, you could sanction people that smoke or are overweight, it is a completely different concept. **I don't feel comfortable with sanctions as there must be a better way.**

Do you think you could work a little bit more to improve your collaboration with the diabetes educators.

Yes, we are always trying to do that and again we could always do more by discussing the invitation process with them and we find there are pockets of centres in EB that work very well and they have good attendance rate in comparison to others. We are always constantly trying to forge good links with all the healthcare professionals and we have a mobile telephone line, so that is a good way of communicating and we are accessible and we can easily answer any questions they have.

Back to the QOF points, do you think the point should be based on the number of people who attended rather than the number of people that were referred?

That would be good. Although it may reduce the number of people who are being referred because we may need to assess their motivation for attendance.

Is that a good thing?

We have to try it before we can say yes.

Or do you envisage any problem with that?

Not really, but **you need to have staffs who know what they are doing, staff who can follow guidelines** and have a lot to offer the surgery.

Because you would get money based on the number of referrals that turn into attendance and just ticking a box for referral will not be sufficient?

It is not about ticking boxes at all. Although motivating patients to attend is difficult but I think we have tried to respond very much to their need. We have adapted our systems many times in trying to get more people recruited and the staffs always gives adequate information about the education that is provided in S, B, W, M, not sure if I missed one out but they are the main ones so they can go to one locally to them. We have tried to increase the profile of the referral by giving more information on what the education is all about. **Some GP surgeries are thinking of funding weekend education** but I do think it has been done before and again we will still have the same problems of attendance at weekend.

Why can't the DEC consider offering weekends as a way of offering more flexibility on their own?

It is a form of chicken and egg situation, because we are the ones paying for the services and they are happy to deliver the services but if it is not part of the specifications, it doesn't happen; otherwise they won't get paid for it.

Some previous interviews have suggested that is hard for the CCGs to fund practice nurse's training. What is your view on this?

It depends on the circumstances, however, appropriate training are funded from time to time on the basis of need and equity.

It is interesting that you have done so many great things; however, what are your suggestions on ways to further improve attendance?

They may need to more sessions in the summer holidays and we hope we can catch people back from university so trying to be more flexible. I could add that we may need to ring them as a follow up if they really don't engage. I'm not sure whether that would make a difference or maybe more advertising. That's a resource issue in terms of admin and we have posters already in the GP surgery to advertise type 2 education. Some patients look on the internet and maybe that is another way of doing it through the Trust websites. I think patients really benefit a lot and it's not just information giving, it's about the mix and match and I think maybe more research can be done on what type of education will work better on-line. Notwithstanding, there are benefits that they get from being in a group of people that all have got diabetes and they can talk about how they feel about it and I just think it's a very beneficial thing. Finally, we may need to market it more. Whatever it takes to get the message out because lack of awareness of the problems associated with what can result from diabetes.

Thank you very much.

Interview 4

The Government has introduced an educational policy for all newly diagnosed patients with type 2 diabetes because of its benefits. Based on your experience, can you tell me why you think some patients are not attending the education sessions following referral?

You have to remember that the role of the practice nurse have always been to care and cope with chronic conditions so I think practice nurses do have a lot of knowledge to which perhaps is unrecognized in some ways and many of us have diabetes experience, although we are not diabetes specialist nurses we are able to help people to understand the impact of diabetes.

But I think you've got limited time to perform the role?

Well, there is limited time but you have to think – what is the best use of my time? You see, and sometimes you have to put aside, Oh I need to do this, this and this just to take that little bit of extra time if at all possible and it pays dividend, it really does. If you form that relationship early on and they start to trust you and they are much more likely to listen a little bit and we've got a philosophy here on diabetes – “Every little helps” just like Tesco's!!

Do you mean that any little thing that you can do is helpful?

Yes.

That's good, but don't you think that you should be referring and emphasising the importance of the education instead of taking up the responsibility of teaching them?

No, no but I think you're probably right that **I could sell it a bit more**, but having attended the sessions I felt that they were very generic, obviously they have to be and the sessions I attended tended to be taken over by 2 or 3 very strong people who had everything wrong with them and they just wanted to talk about their problems, and I think that the people who are doing the sessions need to be a very good facilitators of learning rather than just teachers, because it's quite hard to control a room full of people and enable people to learn.

Plus I think that it's frightening – your feet will drop off, you'll go blind, you'll become impotent so all of these awful thing are going to happen to you and actually if you take care of yourself it's not true! So it's all very, very piled into one session which is a very poor way of doing it I think. I can understand why it's done like that but I just don't think it's the answer to give people all the bad news all at once. You know that we try to create a culture of fear – either they fear it or they ignore it or avoid it.

Some responses have suggested the use of various forms of sanction to motivate attendance, what is your view on this idea?

To sanction people? Counterproductive wouldn't it. I think it'll be far better off putting energy into developing programmes that people could either do online, interactively, have some sort of helpline available, developing GP practices to deliver more personalised care i.e. more time perhaps talking about nurses holding small group sessions in various practices, what else could we do – anything to keep them out of hospital as that is far too expensive and I just think that somebody's thought "oh we must educate these people" therefore they sit them in a room and educate them and that's it boxed ticked and job done – very poor and you can't put sanctions over peoples head's it really isn't any way to run a health service at all. So, I would not be for sanctions!

That's alright.

Rather this is how you can get through this and this is how you continue to live to improve your health, yes you've got diabetes but it doesn't have to be the end of the world.

That is quite interesting. How do you refer them to the education centre?

It's a one off referral so the form is filled in along with the blood sugar results, age, weight, blood pressure, address, contact details, so they can triage the diagnosis.

Thereafter, you will send the information to the Diabetes Centre?

Yes and they will send them an appointment or tell them when the session is.

Who will send the invitation letter?

They send an invitation from the Diabetes Centre.

Please do you follow it up or don't you think the process of invitation might be part of the problem?

No but I do ask them during their annual review. If it's a person I'm seeing, I'll go onto the screen and if they didn't attend, when I see them again I might say to them – didn't you want to go? ... or what was the reason behind it. A lot of people will say oh! I forgot or I was too busy and life gets in the way and it's not always that easy and I think a lot of people often forget because people don't want diabetes –no one wants to be diabetic.

That's true.

Well not very many people anyway. So once you are given a diagnosis many people think ok that's fine and I'll just put that to one side and I'll think about it later because

of course they don't often feel ill so it's very hard for some people to accept the diagnosis.

So sometimes they forget or they are too busy. That's means they have good reasons and it is not always deliberate?

Yes people do forget, don't they and the session is not run at different times and they are quite long sessions. There is no afternoon or an evening one. But, I do have people that have got a lot out of the sessions and some people have responded well to the sessions and have said they've took their wife or husband and they thought it was really good so...

That's good, again some people talk about targets and incentives when it comes to GP surgeries. What is your view on the role of targets on attendance?

Oh yes the good old targets. We must all hit our targets!! It is very difficult because the government needs to see statistics they can't work in any other way they cannot be interested in minute level of individual lives can they, it's ridiculous, so you know you've got this target that everyone sees and the staff are always striving to hit it and it's frustrating for us because if they knew the patient, knew the person they might understand why they are not hitting that particular target and why an HbA1c of 7.6 or above is actually very good for that particular person. There are always reasons but I do understand that it a difficult thing to solve and you have to have some sort of target to prove you are improving things.

Is it more important for you to think about lowering their HbA1C because it is more rewarding for the practice?

Well yes there is a correlation isn't there between education I don't know what research says but I believe there has been a link between the two, people that have attended the education session are supposed to have a better control is that right? Is that what research says? Well as there are 10 ways to skin a cat, really so for me there is a lot around bringing HbA1c crashing down which is really bad, people have had high HbA1c without even knowing it, prior to diagnosis and a lot of these folk have type 2 it's not good practice to bring them crashing down and so you have to do this slowly and I think you have to get people to understand that food isn't the enemy, you actually need food and you need it for various reasons so there is just so much more to it and you can't just say oh you can't eat sugar anymore and you must not have bread or rice it's just yeah to lower a person's HbA1c can take a long time and many drugs to which people react to and all have side effects and all to which you have to make sure people know what they are doing with and it's quite a complex process that helps to lower the blood sugar level.

But part of your job is to manage their blood glucose level?

Yeah and that's what we try to do very hard within reason oh and blood pressure which is extremely important almost important as blood sugar level.

That's quite good, so within the last two years, would you say there have been changes to your procedure when these new changes within the NHS came forth?

In this particular surgery I think I'll probably say no changes in terms of diabetes care, no. I think we've always said we have a very good ground in the nurses been allowed a lot of say, if you like how people are helped and the nurses have been truly allowed a lot of freedom around seeing people and helping them and that is down to the Doctors trust. In terms of our procedures, once a person is diagnosed, we have to take it up and the person is always sent to the practice nurse and that's always been the case and yes we do the standard checks, you have to do the weight and blood pressure and that sort of thing but for the last 10 years we've always take the view – let's talk to this person and see how they feel and see what we can do to help. **So no, I don't think our procedure here has changed much. I know that there is a lot of anxiety around time, I am making it sound as if we've got all the time in the world which of course we haven't but we do consider time spent with people with problems like that valuable and very well spent.** That's probably to the detriment of other things but it's good.

Sounds great, so it has not brought a lot of changes to your method of operation?

Well no because I think we are working very morally before, we've always been very aware in this practice and that people are people they're not just numbers or animals and to be herded together and we do work on a personal level whenever we can. Hopefully the patients that attend this surgery can agree with me.

I think so. Would you say there is a good collaboration between the surgery and the Diabetes Education Centre?

I'd say there is very little, very little. I mean I used to know a lot of the Diabetes Specialist Nurses personally and I perhaps know one or two of them now they are very helpful if you phone them up and say we've got a and all sorts of things, so they really are and really do try to be helpful they are a very nice bunch of people and the Diabetes Consultant has recently agreed to talk personally to each surgery to see if he can help with medications as there are so many medications on the market now.

Do you think a little bit more collaboration could aid attendance or not?

I suspect the attendance is down to us selling it. I mean the service is there I don't see what more they can do. They advertise the service, they know all about the service and **I think probably if we sell it better here then perhaps more people would attend**, I'll try and let you know next year.

So you are thinking about changing your process of selling it?

No, I'm not

Ok, you think.....

I think somebody would have to sit me down and say look, these are your figures and when we do our audits of course we see our figures, particularly for the ones that are high. Because we know all of our people that have diabetes, I can say to them, "Rosemary's figures are high because of" or "John's figures are high because of"..... It is very difficult. Yes, it's a very hard question actually... I think if I wasn't interested in them as people I'd say fine go away and do that, and if you don't want to do that that's your loss but I'm much more inclined to say John drives up down the M4 everyday so therefore he cannot be too low in case he has a hypo in the middle of the M4 etc....

You seem to have a good interaction with your colleagues and patients?

I think so yes, and usually here we look after Type 1 diabetics as well who cannot and become frustrated with our secondary care system as they cannot get an appointment. It's fairly unusual for a small practice.

Do you think resources could be part of the problem?

What sort of resources?

Maybe if you have more money?

No, resources aren't really an issue, **staffing of course if there were twice as many nurses doing the job that would be fine** but we are trying to see everyone that has diabetes at least twice a year.

For what?

One is for a major check and the other is for a minor check. Some of them, I speak with them on the phone and try to touch base with them at least twice a year minimum, and some a lot more if I can. Some people don't attend at all of course.

Why is that?

Some people just don't want to engage with the service.

Do you observe people who have families with diabetes who are not really trying to engage, or is that not a problem?

Yes I suppose it is in some ways we do. Some of our main problems are around folks who are recently diagnosed and foreigners. Our area draws a lot of people from Eastern Europe for work but the guys we have are the elderly parents who are now coming to live with their youngsters and they have these problems often before they come and particularly from India they are on some weird and wonderful sets of medications and trying to get that sorted out is difficult but they are and I don't say won't engage but it's more difficult because the diet is different and the diet is very high in carbohydrate and I think that's an area that is quite hard and the young Type 1's are quite hard to help too as their families are over engaged or don't really know what to do and once you are a Type 1, as a youngster you develop habits early on and a lot of youngsters are very hard to help and it's not that they don't understand to take that amount of insulin is reasonable it's that kind of **life is too busy for a youngster and too chaotic** so those are the two particular groups that we find the hardest.

Are you suggesting that you have more issues with the extremely young and the older people?

Yes, those that can't speak English and that have come to live with their sons and daughters and the people that are very overweight are sometimes hard to help because sometimes they just don't know you have to try and explain to them they didn't get this overweight in a week so this is going to be a long process and keep them engaged to the length of the process is sometimes very hard and could take five to six years before starting to lose weight or even longer.. It's all good fun!

That is a good thing ... so sometimes people from ethnic minority background have perceptions and beliefs that can be an issue?

Yes the health beliefs can be quite different, can't they and I think some people can put their trust in herbal things like if I chew this particular leaf then my diabetes will go away and I don't know what they are chewing.

We have a guy who has a long history of diabetes from Northern India and he is convinced that chewing this leaf his mother gave him is going to take away his diabetes and he's probably getting the hang of it now after about eight years and it hasn't fully got it but it's taken him that amount of time because he just doesn't want diabetes and who can blame him.

No, nobody wants any disease, but eight years is a long time?

People don't want the disease so they are using it as an avoiding strategy. Complications would have already set in before they face up to it. Also people keep forgetting the problem, people work and people forget.

What do you think the government can do to further ease this situation?

I think the government should think very carefully about the value of nurses. **The government should put figures aside for a while and let us really increase the ability of our nurses in the community** not just practice nurses but nurses that look after people in their own homes and nurses that are working in hospitals. They really need to increase their ability and get alongside people that way rather than doing things to people and having the time to spend with people then in 10 years' time we would have a much healthy nation.

Doctors are over qualified for the job, health care assistants are under qualified for the job and nurses are perfectly placed to get alongside people – they've got the knowledge (if they haven't got it they can get it) they are known for their caring ability – that's what nurses do, they care and people like nurses and if there was a way of really developing the nurse into a sort of, I don't know what really it is **but the time and the training isn't there.** So instead of nurses doing things that healthcare assistants do and trying to become mini doctors let's try and have the nurses do what they are best at getting alongside people and helping them to understand, helping them to monitor, helping them to see the benefits, talking to them all the way and I just think it would be great to have the years of that programme and to see at the end of it we have more people more in control with less health problems. That's a big piece of work isn't it!!.

It's always a question of is it best to just chuck a load of money at something that's going to lead to ticking some boxes or is it best to think how can we invest this pound for the best return and my argument would be that if you invest in nursing you get more return than ever and once the knowledge is there that nurse can go on for years and working years and years and years. So there you are, I'm on a one woman crusade to increase the value of nursing.

Because at the end of the day they can reap the benefits?

Yes, huge benefits

In really getting these people on board, a lot can still be done or what do you think?

Oh yes, a lot can be still be done.

Can you give me some examples?

A lot of it depend on attitude doesn't it, put yourself in a place that a person has diabetes and you come in to see me and I'm here typing on the computer saying right got to check your blood pressure, look at your feet and test your urine what does that say to you? It says that I don't care doesn't it and it says to you that I need to tick boxes but if I sat here and talked to you and said how are you feeling and what does it feel like, what have you noticed? You would respond to that far better wouldn't you?

I think so?

Yes definitely. Anybody would I'm sure and that's my point really

So most of the referrals are done by the practice nurses?

Yes, sometimes the GP's do, but mostly it's the practice nurses.

Do you have an idea of what happens when the doctor does the referral?

Not really, but I am thinking that when the GP refers them it could even probably be more problematic in terms of time and because they have got 10 minutes. Well they do tend to overrun and GP's do spend time with people that are needed but generally they usually start the discussion that they've booked to see the practice nurse. It is a better use of their time and ours really. I hope this has answered your questions, thank you.

Interview 5

Although there is evidence to support the benefit of Structured Patient Education in diabetes management, nevertheless, patients do not necessarily attend all the time, what do you think is responsible for their non-attendance?

Ok, I think one of the reasons for working people is that in this area there often aren't classes in the evening or weekends and time when they could actually get to them so that is quite a major reason. With the elderly sometimes it's transport and mobility and practical reasons like that. Language is a factor for people whose English is not their first language because a wide range of languages are not on offer. Some people feel they would rather find out from the internet particular working people they just think I can look it all up and why do I need to go to a class and some people I think don't like being in groups they feel that their condition is private and they don't want to discuss it with other people and those are the main reasons I can think of, but the time factor and the convenience and venue are big ones for a lot of people. There was a problem earlier this year that there were not enough places because as from last April referring new patients for Diabetes Education became part of QOF so then it wasn't just an optional thing we had to refer every single patient to the structured education and the whole system got overloaded I think it's better now but a few months ago they were saying that there was a six month waiting list and I think if there is a long wait people will give up and they can't be bothered by the time there is a place available.

Is being part of QOF a good thing?

Well I suppose it reminds you to do it..... So I think it is a good thing and it should be available for people who want it yeah.

Can you tell me a bit about the referral process?

We have a referral form but it is a bit complicated because the patient is expected to ring up the service and book their own appointment but they can't do that until the referral has gone through so I sometimes worry that the patient might forget to ring up and book and they won't automatically get sent an appointment so I have no idea I've never done any research to see how many patient's fall through the net that way.. They get referred and then they forget to ring up and book I just don't know but I think that can be a factor.

So the Practice Nurses are responsible for referring the patients?

I refer them and fill in the referral form and we send it off to Diabetes Education Centres where it's dealt with now they do the administration and then the patient is supposed to ring the number which is Monday to Friday mornings only I think and book themselves in to the classes but the referral has to go through first and I think it makes it more complicated than it needs to be to be honest...

Do you believe that referring all the newly diagnosed patient to the diabetes education centre is a good policy?

I think if you give the patient the option it's a good approach, **I don't think people should be forced to do anything they don't want to do but I think having the option is definitely good because we are just too busy to give all that information in a short 15 minute appointment or 30 minute appointment** you can't do it besides they are going to come back with questions and if you've got a course with 4 sessions then each time they will think during the week and they can go back the next week and ask questions and also the dieticians are very well trained to deal with the latest advice coming out whether is about glycaemic index or carb counting things are changing so rapidly at the moment I think it's really good for them to have a face to face meeting with the Dietician.

So time is a problem?

Generally speaking yes, for an annual diabetic check I get given half an hour but everything else is usually 15 minutes and it isn't enough...

Does it mean that it's the Practice Nurses alone that refer the patient?

Well where I worked before the doctor got involved a bit but more and more I think in most practices all the chronic disease management like Diabetes, Asthma, Cardiovascular disease is being nurse lead so it's much more likely to be a nurse than a doctor doing a referral, the other way they might get referred is that they are restructuring the diabetes service and the idea is to have a better communication with primary and secondary care and also more access to specialist advice so recently they have developed what they call satellite clinics from the hospital so you'll have diabetes specialist nurses who are hospital based coming out and running clinics in the community and sometimes diabetic consultants, the doctors too who will see patient's in the community and people like me can refer patients who are particularly difficult to manage so if we are struggling to keep somebody's blood sugar under control, maybe they have been on insulin for a while and you are thinking actually they probably need to be on another insulin regime but I'm not quite sure which way to go with this patient then we can refer them to these clinics and get advice and they might also I think refer to structured education if they thought it was appropriate because it's not just and it's not intended for newly diagnosed diabetics but we have got so many of them at the moment. I think that is mostly who gets referred but also there is huge advantage in referring people who have been diabetic for some time and want a bit of a refresher course or can't quite remember the foods they should've bought and just different aspects of lifestyle and its good for them to do and occasionally I say "do you think this will be helpful" and "have you ever been on a course like this before?" and sometimes they say oh yes that would be quite useful so yeah.....

How do you normally identify the patients that require education?

Yes that is how it happens we diagnose them, how do we diagnose them is the question. **Any new patient that signs up at a General Practice will be asked for a**

urine sample so sometimes we will find glucose in the urine or they will come to see the GP because they have symptoms like they are thirsty, not been feeling too good, strong family history of diabetes or whatever , anybody actually that comes to GP and says I feel tired all the time will have a series of blood tests, fasting plasma glucose so often they are picked up that way. Sometimes somebody will say oh my brothers are diabetic so I thought I would try out the machine or my blood sugar was too high so a variety of ways you know that we actually pick them up but we are not routinely screening everybody yet, but we could say right everybody under the age of 50 or sorry over 50 should have a fasting blood glucose routine we don't do that because I don't think we could cope with that at the moment we are just identifying new patients all the time just the way we are doing it so you know where **resources are limited** then yes everyone should have a plasma fasting glucose in a health check of some sort but that is not happening yet..

Generally, do you think the referral process could be part of the problem?

Err yes I think it could actually, I think it could because it's a two part process. I do the referral but the patient has also go to ring up and book the classes themselves and patients can refer themselves you can just give them a leaflet and say you can refer yourself but I think the people who run it do prefer it if they have had a professional referral first.

What do you think about the type of information that you are giving to patients during the referral?

There is a little leaflet we can give out but the answer is probably not adequate and the reason why I said so is that I have many times intended to go along to a class but not actually got round to doing it. I think it would be very helpful if I did **but they have never encouraged us to come and see but I think if I ring up and asked they would probably not say no!** it would be so much more helpful in terms of telling the patient **what happens and what to expect if I had actually been to the course myself** I think it would give me a better idea but I'll be honest I haven't actually done that.

What do you think about your relationship with the patient?

Well very good with some and not so good with others you know, some patients you just click with and **some patients come very motivated and keen to accept the fact that they have this diagnosis and do everything they can keep healthy and others are in complete denial and just don't want to know** and their blood glucose level goes up and up and up and we go over the same old thing then their diet hasn't changed at all they're not taking their medication **and they want you to say you are not diabetic really or now it's better now** or something and they don't want to know and they don't know the dangers of having uncontrolled blood sugar even though we tell them they don't take it on board.

So what is your opinion about the relationship between you and the Diabetic Education Centre?

Well probably that it's not good enough and we don't get much feedback from them, the only feedback that I get is from patients occasionally and I say to a patient who has been on it well how did you find it did you find it helpful? And some say yes it was very helpful and some say well no not really I knew it all before so it varies really. But no I think there is room for improvement there.

Do you get feedback from the diabetes education centre?

No I can't remember seeing anybody sending in letters saying this patient did not come or anything like that so

That's not good enough, I suppose?

No

Do you think the target set by the government is part of the problem?

I don't really know whether it is part of the problem I mean obviously our aim is to get the best control in every patient that we can and that is more achievable in some than in others. I think the patients age is very significant if somebody is diagnosed at 35 or 40 you are hoping they will survive another 40 plus years, therefore the height of the blood glucose control the better because they are slightly harder to get complications if somebody is 80 plus frankly they don't want to be bombarded with lots of information, some of them are quite keen and will try hard to adapt their diet accordingly but some of them there is not much wrong with their diet in the first place but I wouldn't be as aggressive in my management with an elderly patient simply because you are obviously not expecting them to live as long as somebody who is in their 30's or 40's and I think research has shown that if you are too aggressive, you will bring their HbA1c down too far then they are more at risk of getting hypos and a high hypo just make patients feel rotten and why put an elderly person through all of that and it depends hugely and if what they need is a little bit of good diet control and maybe one metformin a day then fine and some of them is efficient but if a patient is 85 years and left to me, if they always enjoy having a biscuit with their cup of tea in the afternoon frankly unless they are at high risk of hypo and ketone then I'm not going to say you mustn't do that because you know they have to have a few pleasures left in life and it is really is going to impact as much on them. So you look at the individual patient and the package of care has to be appropriate to who you are dealing with.

Do you tend to focus more on using drugs to bring the blood glucose levels down to the detriment of encouraging attendance at Diabetes Education Centre?

I think there is a tendency to concentrate too much on the drugs and patients do it too and sometimes patients think once they are on medication then they don't need to worry about their diets so much and they can keep eating that biscuit they can have that pudding because the medication will do the work for them and I am constantly saying we never ever say diet or pills we say diet and pills or diet and

insulin it's not either or all... you know you can't expect them to know everything and Type 1 are a bit of a different breed creature and yes of course the type 1's are very experienced and they teach me lots and they know their bodies and they can look at a plate of food and say I need about 16 units for that plate of food I'm about to eat and that is what they will do but I would never say that to a Type 2 and never say that with insulin, you know because I don't want patients to think they can get away with anything when diet is concerned.

Do you think you are promoting the education enough?

I think education should start a lot earlier than it does in the ideal situation and I have had one or two like this and it's much more satisfying when it happens. When you diagnose impaired fasting or impaired glucose intolerance so they are in the twilight zone and not technically diabetic yet they haven't fulfilled the criteria to be diagnosed diabetic but hey they are heading in that direction and if they don't do something very imminently they will be diabetic within the next year or two and if we identify those people in time and we educate them early sometimes that can have fantastic result and make a huge difference and I can think of patients who I have picked up like that and with diet and lifestyle changes alone and they have their blood sugars back into the normal range and yes the likelihood is ultimately they will become diabetic but maybe we can put it off for another 5 years or so and all that time is worthwhile and we know that the later they become diabetic the less likely they are to develop all the complications and disabilities so if we can and in some ways we should be going into the schools and do it before people come to that stage if we could pick out and educate children better in schools and also things like women who get gestational diabetes in pregnancy if we could send them off to classes and things that could prevent a lot of things from happening too later on as often they are pre diagnosed later in life so yes.

Delaying the education seems to be an issue?

Education shouldn't just be for the patient it should be for the person who does the cooking in the house and it's no good sending a man along to these education sessions if he is not very motivated anyhow and it's his wife who cooks all of the meals she should go with him.

Are you suggesting education for the whole family?

Yes exactly.

Some responses have suggested sanctions, for example, the Dentist can fine patients for non-attendance – what is your view on that?

Well we have never done that and Doctors don't and I think GP's should charge a patient that don't turn up for appointments frankly but that is another story!!! I am not hugely for that really because I don't think at the end of the day it will work I don't

think that is what motivates people. I think what might motivate people more I suppose is meeting people who have serious complications of diabetes. I'm not sure how you would do that, the people who know a bit about diabetes when they are diagnosed or know somebody who has gone blind or lost a part of their foot or a whole foot or something those are the people that tend to be more compliant because they are frightened they don't want that to happen to them and but those who come with no knowledge whatsoever often are easily more likely to go into denial just to pretend the diabetes isn't really there and get on with their lives as they were before but I think people who see really bad results of having uncontrolled blood sugar are the people who often are scared into actually taking action yeah.....

Do you observe any trend with patients who have a family history of diabetes?

It just varies so much and varies on the level of education there are some people who are educated and can read and are used to looking things up and used to goggling things and looking up books who will basically teach themselves and for those people I don't know that classes probably help that much. There are other patients who obviously are literate and maybe patients who need that talking and visual aids and things that will help them learn and remember or people who just tend to look up things for themselves and I suspect but I don't know there are one or two patients who quite like the social element of the classes particular some of the older patients who are lonely and don't get out much then go to a group and meet other people. I think this is a true form of support groups generally it doesn't matter what you talk about whether its diabetes or bereavement or I don't know any sort of support group I think some people find a huge sense of sort of positive affirmation knowing that they are not alone with this problem and there are other people dealing with it too and that they are able to get ideas from other people and make friends and that is the value of groups generally and not just this type of group alone but others groups too I don't know because I haven't spoken with them but I would suspect that

In relation to individual differences, what is your view on the role of the patient's beliefs and perceptions on attendance?

That is really hard isn't it why do people show up for things and why other people don't. Well I suppose you know you go to something if you think there is value in it if there is something in it for you and if you think you are not going to get anything from it you don't go. I suspect some people have very negative experience of any sort of class and may have had a bad time at school and didn't engage at school or didn't like school or don't like the whole idea of being taught in a class and so if they hear that this is a class you know and then to come here it might just make them turn off and think I don't want that and I don't like that idea and other people as I have already said for the opposite reason I think I know it all. I don't think there is anything that I can learn from this or I'm just too busy and I can find this out my own way and I haven't got the time to go to these classes how you motivate people to help them to see that there is actually some value in going, I don't know I'm not sure I can suggest that because in some ways the answer is probably different in each person.

Ok, that takes us to your views about ways to enhance attendance?

Well I think putting in convenient times so have evening sessions maybe a Saturday morning session, in places that are accessible and close to public transport systems and not off the railway station and not too far from the patients' homes, I think something like a welcoming letter or a phone call from the person leading the class before they come which I think would motivate people and they would think oh they are expecting me and somebody is concerned that I am coming if there is a sense that really who is going to notice if I turn up or not obviously they are more likely to attend. So, if there is a personal invitation then of course the organiser gives them a call saying the class is starting next week as we have already told you as you are booked on and are you still able to come, we are really looking forward to seeing you... that would help as it's the personal touch that makes a difference to people.

Do you think more resources could be helpful?

Well I'm just not involved in that side of things but I'm sure they could I'm sure the more classes available the better and less time people have to wait to get on the class the better. I think when people are first given a diagnosis of diabetes many of them are in shock and even if they are quite knowledgeable and you know there are things that can be done for them and it doesn't need to be a death sentence but it's still quite shocking for them to come to terms with having a condition that you are going to have for the rest of your life and I think if there is an opportunity to have your fears allayed in some way and explained and showed how you can make a seemingly bad situation better and that you can take ownership of this and improve the situation for yourself then that's all got to be good so being able to have more classes available, more readily available, shorter waiting lists I would've thought would always be helpful.

Do you think the government could do a little bit more?

Well I think that they are trying to do this to some extent to make the whole of society aware and not just people diagnose but there needs to be more education and the media for example what to look out for its interesting they have one or two adverts on TV like that and you see a woman brushing her teeth and spitting out oh no its not her eyes it's her teeth – she is putting on make-up and there is a drop of blood and they say something like you wouldn't ignore this well you shouldn't ignore it if you brush your teeth and you start bleeding because it's a gum disease, it's a dental ad and I think making people aware of signs and symptoms so that they know when to seek help would be a good thing but not only that it's the whole message and the government in all fairness have been trying to deal with healthy living and eat plenty of fruit and vegetables, eat 7 a day or 5 a day and regular exercise and not being overweight and not just living on too many salt and sugar and cutting those things down and all those things there have been measures but they are clearly not enough because the problem is still growing and how they can do more I'm not entirely sure. So I suppose it's a question people having to take some responsibility and be accountable for themselves you can't expect the government, the Doctors or the Nurses to do everything and also about using your own initiative about things and what is frustrating in our job is just having time to do that one of the things. A lot of courses have been ran on motivational interviewing so that is about motivating your

patient to take on board the advice we give and actually put it into practice and there are ways of doing that and ways of actually identifying what could make the patient to shut down and not really listen and however because I have not been on one of these courses **it really requires time and time is one of the things we don't have we are constantly fighting the clock so that is the problem as I see it.**

What do you think that you can change in your practice to make things better?

Well organisation, one is the satellite clinic and they have started and what we call integrated care pathways and now there is going to be more communication between primary and secondary healthcare the idea being that the complex cases were identified and discussed sooner rather than later for advice on how to manage these patients because so many of them now are being managed in primary care who would traditionally have only been seen in secondary care. So there is that and in terms of my practice I can't think of huge changes obviously we just have to take on board every change that comes along and **changes are happening all the time – QOF changes slightly every year** and now we have all this care planning from this year that we are supposed to do to identify the most vulnerable and try to reduce the hospital admissions I spent quite a lot of time educating patients to use insulin and that sort of thing so I am following those patients up quite a lot and checking up on how their blood sugar readings are at home and look at what adjustments we can make there is much more emphasis now on looking at your carbohydrate intake. Diabetes UK is a good source of health education information and there is a book they recommend called Carbs and Cals and I recommend that to patients quite often so they are more aware of what they are eating and another thing that we do a bit more these days is we have one of the company's book which is called the Discovery Sheet and you have a whole week laid out on a sheet and you fill in what you are eating, each meal, every snack, Monday to Sunday and write it all down and every time you record your blood sugar then they bring it into us and we can see a pattern of a week, the highs, the lows and what type of foods they are actually eating because patients are not often aware of certain foods that actually are not good for them in terms of blood sugar control and sometimes you can pick them up when it's all written down what you won't pick up in a conversation as they won't always tell you everything they have eaten and they don't always remember! If you ask a patient ok what did you have for breakfast this morning you know by 4-5pm in the afternoon they would've forgotten and some are not truthful either so they will tell you what you want to hear so it's this sort of thing, therefore, getting patients to write it down and not only teaches them. They think gosh I'm eating a lot and portion sizes is another factor that is a bit harder to assess this book Carbs and Cals is good as it shows different portion sizes and it helps them to think about those things more.

Has the yearly changes to QOF and the NHS Act 2012 impacted on your services?

Yes so much in terms of organisation and it's not just in this one thing it's in every area and I have been practicing nursing over 19 years and in the last couple of years we have had the GP commissioning the..... Federation we have had on-going QOF changes, the care planning being brought in, the ICP being brought in, in the last year more new immunisations brought in than ever before in terms of the general

immunisation programme so we have had to get our heads around that too and educating all of the patients with that not just immunisations but things like shingles for the elderly and all of that you know and diabetes is an area that so much is going on and new drugs are coming in all the time at the moment and just keeping abreast of all of that is hard work it is really keeping up to speed and that is why I am delighted that they are happy to run courses that we can send patients to and focusing much more on that area, as I am a jack of all trades and a master of none and they can hopefully give the best and up to date advice although I seek to keep up to date as I can obviously do.

So there is an issue of organisational complexity?

Oh huge, I've never known General Practices so busy and the Doctors are just struggling to keep on top of things and then all the A&E closures in this area that is going to happen and they are trying to measure the impact of that now so that they are looking at trying to measure how things will change or how they have changed as a result, and there is so much going on.

I suppose non-attendance in Diabetes education Centre is part of the complexities?

Yes because the patient has to travel further and they have to wait longer for appointments when they get to appointments things don't always run smoothly like I had an elderly patient on the phone this afternoon who was rung by the hospital to say "why didn't you come to your outpatient appointment" but she had total organisational chaos and then they checked their records and said oh yes oh yes you did, sorry! So I think it is very worrying and it's a huge loss in the health service generally as a result of that. So that is maybe another factor. Do they trust the advice we give because you know again today I had a patient who said one doctor told me one thing and another told me quite the opposite so who am I to believe.

Does somebody need to reduce the organisational complexity and maybe teaching could be done in the same area where they are referred to aid monitoring?

Let's hope and hope there is a way through all of this, it is a worry.

Would you say that the attendance rate is improving within the last two years?

I can't speak for structured education, I don't know what their attendance rate is like but my attendance rate for my clinic is better than it was ever before. When I first started doing diabetic clinics 10 years ago it was a different practice admittedly, attendance was only about 50% it was very poor and we had lots of missed appointments.

What do you think is responsible for this improvement?

I don't know, I think whether there is greater awareness and I think there was a bit of a crossover period where we had diabetics seen at hospital then we were inviting them to the surgery and they were thinking why do I need to go to the surgery when I have already been seen at the hospital and that is happening less now because most of them have been discharged back to the surgery, but that cannot account for all of it so I think it might depend on other things and I am very new in this place I am working in now it would depend on a little bit how the surgery manages appointments, do they send texts to remind people that they have an appointment the next day or do they ring them up? Or do they make an appointment 2-3 months ahead give them no reminder whatsoever...

And that is happening at your present place of work?

They are coming on but before they come a week or two they are invited in for a blood test so if they have made the effort to come in for the blood test they will probably come for my appointment as they want to know the blood results.

Could that be slightly different when it comes to education?

Yes that is true.

That means we need to find ways of aiding attendance at Diabetes Education Centres?

The figures are rising but the resources are not rising so it's just becoming more difficult to keep on top of it and I mean we are aiming to see all our diabetics at least twice a year to do bloods at least, but then you know frequently I need to call people back in-between those times for various things.

But it is now GP Commissioning and that should be to your advantage as a GP surgery?

We haven't seen the advantage yet!!! I don't think it's really filtered through yet.

Ok, a lot hasn't changed?

In terms of the workload the workload has just gone up. I think the GP's are obviously anxious to work within their budgets and they are not going to commission services that are of no quick financial value because it's just not going to happen.

Is referring patients to the education centre one of the services that could bring a lot of money in?

Well I'm not involved with any of that thankfully so I just keep my head down and seeing the patients but yes at the end of the day that's where most of the decision

making lies and yes you know what they've perceived they can afford and what they can't afford.

Thank you very much and do you have other ideas on how to promote attendance?

Well as I said I think the personal touch works better than anything else and if you had the person running the groups need to make a courtesy call or a text just saying we are looking forward to seeing you next week just to remind you of the time and venue that sort of thing. I think that could help but on the whole you know surgeries don't work like that and **that in its self is time consuming as you have to have somebody yourself that has got the time to actually make sure that happens.**

In all, it seems that you really don't have enough time to promote the education service?

Which is funny they ran a session in this area a year or two ago, because it was poorly resourced most of our patients could not go and some of them are very elderly you know and can't easily use public transport all of those factors and we asked please could they run a course closer so they did, they ran one course and I think almost nobody came. **But the problem was they didn't tell us in time till about a week before the course was starting that it was happening so that's just a very basic practical thing** had we known say 2 or 3 months in advance obviously we would've said to people by the way there is this course just across the road or wherever and we would've invited people to come but it was almost as though it was a sudden last minute decision and because people didn't come I think they then thought it's not needed here so it didn't happen again and I'm going back two or three years now but I thought and I don't know what is happening now whether they have got anything running now at the moment but I just thought what a shame because I knew people that would definitely have gone had we known and we had enough advanced warning of it.

So they don't involve you in the planning?

No, **there has never been a two way communication** really and I also think that a **really user friendly leaflet** as the leaflet they have at the moment is ok but it possibly could be improved on and we need plenty of them so we can hand them out to patients, **something eye catching and colourful and attractive.**

Don't you produce your own leaflets?

No we don't produce the leaflets. **I think the leaflets come from them and I have to print if off from the computer now if I want one and I can never find the thing on the new computer system so that doesn't help you but I think that yes something quite eye catching and that has perhaps some punchy headline that you know a heading that is attractive.**

So they are sending it to you via a computer but they don't bring hard copies?

No, a year or two ago, I was posted hard copies at my old surgery but I haven't seen anything since but I don't think the design of that leaflet has changed at all in 3 or 4 years.

Do you think you are doing enough?

Well I think if they are running the course then they should design the leaflet because they know what they are advertising and I don't know what they are advertising exactly so I think if they would send me some nice leaflets I would happily hand these out and it wouldn't be a problem and we could even have some in the waiting room .

So a lot could still be done?

It could and you are absolutely right. Yes, like so many of these things is organisation where things often fall down.

What else do you think can be done?

I will just tell you about one other situation which isn't common but is a factor and I think about it I had a patient in my old surgery with learning difficulties now she lived on her own and had carers coming in and she was able to take her own medication and get her own food yet she was eating all the wrong things and obese. I sent her to diabetes Education Centre and she went to one class she didn't like being in a group and she felt intimidated. But I think she felt that the information was probably at a level that was too difficult for her and didn't want to look stupid in front of other people but then I sent her to another group a year or two ago somebody was running some exercise classes for people with heart disease and diabetes and that was a much longer course and her carer was willing to take her and she went to those and thoroughly enjoyed it. Now I don't quite know what the difference was but I suppose getting up and doing exercise is different to sitting in a group and being given lots of information so maybe that was the difference then for her I decided to refer her to a Dietician for a one to one appointment because then it would be tailored more to her needs and she did have learning difficulties and its different you know the majority of patients would not be in that situation.

Yes the majority do not have learning difficulties.

No, I hope that has been of some help.

Interview 6

The purpose of the interview is to explore your views about why patients are not attending diabetes group education that they have been referred to and what are your thoughts about how to motivate attendance.

There is evidence to suggest that education helps to alter people's behavior and the Government has introduced an educational policy for all newly diagnosed patients with diabetes. What is your view about the Government policy of recommending education for all people diagnosed with diabetes?

Although NICE guideline is a must and not an option, however, I don't think you should be referring everybody because everybody's situation will not necessarily allow people to attend the session.

What do you mean by that?

We need to look at individual to consider whether we should refer them. *If you are old, you might be able to attend. The people that seriously need the service and can conveniently attend are more socially deprived people, those that are not working, I mean the unemployed.*

In terms of age, type 2 diabetes normally affects people of 40 years and above, therefore, that shouldn't be a problem?

Look at me, I am over 40 years or do you think I am old. I mean if you are over 60 years, you are more likely to attend. A 40 years old patient is still actively engaged with all sorts of things in life.

Like what?

I mean they have work issue, child care problem, education and other things that can disturb them from attending the education session.

(2) Knowing fully well that you are responsible for referring patients to structured patient education programme, who else are involved in the referral process?

Definitely yes, I am responsible for referring patients to the education centre. In my surgery, it is mostly the practice nurses or the GP when the practice nurse is not available.

Does it mean that the doctor don't routinely refer them?

Sometimes the GP may refer them if the practice nurse is not available but most of the referral is done by us.

How do you identify the patients and what is the referral process?

We have a diabetic register and we see patients on a six months basis depending on their HbA1c. The patients are also expected to have an annual diabetic review. They are identified when they are first diagnosed or during their visit to the surgery or annual review. Then we inform them about the decision to refer them to a Diabetic Education Centre (DEC) and fax their information to the DEC.

5) Do you think the referral process is a contributory factor to non-attendance?

I don't think so. We give loads of information and we give leaflets. We try as much as possible to sell it to them. But what happens is that 2 weeks down the line, they changed or don't have the capacity to go.

So you think the referral process is not part of the problem?

The process of invitation is not an issue; I don't think it is part of it.

What about the Doctors when they occasionally refer them?

Well, you know the doctors; they don't give a lot of explanation generally. They would just say I am referring you to an education programme. But that applies to all the disease management, they don't give adequate information. They may not even know where the leaflets are in the surgery. However, the GP only refer them when the Practice nurses are not available which is infrequent.

What about the process of invitation?

The Diabetes Education Centre are responsible for booking them onto the programme and equally sending a letter with details such as their names, NHS number, date, venue and so on.

Leaving the issue of referral and based on your experience, can you tell me why you think some patients are not attending the group education following referral?

In most cases patients often agree to go, but the commitment is often difficult for them. **Attending three hours lecture more than once is a lot of commitment**, don't you think so. It is the commitment because it is a programme for several weeks and patient may find it difficult to commit to it. **This may be due to work, childcare and lots of different issues. I would say for most female it is due to childcare and work for male. I found the elderly patients are more compliant. For example, if they live alone, it gets them out of the house to meet other people and they may enjoy the programme. Also the elderly are the retired population who would go because they don't work.** Whereas the young people find it difficult to commit to the programme

because the work will not let them go because they need to take time off which they may not get.

Probably so, but this is important to develop their self-care abilities?

Yes, it is important but patients will refuse because they don't have the time or due to other reasons. Things happen in life, partner's sickness, forgot because of the length of time, I have had it for a long time and it is not a problem. Some of my patients will say they are borderline; therefore, they don't put enough effort. The understanding is not enough, they need to take ownership of their medical condition. Again, there is an issue with I've got a choice, I know what I am doing, they think they know everything and don't really think about the decisions they are making. Some also think they can get information from friends, family and internet. They even go to American Diabetes association website and Canadian Diabetes association website without checking or thinking that their approaches might be from us. Generally, some patients don't see it as part and parcel of their diabetes management.

What do you normally do in cases like this?

We can only advise and encourage them because everybody has a choice as you also know yourself. To get a QOF point which will yield more finance, we have to prove that we have seen them in the clinic.

See them in clinic in what way?

I mean see them and review their condition in practice. This applies to all the chronic diseases and there are several of them. This gives the practice points, more money, and it is also a good practice and good patient care.

Does this include referral to diabetes education centre?

I don't think so and I can't remember that it attracts a point - I may need to ask to confirm.

A big issue is how to implement the policy ----- I mean how to bring the patients to the education centre. Judging from your experience, what do you think can be done to improve the attendance rate?

If you were to have perhaps a more flexible hour of delivery, there may be an evening time that people could go, may be dip in and out of the course. If they can go to day one of this session and day two of another, they may eventually go. There could be some online learning to those who are computer literate and have access to a computer. I think the session should be shorter because patient doesn't want to stay for that length of time. I think it's got to be more flexible.

Some people have been talking about sanctions, take for example, the Dentist occasionally charge the patient for missed appointment or occasionally discharge some patient for not cancelling appointments? What is your view about using any form of sanction to motivate attendance?

Although, there is a lot of time wasted in the NHS but **may be before the appointment they are already feeling well. I don't know but I think there would be an outcry, a complete outcry; patients won't even pay their fine.** Now for the surgery, we do send text and letters to remind them and threatened them that they would be discharged following repeated non-cancelled appointments. **Non-compliance is always a problem. I see it every day, you see patient telling you that I don't take my water tablet when I am going out for a social event and you look down at their foot, it is very oedematous.** We can offer them anything but we cannot force them, though we can make it as flexible as we can. Alternatively, it is the patient's choice. Although a lot of money is wasted but you can only take a horse to the river but you cannot force it to drink water. **I don't think any financial sanction will work; after all, the NHS is free.** We have tried it with our clinic appointment but it didn't work. We threatened them with a letter that they will be discharged, some will call to insult us, call to tell us off, some make up stories and few take it serious.

(9) Do you think there is anything that the Government can do probably to aid attendance?

I think the government needs to make some reimbursement to their place of work.

What do you mean by that?

I mean something similar to the jury service; the employer is legally bounded to release them from work.

Do you think that would not have a negative effect on their employability?

Well, if you think so but why are they not advertising it more.

How, what about the practice surgery and the education provider?

You could say that but you have the radio advert for immunization such as flue jab for pregnancy. **Why aren't they doing similar advert for diabetes education.** They just introduced the programme without adequate support. If they want it, they need to do more.

Please can you give me another example of what they need to do to further aid attendance?

There need to be more effort put into it and patients will be more aware and know that they need to attend the education that they have been referred to. As a practice nurse, we have 15 minutes with a patient. **Time is a massive issue in the surgery with other targets to meet** and we see the patients with chronic disease more. The GP have 10 minutes appointment and predominantly see the acute ill patient more.

Again, some GP cut corners by using the healthcare assistant to refer patients who are task oriented.

What do you mean by that?

I mean they cannot see outside the box because of lack of education. The government needs to increase the number of practice nurses. They need to put more funding into practice nursing training and education of practice nurses.

Are you not having appropriate training at the moment?

At the moment our training is totally dependent on what the GP would pay for and ehm most GP will not pay £1,500 for a diabetes course just to cite an example.

Do you observe any changes in your clinical practice in relation to diabetes Education Programme within the last 2 years?

I won't say there is any significant change to the process but increase inadequate staff, more administrative work and lack of training.

But the CCG's hold the money string now?

Yes, it depends on what is important to them. Cost is an issue and the people sitting at the top are thinking about how many patients have you seen. So many new things are coming out and it is difficult to keep abreast and yet to secure a training fund is a problem. Sometimes, it may be easier for them to change their medication instead of investing in motivating attendance at Diabetes Education Centre. A lot of staff are also part-time, there is shortage of staff and there is no training, yet we need continuity and quality care. The time we've got is not enough to go through the blood result, to talk to patients so it is prescriptive not descriptive. 15 minutes is not enough to look at a, b, c, d.

Do you have other thought on how to motivate attendance?

Language is a barrier, for example, we have a lot of EU people, too many dialects. The big industries or companies could also help with education.

How?

For example, instead of just sending different types of glucose meters all the time, they could help with translation of pamphlets to other languages because we are curtailed with finances. Thank you.

Interview 7

Thank you for agreeing to speak to me on this topic. What do you think is responsible for non-attendance in the Diabetes Education Centre?

A: Well possible reasons like **not being able to get there, not understanding why they have been referred** to go to the education programmes.

B: Yes that is what I found as well – I'll give you an example of a big Italian community and they often say oh no there is no need to go so **language seems to be a barrier** and also age as I find the younger the patient, the less likely they are to accept the offer of education in a group of people, they often say oh no I can't be bothered with that.

A: Some of it is a bit of apathy too, they kind of try to accept it and give them an appointment and then it comes to the day and they decide they don't want to go. **I guess, perhaps they don't understand the importance as to why it will help, so perhaps its lack of education.** We do offer it it's not that we don't as it's on the template when we go through the diabetic reviews.

B: **It is obviously on diabetic reviews in every surgery and it's always on the template and generally I find it's the younger ones that mostly say yes but then they will not turn up.**

Do you know why they don't turn up?

B: No, **maybe work or stayed in bed**, I don't know we never really get told either.

Some responses suggested that the referral could be part of the problem, what would you say about your referral process?

B: Ok, that is what they are saying?

Not in that way but different set of interviews have suggested that this could be part of the problem, what do you think about your referral process?

A: Well because in practice nursing, it's a turnover of patients as you know we see patients for 15 minutes, so we tend to just follow a template. I generally ask the question that are on the template and all I say to them is would you like to be referred to the education programme and I try to stress the importance of it but **nine times out of ten they say yes and they just don't show up so....**

B: Sometimes it is just trying to work out which one they need referring to so **we don't seem to have adequate leaflets** that seem to be a bit of a problem. I don't know why we don't have enough But I know that we definitely need it, but then it is trying to work which one they've had as they haven't been in quite a few times or they have been diagnosed with diabetes a long time but they have never had a first structured education programme so are they then suitable to go on the new course before they go to the second course so I think some of it is because the patient that we see has either been newly diagnosed or has been diabetic for a while and then

it's trying to work out if they haven't been offered it in the first instance so then do you offer them the first course or what sort of information do they require.

A: That is so, true.

Do you think giving inadequate information can be a contributory factor?

B: I am trying to think where the information is for our courses and education and we don't have a lot of leaflets but I like to say I don't know. And also just clarifying when they should be referred to the programmes in terms of if they have been diagnosed for a long period of time and have never had the education programme before.

So sometimes you don't have adequate information to be able to direct them?

A: No, but we complete a referral form for every patient.

B: No and each area has a different referral system, because our system here is different from my previous GP surgery.

Although there are differences, are they all about ticking a box?

B: No, no, because I talk them through the diet and **we don't have enough time** and my problem is which one I'm supposed to be referring to and also having the right leaflet to give the patient. **I don't know a lot about the service provider and I don't know what it does so it's very difficult to sell a service if you are not entirely sure what it is you are trying to describe what you are offering to the patient as I spend a long time going through their diet and their food and I've only really got 20 minutes so I know it's a very short snap shot** and I'm trying to make sure they try and go to the education because that actually I know that it's different and they have longer periods of time to spend with them **but what I don't know is that perhaps this is highlighting something that is lacking in me to go and look at what actually happen, therefore, what it is and it's not something that we need to have lots of information.**

You kept on referring to time, so you have got just 20 minutes per patient?

A: Yes, so you have to do the weight and everything, the BMI all the review checks to go through their blood results, HbA1c, what it implies the cholesterol results all this to do in the 20 minutes plus the referral.

Does that has to do with QOF?

B: No, it is because that is the allocated surgery times, its nothing to do with QOF. It has to do with the fact that it is a busy surgery. **I mean we get longer for doing diabetic reviews than normal treatment as we normally get only get 15 minutes for other patients.**

So you have fewer minutes for other patients?

A: Yes for every other treatment its 15 minutes so we get slightly longer for the diabetic reviews, 20 minutes which is considered generous.

B: Yes for this practice, some only get 15 minutes.

So time is a big issue?

A: Yes its time – we need to cover so much and if you only have a short amount of time then it's taking that long to do the blood pressure, the weight and you've got to do their full foot check and you have to discuss their BM and try to go through what the structured education is as well, when you don't know that person very well unless you go through it fully they will not understand it then.

B: Having said that we do offer it all of the time but **we just don't have enough information** as to where they can go and the patient will turn around and say especially where do I go and who is going to refer me and sometimes it's the case we will check with the GP

And does the GP always know?

B: Capital no, not always, no and especially we are very lucky, **some surgeries use a lot of locum doctors so that is in itself is problematic.** I'm not saying that they don't care as they do care but it's just yeah....

What do you think about your relationship with the education provider?

B: **I don't think there is a good relationship**, there isn't one!!! Although, I am new in this surgery, she is one of our senior practice nurses here and she rarely have any contact with them.

Don't you think that you need to improve your collaboration with the education provider?

B: **It would be great if they invite us to the courses and we were able to go and see what they say and do that would be great** because, for an example in tissue viability we have patients with leg ulcers and the tissue viability service puts on lots of training courses throughout the year and we know them quite well but the education people we don't hear from them to be honest. **To be fair to us they haven't actually contacted us to say why have you not referred enough of your patients, do you see what I mean?** They haven't contacted us to say well we haven't had many referrals in the last six months what is going on?

Do you monitor what happens after that or you are just leaving it at that?

A: Well yeah I do my review, it comes through the annual or 6 monthly review depending whether there are lots of patients who decline perhaps because we haven't had a chance to go through it but I would generally see them at their annual review and go through it with them particularly about their diet and tell them whether they are happy with what they are doing and if they are happy with what sort of diet they need to be following in that respect.

So the referral is in fact about meeting your target?

B: We keep telling you that's not what we are doing!!

So you are aware that referring them is a policy initiative?

B: We follow the NICE guidelines and we are not doing it to tick a box with diabetes it's critical that their diet is And if you are not getting that right then it doesn't really matter what necessarily else is going on **that is why I spend so much time talking to them about food and some of it** is that we need to make sure we have the right information.

Some people have suggested the use of sanctions to motivate people to go to the Diabetes Education Centre, so what is your view about using any form of sanctions to motivate patients to attend?

A: Well I think eventually it might be the way, but

B: I have to say I don't agree because **I think there is normally a reason why they are not taking it up is perhaps they are not interested in what the issues are or the complicatedness and perhaps that is due to lack of time.** I am constantly aware that I could do so with many things that we are talking about with the patients but **we are short of the amount of time that we are unable to go into depth and a lot of these patients just don't want to have diabetes so they are very resistant to their diagnosis in the first place so anything else that they have to do on top of it, like just coming here, they are not at that point where they are willing to accept that..** so it takes a lot longer and more visits in the long term with them keep coming back and you go through it with them to actually accept their diagnosis and then so they try anything like **this until they have accepted their diagnosis which can take quite a long time with a lot of patients and having that time to go through things with them.**

A: I think that is also part of the problem why because actually they don't want any more to do with it they are just functioning with their medication and their diet is something that they are interested at that moment and they are not willing to let someone else help them change what they are doing.

B: For me personally probably **I could improve my practice by selling it a bit better. I must admit, all I generally do is say would you like to be referred to the educational programme and I quickly explain to them how it could help them and that's it. So I don't know, so do they want us to give them a hard sell or by bearing in mind we only have 20 minutes as she said so** I would find it better to improve and to have a better

relationship and know what they are doing and go if they are running a course so we would know what it is they were going to go for, where actually they do the courses, the time **because patients always say where is it and when is it and what time is it? And we don't know any of that so that is quite hard too and even on the form it doesn't say any of this information.** Anyway, it is a crucial course for the patient.

So sanction is not an option?

B: I would not opt for it though... No, no a lot of these patients their general health is not very good and... I'm not saying they all came from deprived situation economically but a few of them do and the last thing they need is added pressure of people imposing sanctions on them as its stressful as it is for them that is why sometimes their diet is poor... but I think it's cheaper to buy burgers or fast food. All the same, it is complicated because it is cheaper to drink water as opposed to coca cola but people have their own personal things going on with them.

A: Also spending a lot of time to talk about carbs and protein is not there and that's assuming they know what a carbohydrate is and protein is and so I know what it is and that is why having a long period of time is better because they can actually go through that in terms of longer time but sometimes there are patients that refuse to go so you spend a lot of time in trying to talk to them.

B: I found the more educated and the more affluent are quite keen and ask you what is this education and yes I want to be referred and generally what you find with diabetics, they just want to get along with life and I think imposing the sanction on this particular section of society if that is where the government is thinking or looking to go it would be very sad actually as it is almost like punishing those who are already punished. I'm not making up excuses for them and yes they should take up the offer of the education programme but I just think it will be too much for them to bare.

Are you experiencing any changes relating to your diabetes education referral service within the last two years due to the new NHS structure?

B: It has definitely increased because it's great having somewhere to refer people to and have something to go forward rather than just going swiftly through a leaflet so **I think we have referred more people than before and our referrals have significantly gone up.** I think those who have been to the education have learnt from it and then it's trying to work out where I can refer them to an education centre because they will need it again if they have forgotten and need refreshing.

So your referral has gone up?

A: Yes, as we are more aware of it and I don't think about it like this over two years ago. But I know that since the last two years or so that it's definitely something I talk about with patients that I'm seeing and that are newly diagnosed we refer them all the time.

B: We refer all the patients now because it is part of QOF and the GP want you to tick the box because if it is not ticked, they don't get the money.

Will you generally support the idea of referring everybody to Diabetes Education Programmes?

B: Well, I think you can't refer someone if they don't want to be referred but that is not to say you stop trying to say they should be referred. So I think it is important to have the access to it and to know how and we should be able to give them that opportunity even if they don't accept it and if they have good standing and they go and actually research the information themselves they may feel that they don't actually need an education programme so I think we have to actually listen to patients what they are saying and is it because they have done a lot of research and have a good understanding themselves and worked out what their diet needs to be and they have used the internet and things like that so they have a good understanding and that actually is good for them at that moment or is it because they think there are more important things that they want to do at the moment or like I say they haven't accepted their diabetes and realise it is a progressive problem and need to do something about it in which case we need to make sure and try to explain and make it as easy as possible to access it so I think we should make sure that everybody has the opportunity to access it but whether everyone access it is a different story.

So if you perceived it to be a good policy, how can you increase the uptake?

B: I think making sure that us, the healthcare providers know what the service is for a start so that we can adequately really go through it with them, as we have a small leaflet that is kind of interesting but not kind of particularly informative and for us knowing what we are trying to get patients along to and understanding the patients ourselves, and at what point are they referred and are they newly diagnosed and can it happen later on and can they attend it more than once?

Can the government do a little bit more or are they doing enough already?

A: I think they are doing... my personal feeling is they are doing a lot but sometimes it's a case of the public thinking, sometimes the hospital nurses are having unrealistic expectations sometime and not all the times. I think that it's the case that maybe now push and try to help yourself and be willing, there is no point of saying to the Doctor I have a pain on my chest but still smoking 40 cigarettes a day.

B: I think we need to have accessible locations and they have to be able to take control of themselves and we can help them get to that but unless they are prepared to take it on board themselves it will be very hard for them to follow the programmes and I don't think it's helpful saying that I think it's from a government. We should make sure that we are not forgetting that important part of being a good practitioner you should be anyway and be offering the service and making sure there is funding

and adequate advertising of the service and to make sure the service is resourced to have adequate time to go through what it is, offering it at different times and different places.

In your personal experience, do you observe situations where patient's perceptions and beliefs seem to be part of the reasons influencing non-attendance?

B: We do see that in the consultation and for example, one patient that I started seeing once and he was completely fed up with the diabetes and didn't want to engage with us at all and his HbA1c started going up and he couldn't see the point and he wasn't taking good care of himself and I spent a long time and we went through it and discussed with him and basically trying to give him back control of it **because he was trying to feel that it was out of his hands** and I saw him three months later and he had made some small changes and he had taken back control of it and his HbA1c was coming down and obviously that motivates the patients to carry on and some of them are young patients and I've had some other patients that basically are saying **they don't care they perhaps lost a partner and this is just another long thing that they are trying to get through and they are not perhaps interested in education but they are not motivated and preparing them enough and perhaps it's an underlying thing in preparation as part of grief.** So it's really trying to get out there and having time to spend with the patient and that is the downside that sometimes people are very **quick to go through the information but it is taking it in and they may just need a lot more time and a lot of time we don't have to really understand what they think about the diabetes and the progressiveness of it and what they can do to help themselves and get their head around it.**

What other thing do you think can help you improve attendance?

A: Another thing is our training.

In what way?

A: **The education of practice nurses is important but it is very hard for the GPs to fund any training.**

Why?

A: It is just the way it is, I did all my personal development in my own time and with my money. Some GP will not pay for training, conference; name it except if you really push it.

I expect you to have a good relationship to be able to get things done?

B: Not really. **I really see my GP here, you come and get in your own room till the end of the shift and that's it.**

In this small environment?

A: It is true. In the past, you have coffee break together with other staff and meet daily but not anymore.

I hope the practice managers are helpful in the process of referral?

A: The practice manager doesn't refer or see the patients.

In what way?

B: They are responsible for managing the practice and will only be interested in their yearly review.

How?

B: But that's their job, they are not nurses or doctors, why should they?

So the practice nurses are not medical personnel?

B: Not in all cases, for example in our region, some are from business and accounting background. They are not familiar with patient's needs but come with this big ideas that are not necessarily patient focused. Thank you very much.

Details of participants

B CCGs is divided into East B. and West B.

East has one CCG while West has 2 CCGs.

East B.

S. CCG – Area 1

Interview 1 Participant 1 GP surgery 1 (Practice Nurse)

Interview 2 Participant 2 GP surgery 2 (Practice Nurse)

Interview 2 Participant 3 GP surgery 2 (Practice Nurse)

Interview 3 Participant 4 GP surgery 1 (GP)

West B.

B & A. CCG – Area 2

Interview 4 Participant 5 GP surgery 3 (Practice Nurse)

Interview 5 Participant 6 GP surgery 4 (Practice Nurse)

W., A. & M CCG – Area 3

Interview 6 Participant 7 GP surgery 5 (Practice Nurse)

Interview 7 Participant 8 GP surgery 6 (Practice Nurse)

Interview 7 Participant 9 GP surgery 6 (Practice Nurse)

Appendix 18

Level 2 coding

Participants	Direct quotes from the transcript	Code	Remarks
Interview 1 Participant 1	People are not happy to go to wherever it is.	Distance	Commitment
	I think the hospital	Location	
	they say they can't be bothered to go and to get a bus	Patient's attitude	Motivation
	haven't got any money	Finance	
	I think maybe the nurses and doctors don't explain enough what it's about...	Inadequate information given to patient	Communication
	So it's not really explained, what it is and how it would help them.	Inadequate information given to patient	Communication
	lack of time	Practitioner's lack of time	Workload
	you hardly have time to do the referral let alone explain to the patient what it's about	Practitioner's lack of time	Workload
	it's a tick box on the template that comes up.	Working practices	Target oriented goal
	there are so many boxes you have to tick now	Working practices	Target oriented goal
	you've only got 10 minutes or a quarter of an hour it's not long to explain all of these things.	Practitioner's lack of time	Workload
	we have language problems so that takes a lot of the time when somebody doesn't speak English and I don't speak Punjabi or anything	Language problem	Communication
	Because when you are told you are diabetic it is frightening and people get really worried so you have to spend a lot of time with them trying to explain	Anxiety	Coping/Adjustment to sudden news
	the patients' needs to understand why they need to go and be in the right place.	Information delivery	Communication
	So you need to prepare them mentally so they know ok... so they can be more receptive and prepare to take it on board	Psychological impact of the diagnosis	Coping/Adjustment
	Most nurses have done it for so long	Practitioner's	

	because we didn't have this facility for having diabetes education then yes maybe it's not very high on our agenda.	attitude towards education	
	But now that we have this tick box to say that we have sent the patient to diabetic education then now it's probably higher on the agenda	Working practices	Meeting target
	Yes I think probably more people are being referred, but I know the people that we refer don't go.	Working practices	Bureaucratic practice
	it might be part of the thing that you need to educate the practitioner and each nurse or doctor or whatever needs to go to the education to see what it is that is happening	Training of practitioners	Personal development
	No, we don't have the time to do that.	Practitioner's lack of time	
	it's a two way thing and maybe we need to attend one of the sessions and see what happens maybe they need to tell us a bit more about what is happening maybe that would help so that we can educate the patients.	Working practices	Practitioners versus practitioners relationship
	he said he knew more... than they could teach him	Patient's perception about education	Health belief
	I think that's probably a key part of it actually, the patient perception of what it is because we haven't given them the information, we haven't given them the enthusiasm to go and they don't really understand what it is about so they think it's a waste of time.	Patient's perception	Health belief
	they haven't got any money or there is no bus or it was too far. or I haven't got time or I work you know all these excuses they give so but I wouldn't follow it up anymore, because we have thousands of diabetic patients and you know we would follow them up in an ideal world	Individual Circumstances	Personal difficulties
	we just don't have the time to monitor like we used to.	Practitioner's lack of time	
	And again you have too many people walking in with all these sick bugs and that seems to be more important	Working practices	Meeting target

	anyway because we are being judged and the boxes need to be ticked.		
	QOF in a way started as a good idea but there are too many tick boxes and too many things to look at and too many things we have to do to get the money and in a way it's spoilt the way we look after the patients	Government incentives	Regulations
	There are too many things that you need to produce to ensure for that outcome. So the government have set too many goals that we haven't got hope of keeping. And without keeping these goals money will not come in, so you have to find a way of keeping the money coming in which makes sense anyway.	Government regulations	
	But we've got same number of staff that we have always had and there has not been an increase and now we are having trouble finding practice nurses anyway	Staffing issue	
	we just haven't got enough practice nurses we haven't got practice nurses around.	Staffing issue	Resources
	speak to most practice nurses they just don't have the time and I'm sure they will all tell you that.	Practitioner's lack of time	
	if the education was near to the patient and at a time they could go because a lot of the patients work so they can't really go in the daytime or	Location Employment	Possible solutions
	I'm sure work won't let them off to go to the diabetes education	Employment	
	I mean that's really almost punishing them for being diabetic to put sanctions that seem really harsh.	Negative view about sanctions	
	The practice nurses can do a lot of the education so it's not as though the patients are not getting any and most of the practice nurses do basic education for them and you know we tell them to look at Diabetes UK website and things like that so they can do a bit of research themselves	Practitioner's attitude towards diabetes education	
	but again in this area the language barrier is a problem.	Language problem	Communication

	No it hasn't it's a shame but has increased the pressure and it hasn't really increased the attendance.	Working practices	Organisation
	its language,	Language problem	Communication
	it's not having maybe the education at the right time or in the right place,	Timing and location	Flexibility as a possible solution
	the policy is good but maybe it's the way it's been implemented.	Practitioner's view about the policy	
	it's a time and place where the patient can go to, and are happy to go	Time and place	Flexibility as a possible solution
	being done in different languages	Language problem	Communication
	No, I think they interfere too much, too much as it is.	Government directives	Government control
	It will probably encourage them and probably solve the problem of things like location because people are more likely to live locally and would have registered there.	Location	Flexibility
	maybe several practices joined together. I think how it would work best is in the practice and then the specialist nurse could come out and talk to the people who are on insulin and that sort of thing and help with all of that.	Location	Flexibility
	I wish we could do it here but we don't have enough rooms at the moment because the Walk-in Centre takes up a lot of space	Location	Resources
	I'm sure they would come because they are already familiar with the GP surgery and then seeing an old faces. They can see the nurse that they are used to and they would know	Location	Flexibility
	it's a huge shock to be told you are a diabetic as there are all sorts of myths that go round about diabetes you know like how you're going to go blind and you will lose your legs those sort of things so they need to understand	Patient's perception about the disease	Health belief

	why they have got to learn about it.		
	a lot of my patients say to me oh my mother died of diabetes so they have a lot of maybe wrong ideas about how diabetes can be treated, or maybe they don't even know it can be treated	Patient's perception about the disease	Health belief
	it's a bit tricky to motivate somebody who doesn't believe in taking responsibility for his/her health.	Patient's perception and belief about diabetes	Health belief
	people from this ethnic background can just easily see the benefits of tablets in comparison to education	Ethnicity	Health belief
	it's a sort of side line because they don't see the importance of looking after themselves	Patient's perception about self-care	Health belief
	because you can't impose things on a patient, it doesn't work	Patient's autonomy	Motivation
	because round here they will not travel	Distance	
	I gave up I couldn't go further because I didn't know what to say and I think I did refer him but I put on the referral this man will not turn up as he doesn't have any money.	Practitioner/Patient interaction	
	I think it seems an obvious way to improve the attendance rate is by offering the service in the local area so people can come together	Location	Nearness as a possible solution
Interview 2 Participants 2 & 3	What some patients are concerned about is their educational level.	Patient's level of education	
	especially some of the older ones they want to know where it is, who they will be meeting and mixing with and a lot of them don't want to go and they think oh that's too far and I may not feel comfortable mixing with other people and may not understand what they are saying.	Location of the education Patient's perception about group education Distance	Individual preference
	she didn't feel comfortable and that she wouldn't be able to cope with what was going to be said, even though I said to her it's very visual and you don't have to be reading a lot or	Patient's perception about group education	Individual preference

	anything because there are so many different groups involved whether it be Asian or whatever group, so it is that group thing perhaps		
	the working patients	Employment	
	these patients are not going to give up working or they may not be allowed to leave work and if you are going to lose income or your work won't let you go then that is not feasible.	Employment	
	education sessions are not suitable for them, very often they are working full time and there needs to be flexibility, for example, Saturday appointments, evening appointments and the other is the venue there needs to be a more varied venue and I think that sometimes there is a fear that they won't understand although we always reiterate that they can have them in another different languages so if English is not their first language that sometimes can be a barrier and there are lots of different people speaking other languages.	Unsuitable time of the education Employment Venue of the education Fear of understanding the content Language problem	Lack of flexibility
	May be transport	Transport problem	
	we often encourage them to bring a family member or if it's a male, a female who does the shopping is a good idea to bring her with him because she is doing the buying and not always can they organise that.	Inconvenient time	
	I think in this area they have started Saturday appointment but that's not clear and that information needs to come down to us	communication	Inter-professional working
	so it's time	Practitioner's lack of time	
	For young people it's time and they're not going to go if they can't access it within their off hours so that is one of the main reasons. Obviously language in my demographics, my practice we have a large Asian community and 7% of our practice are diabetic and that is just growing so a lot of the Asians if English is not their first language they	Patient's lack of time Language problem Distance Patient's opinion about	Individual circumstances

	do not feel comfortable to go out of our area. A lot of the elderly Asian women are not comfortable with bus routes and simple things like that; to go and get two buses to go to a diabetes education centre is not what they would like to do.	using public transport	
	maybe we need to think about having more educational sessions with practices around here.	Introduce GP practice-based education	Potential solution
	you know if the education is here whether other practices in my locality would come here rather than go up to the main hospital or go to a very far community centre, patients don't like to travel they like to be in their own area with their own people so that's one of the other main things.	Introduce GP practice-based education Distance	Potential solution
	so working patients will not go	Employment	
	because it's actually really popular the waiting list has got longer	Longer waiting period	Care management
	when QOF came in, other less proactive GP's said oh there's QOF points here so they were firing off all these referrals for patients that they've never sent so it overwhelmed the system, the system can't cope and it was just a tick box exercise but that's another side of it.	Overwhelmed system	Target oriented goal
	the people that organise the programme need to get that information out because as far as I'm aware it's unknown so that information is not good and if that information isn't coming out to me I can't give it to the patient.	Communication	Inter-professional working
	we have had some comments that they haven't had a phone call in a month, then by that time they are disheartened and they have forgotten about it	Longer waiting time	Motivation
	So I think if the phone call is quicker, to put their name down even if you say you cannot come in the next week but just a phone call that you are on our list and we will be writing to you or even fixing a date and time there and	Sustaining patient's interest	Motivation

	then would be ideal and then confirm it in a few week's time.		
	But now the system has become overwhelmed and if you have to wait for over 3 months to be seen then that's not going to help	Longer waiting period	
	the service provider needs to update us more	Practitioner's Working practices	Inter-professional working
	We have all these brilliant ideas which don't come to fruition because once you've established the service and the service is known the service becomes overwhelmed and then it's not fit for purpose because patients won't go.	Overwhelmed service	
	if you have a GP who wants his QOF points and decided to overwhelm the service by just generating maybe 40 referrals in a day	Overwhelmed service	
	That's the thing because if there is no QOF point then it's not going to get done in practices as there is no payment.	Government regulations and incentives	Target
	It's just another tick box but it's on the template and it ensures that we ask that question and I think it's a good thing.	Government regulations and incentives	Target
	I think it's a memory jogger so that when they are in with us and we are going through the template at their diabetic review and have you referred them to the diabetes education Programme pops up that is our trigger.	Government regulations and incentives	Target
	but at least it ensures that we have asked the question because you can lead a horse to water but you can't make it drink	Government regulations and incentives	Target
	Absolutely it has overwhelmingly added to the problem of the service, every year with diabetes we have so many QOF points.	Government regulations and incentives	Target
	I don't think that a lot of the patients just DNA, you can't sanction them;	Negative view about the use of sanction	
	there is just no way of going down that route, you'll just be giving yourself a headache so a letter saying if you would like to continue please rebook, I	Negative view about the use of sanction	

	think where the issue is that we give them the information then the education provider don't contact them quickly and that's when they ignore it.		
	There is such a huge gap between us referring and the education provider contacting them even if they just give them a phone call to say we have you on our list, we will be contacting you to arrange a convenient time, it will keep that motivation.	Working practices Long waiting period	Inter-professional working
	because it's an educational programme and it takes longer time	Practitioner's perception about diabetes education	
	these people also lead such busy lives	Patient's busy schedule	Individual circumstances
	They do that at the hospital also. Would you then say you've DNA and if you do it again you won't get your referral for your hip, your back, your leg, or your arm?	Negative view about using sanction	
	We don't have that mind set yet that this is preventive care, what they are going for when they've got their appointment with a Consultant is therapy – in this case they are sometimes in a very bad state of health. For the education, they don't feel any different at this stage	Perceptions toward preventive care	Health belief
	And they say to us well I don't feel ill... I haven't got diabetes as I don't feel ill.	Patient perception about diabetes	Health belief
	it's a public health issue here that we want a tablet to cure all disease and we don't think education will change it so it's a mind-set isn't it and it's a very ignorant mind set and it's cultural we want something to fix it but we don't want to do anything about it.	Patient's perception about diabetes	Health belief
	its voluntary and it was an ex nurse who worked here that organised it on her own	Voluntary service	Resources
	Again, it is education and we don't see the health benefits from education immediately, but we see health benefits from a tablet and the other	Patient's perception about diabetes	Health belief

	programmes like eye screening.		
	We need campaigns, we need posters, and people need adverts on education.	Raising awareness	Motivation
	It is brand new, it has not established itself yet, it's barely off the ground.	Working practices	
	we get paid shit money, absolutely rubbish money to do this and you get to the point when you think to yourself actually I don't have any more left in my reserves to keep giving	Job satisfaction	
	I think it's a great thing that the government have made this a QOF point because they want to earn a little bit of money, they might wake up and things may change	Government regulations and incentive	
	But it is one thing ticking that box and referring them and it's another thing making that patient get off that chair and going to the appointment	Working practices	Meeting target
	we are absolutely struggling and inundated with referrals because it has now become QOF points	Work overload	Meeting target
	it has to come from the education provider office by keeping up the momentum going and keeping the enthusiasm of what we have told them	Working practices	Meeting target
	so you want a wider mix of time	Timing of the education	Possible solution
	more sessions need to be available, the timing of the sessions	Accessibility and timing of the education	
	you think how can you be diabetic for 7 years and not understand what a carbohydrate is and what is a simple sugar, we are not talking that they should have a degree, we expect them to understand that a plate of rice with that japattee or that pasta with that garlic bread is going to bump up your glucose level because you have two carbohydrates	Patient's understanding	
Interview 3 participant 4	It could be work commitments. Sometimes its health issues because they just don't feel well enough to attend. Some may believe that God brought the disease and the GP has nothing to do with it. It could be language problem, being in	Personal difficulties	

	school. The venue and time may not be convenient.		
	I don't feel comfortable with sanctions as there must be a better way.	Sanction	Motivation
	you need to have staffs who know what they are doing, staff who can follow guidelines	Working practices	
	They may need to more sessions in the summer holidays and we hope we can catch people back from university so trying to be more flexible. I could add that we may need to ring them as a follow up if they really don't engage. Some GP surgeries are thinking of funding weekend education	Flexibility	Possible solution
	Because lack of awareness of the problems associated with what can result from diabetes.	Perceptions	
	Attendance at a DEC is a process measure. It is not about ticking boxes at all. We need to determine the outcome measure and should everybody be referred?	Working practice	Target setting
	Another issue is poor data collection		Organisational issue
	With gestational diabetes, the attendance is significantly different and the process is the same they don't realise the impact that diabetes would have on their lives Some patients may have a strong family history and say oh well I knew I would get it at some point. people are not always receptive to lifestyle changes	Individual differences	Motivation
Interview 4 participant 5	I could sell it a bit more	Working practices	
	Plus I think that it's frightening – your	Psychological	Coping/Adjustm

	feet will drop off, you'll go blind, you'll become impotent so all of these awful things are going to happen to you and actually if you take care of yourself it's not true!	impact of diabetes	ent
	To sanction people? Counterproductive wouldn't it.	Negative view about using sanctions	
	I think it'll be far better off putting energy into developing programmes that people could either do online, interactively, have some sort of helpline available, developing GP practices to deliver more personalised care i.e. more time perhaps talking about nurses holding small group sessions in various practices,	Flexible delivery	Possible solution
	you can't put sanctions over people's heads it really isn't any way to run a health service at all	Negative view about using sanctions	
	It's a one off referral so the form is filled in along with the blood sugar results, age, weight, blood pressure, address, contact details, so they can triage the diagnosis.	Referral system	
	No but I do ask them during their annual review	Working practices	Lack of follow-up
	I forgot or I was too busy and life gets in the way and it's not always that easy and I think a lot of people often forget because people don't want diabetes –no one wants to be diabetic.	Patients may forget Patients having other commitments	
	So once you are given a diagnosis many people think ok that's fine and I'll just put that to one side and I'll think about it later because of course they don't often feel ill so it's very hard for some people to accept the diagnosis.	Patient's perception towards the diagnosis	Health belief
	The session is not run at different times and they are quite long sessions.	Timing and duration of the education	Organisational protocol
	There is no afternoon or an evening one.	Timing of the education	Organisational protocol
	It is very difficult because the government needs to see statistics	Government regulations	

	they can't work in any other way they cannot be interested in minute level of individual lives can they, it's ridiculous, so you know you've got this target that everyone sees		
	So no, I don't think our procedure here has changed much.	Working practices	
	I know that there is a lot of anxiety around time, I am making it sound as if we've got all the time in the world which of course we haven't but we do consider time spent with people with problems like that valuable and very well spent.	Practitioner's lack of time	
	I'd say there is very little, very little. I mean I used to know a lot of the Diabetes Specialist Nurses personally and I perhaps know one or two of them now	Working practices	
	I think probably if we sell it better here then perhaps more people would attend,	Enhanced information for patients	
	staffing of course if there were twice as many nurses doing the job that would be fine	Staffing level	Resources
	Some people just don't want to engage with the service.	Patient's lack of motivation	
	Some of our main problems are around folks who are recently diagnosed and foreigners	Recently diagnosed and foreigners	
	Our area draws a lot of people from Eastern Europe for work but the guys we have are the elderly parents who are now coming to live with their youngsters and they have these problems often before they come and particularly from India they are on some weird and wonderful sets of medications and trying to get that sorted out is difficult	Patient's perceptions and belief	Health belief
	life is too busy for a youngster and too chaotic	Patient's life pressure	
	Yes, those that can't speak English and that have come to live with their sons and daughters and the people that are very overweight are sometimes hard to help	Language problem	Communication
	Yes the health beliefs can be quite	Patient's	Health belief

	different, can't they and I think some people can put their trust in herbal things like if I chew this particular leaf then my diabetes will go away and I don't know what they are chewing. We have a guy who has a long history of diabetes from Northern India and he is convinced that chewing this leaf his mother gave him is going to take away his diabetes and he's probably getting the hang of it now after about eight years	perceptions and belief	
	People don't want the disease so they are using it as an avoiding strategy.	Denial	Coping mechanism
	Complications would have already set in before they face up to it.	Denial	
	Also people keep forgetting the problem	Forgetting the problem	
	People work and people forget.	Employment Forgetting	
	The government should put figures aside for a while and let us really increase the ability of our nurses in the community	Government regulations	
	But the time and the training aren't there.	Practitioner's lack of time and training	Staff development
	It's always a question of is it best to just chuck a load of money at something that's going to lead to ticking some boxes or is it best to think how can we invest this pound for the best return	Government regulations and incentives	
	A lot of it depend on attitude doesn't it, put yourself in a place that a person has diabetes and you come in to see me and I'm here typing on the computer saying right got to check your blood pressure, look at your feet and test your urine what does that say to you? It says that I don't care doesn't it and it says to you that I need to tick boxes	Working practices	
Interview 5 participant 6	for working people is that in this area there often aren't classes in the evening or weekends and time when they could actually get to them	Employment Timing of the education	Organisation

	With the elderly sometimes it is transport and mobility	Transport and mobility issue	
	Language is a factor for people whose English is not their first language	Language problem	Communication
	Because a wide range of languages are not on offer.	Language problem	communication
	Some people feel they would rather find out from the internet particular working people they just think I can look it all up and why do I need to go to a class	Accessing information through other sources	
	some people I think don't like being in groups they feel that their condition is private and they don't want to discuss it with other people	Patient's perception about group education	
	But the time factor and the convenience and venue are big ones for a lot of people.	Timing, convenience and location of the education	
	as from last April referring new patients for Diabetes Education became part of QOF so then it wasn't just an optional thing we had to refer every single patient to the structured education and the whole system got overloaded	Government regulations	Meeting target
	There was a six month waiting list and I think if there is a long wait people will give up and they can't be bothered by the time there is a place available.	Longer waiting period	Organisation
	I sometimes worry that the patient might forget to ring up and book and they won't automatically get sent an appointment so I have no idea I've never done any research to see how many patient's fall through the net that way.	Working practices	Referral/invitation divide
	The patient is supposed to ring the number which is Monday to Friday mornings only I think and book themselves in to the classes but the referral has to go through first and I think it makes it more complicated than it needs to be to be honest...	Working practices	
	I don't think people should be forced to do anything they don't want to do	Patient's autonomy	

	but I think having the option is definitely good because we are just too busy to give all that information in a short 15 minute appointment or 30 minute appointment		
	Any new patient that signs up at a General Practice will be asked for a urine sample so sometimes we will find glucose in the urine or they will come to see the GP because they have symptoms like they are thirsty, not been feeling too good, strong family history of diabetes or whatever, anybody actually that comes to GP and says I feel tired all the time will have a series of blood tests, fasting plasma glucose so often they are picked up that way.	Process of identifying new cases	Asymptomatic nature of diabetes
	resources are limited	Limited resources	
	But they have never encouraged us to come and see but I think if I ring up and asked they would probably not say no! it would be so much more helpful in terms of telling the patient what happens and what to expect if I had actually been to the course myself	Working practices	Inter-professional collaboration
	some patients come very motivated and keen to accept the fact that they have this diagnosis and do everything they can keep healthy and others are in complete denial and just don't want to know	Motivation Denial	
	and they want you to say you are not diabetic really or now it's better now	Denial	Coping
	Well probably that it's not good enough and we don't get much feedback from them, the only feedback that I get is from patients occasionally	Working practices	Inter-professional collaboration
	And some say yes it was very helpful and some say well no not really I knew it all before	Patient's feedback	Previous experience
	No I can't remember seeing anybody sending in letters saying this patient did not come or anything like that so	Working practices	Inter-professional collaboration
	if somebody is 80 plus frankly they don't want to be bombarded with lots	Practitioner's perception	Ageism

	of information, some of them are quite keen and will try hard to adapt their diet accordingly but some of them there is not much wrong with their diet in the first place but I wouldn't be as aggressive in my management with an elderly patient simply because you are obviously not expecting them to live as long as somebody who is in their 30's or 40's	about elderly patient	
	I think education should start a lot earlier than it does in the ideal situation	Early delivery of education	
	we should be going into the schools and do it before people come to that stage if we could pick out and educate children better in schools and also things like women who get gestational diabetes in pregnancy if we could send them off to classes	Early educational intervention	Possible solution
	I am not hugely for that really because I don't think at the end of the day it will work I don't think that is what motivates people. I think what might motivate people more I suppose is meeting people who have serious complications of diabetes.	Negative view on the use of any form of sanction	
	the people who know a bit about diabetes when they are diagnosed or know somebody who has gone blind or lost a part of their foot or a whole foot or something those are the people that tend to be more compliant because they are frightened they don't want that to happen to them and but those who come with no knowledge whatsoever often are easily more likely to go into denial just to pretend the diabetes isn't really there	Patient's level of awareness about diabetes complications	
	there are some people who are educated and can read and are used to looking things up and used to goggling things and looking up books who will basically teach themselves	Accessing other sources of information	
	I suppose you know you go to something if you think there is value in it if there is something in it for you and if you think you are not going to get anything from it you don't go. I suspect some people have very negative	Perceptions of patients about diabetes education	Health belief

	experience of any sort of class and may have had a bad time at school and didn't engage at school or didn't like school or don't like the whole idea of being taught in a class and so if they hear that this is a class you know and then to come here it might just make them turn off		
	I think I know it all	Patient's perception	Health belief
	I don't think there is anything that I can learn from this	Patient's perception	Health belief
	I'm just too busy	Busy lifestyle of patient	
	I can find this out my own way	Patient's perception	
	I haven't got the time to go to these classes	Patient's lack of time	
	I think putting in convenient times so have evening sessions maybe a Saturday morning session, in places that are accessible and close to public transport systems and not off the railway station and not too far from the patients' homes.	Timing of the education Accessibility	
	I think something like a welcoming letter or a phone call from the person leading the class before they come which I think would motivate people and they would think oh they are expecting me and somebody is concerned that I am coming if there is a sense that really who is going to notice if I turn up or not obviously they are more likely to attend.	Prompt patient contact Sustaining patient's interest	Motivation
	less time people have to wait to get on the class the better	Waiting period	
	I think when people are first given a diagnosis of diabetes many of them are in shock	Psychological impact of the diagnosis	
	but it's still quite shocking for them to come to terms with having a condition that you are going to have for the rest of your life	Psychological impact of the diagnosis	Coping
	I suppose it's a question people having to take some responsibility and be accountable for themselves	Patient's taking ownership of the disease	Motivation

	what is frustrating in our job is just having time	Practitioner's lack of time	
	It really requires time and time is one of the things we don't have we are constantly fighting the clock so that is the problem as I see it.	Practitioner's lack of time	
	changes are happening all the time – QOF changes slightly every year	Frequent organisational changes	
	Yes so much in terms of organisation and it's not just in this one thing it's in every area and I have been practicing nursing over 19 years and in the last couple of years we have had the GP commissioning the..... Federation we have had on-going QOF changes, the care planning being brought in, the ICP being brought in	Frequent organisational changes	
	the patient has to travel further	Distance	
	they have to wait longer for appointments when they get to appointments things don't always run smoothly	Waiting period	Organisation
	she had total organisational chaos and then they checked their records and said oh yes oh yes you did, sorry	Practitioner's oversight	Organisation
	Do they trust the advice we give because you know again today I had a patient who said one doctor told me one thing and another told me quite the opposite so who am I to believe.	Trust and confidence in the system	
	We haven't seen the advantage yet!!! I don't think it's really filtered through yet.	Official protocol	Organisational process
	I think the GP's are obviously anxious to work within their budgets and they are not going to commission services that are of no quick financial value because it's just not going to happen	Finance	Economy
	that in its self is time consuming as you have to have somebody yourself that has got the time to actually make sure that happens	Practitioner's lack of time	
	But the problem was they didn't tell us in time till about a week before the course was starting that it was happening so that's just a very basic	Working practices	

	practical thing		
	there has never been a two way communication	Working practices	Inter-professional working
	I also think that a really user friendly leaflet	Information delivery	
	Something eye catching and colourful and attractive.	Information delivery	
	I think the leaflets come from them and I have to print it off from the computer now if I want one and I can never find the thing on the new computer system so that doesn't help you	Working practices	
	Something quite eye catching and that has perhaps some punchy headline that you know a heading that is attractive.	Information delivery	
	I think if they are running the course then they should design the leaflet because they know what they are advertising and I don't know what they are advertising exactly	Working practices	Inter-professional collaboration
	so many of these things is organisation where things often fall down	Working practices	
Interview 6 Participant 7	If you are old, you might be able to attend	Practitioner's perception about age	
	The people that seriously need the service and can conveniently attend are more socially deprived people	Social deprivation	
	Those that are not working, I mean the unemployed.	Employment	
	Look at me, I am over 40 years or do you think I am old. I mean if you are over 60 years, you are more likely to attend. A 40 years old patient is still actively engaged with all sorts of things in life.	Practitioner's perception about age	Ageism
	I mean they have work issue	Employment	

	child care problem	Childcare issue	
	Education and other things that can disturb them from attending the education session.	Patients who are studying	
	Attending three hours lecture more than once is a lot of commitment	Patient's commitment	Motivation
	This may be due to work, childcare and lots of different issues	Employment Childcare issue	Personal difficulties
	I would say for most female it is due to childcare and work for male.	Childcare issue Employment	
	I found the elderly patients are more compliant. For example, if they live alone, it gets them out of the house to meet other people and they may enjoy the programme. Also the elderly are the retired population who would go because they don't work	Availability of time due to old age and retirement	
	Work will not let them go because they need to take time off which they may not get.	Employment	
	Things happen in life	Contingencies	
	partner's sickness,	Sickness	
	forgot because of the length of time	Forgot	
	I have had it for a long time and it is not a problem.	Patient's perception about the disease	Health belief
	Some of my patients will say they are borderline; therefore, they don't put enough effort.	Patient's perception and understanding of the disease	Health belief
	Again, there is an issue with I've got a choice, I know what I am doing; they think they know everything and don't really think about the decisions they are making.	Patient's perception and understanding of the disease	Health belief
	Some also think they can get information from friends, family and internet. They even go to American Diabetes association website and Canadian Diabetes association website without checking or thinking	Access to various other sources of information	

	that their approaches might be from us.		
	Generally, some patients don't see it as part and parcel of their diabetes management.	Patient's perception about education	
	To get a QOF point which will yield more finance, we have to prove that we have seen them in the clinic.	Government regulations	
	A more flexible hour of delivery, there may be an evening time that people could go, may be dip in and out of the course. If they can go to day one of this session and day two of another	Flexibility of delivery	Possible solution
	There could be some online learning to those who are computer literate and have access to a computer.	Flexibility of delivery	
	The session should be shorter because patient doesn't want to stay for that length of time.	Shorter delivery of education	
	I think it's got to be more flexible	Flexible delivery	
	may be before the appointment they are already feeling well	Improve accessibility	
	I think there would be an outcry, a complete outcry; patients won't even pay their fine.	Negative view about sanction	
	Non-compliance is always a problem. I see it every day,	Practitioner's view on non-attendance	
	I don't think any financial sanction will work; after all, the NHS is free.	Negative view about sanction	
	I think the government needs to make some reimbursement to their place of work.	Government assistance	Possible solution
	I mean something similar to the jury service; the employer is legally bounded to release them from work.	Government assistance	
	Why aren't they doing similar advert for diabetes education	Improve awareness	
	Time is a massive issue in the surgery with other targets to meet	Practitioner's lack of time	
	The government needs to increase the number of practice nurses.	Staffing level	

	They need to put more funding into practice nursing training and education of practice nurses.	Funding	
	I won't say there is any significant change to the process but increase inadequate staff, more administrative work and lack of training.	Working practices	
	Cost is an issue and the people sitting at the top are thinking about how many patients have you seen	Working practices	
	A lot of staff are also part-time	Staffing issue	
	There is shortage of staff there is no training, yet we need continuity and quality care.	Staffing issue	
	The time we've got is not enough to go through the blood result, to talk to patients so it is prescriptive not descriptive. 15 minutes is not enough to look at a, b, c, and d.	Practitioner's lack of time	
	Language is a barrier, for example, we have a lot of EU people, too many dialects.	Language barrier	
	The big industries or companies could also help with education. Instead of just sending different types of glucose meters all the time, they could help with translation of pamphlets to other languages because we are curtailed with finances.	External agency support	
Interview 7 Participants 8 & 9	not being able to get there, not understanding why they have been referred	Distance Insufficient information given to patients	
	language seems to be a barrier	Language barrier	
	I guess, perhaps they don't understand the importance as to why it will help so perhaps its lack of education.	Perceptions of patients to education	Health belief
	It is obviously on diabetic reviews in every surgery and it's always on the template	Government regulations	
	and generally I find it's the younger ones that mostly say yes but then they	Patient's attitude	

	will not turn up.		
	maybe work or stayed in bed	Employment	
	Well because in practice nursing, it's a turnover of patients as you know we see patients for 15 minutes, so we tend to just follow a template. I generally ask the question that are on the template and all I say to them is would you like to be referred to the education programme and I try to stress the importance of it	Practitioner's lack of time	
	but nine times out of ten they say yes and they just don't show up so....	Patient's attitude	
	we don't seem to have adequate leaflets	Inadequate leaflets	
	it's trying to work out if they haven't been offered it in the first instance so then do you offer them the first course or do you go for the second course.	Practitioner's lack of adequate information	
	we don't have enough time	Practitioner's lack of time	
	I don't know a lot about the service provider and I don't know what it does so it's very difficult to sell a service if you are not entirely sure what it is you are trying to describe what you are offering to the patient as I spend a long time going through their diet	Practitioner's lack of adequate information	
	I've only really got 20 minutes so I know it's a very short snap shot	Practitioner's lack of time	
	but what I don't know is that perhaps this is highlighting something that is lacking in me to go and look at what actually happen, therefore, what it is and it's not something that we need to have lots of information.	Practitioner's attitude	
	Yes, so you have to do the weight and everything, the BMI all the review checks to go through their blood results, HbA1c, what it implies the cholesterol results all this to do in the 20 minutes plus the referral.	Practitioner's lack of time	
	I mean we get longer for doing diabetic reviews than normal treatment as we normally get only get 15 minutes	Practitioner's lack of time	
	Yes its time – we need to cover so much and if you only have a short amount of time then it's taking that long to do the blood pressure, the	Practitioner's lack of time	

	weight and you've got to do their full foot check and you have to discuss their BM and try to go through what the structured education is as well, when you don't know that person very well unless you go through it fully they will not understand it then.		
	we just don't have enough information	Inadequate information for practitioners	
	some surgeries use a lot of locum doctors so that is in itself is problematic	Staffing issue	
	I don't think there is a good relationship,	Working practices	
	It would be great if they invite us to the courses and we were able to go on them and see what they say and do that would be great	Working practices	Inter-professional working
	To be fair to us they haven't actually contacted us to say why have you not referred enough of your patients do you see what I mean?	Working practices	
	I think there is normally a reason why they are not taking it up is perhaps they are not interested in what the issues are or the complicatedness and perhaps that is due to lack of time.	Patient's interest and lack of time	
	we are short of the amount of time that we are unable to go into depth	Practitioner's lack of time	
	and a lot of these patients just don't want to have diabetes so they are very resistant to their diagnosis in the first place so anything else that they have to do on top of it, like just coming here, they are not at that point where they are willing to accept that.	Patient's attitude towards the disease	
	I could improve my practice by selling it a bit better. I must admit, all I generally do is say would you like to be referred to the educational programme and I quickly explain to them how it could help them and that's it.	Practitioner's attitude towards referral	
	so do they want us to give them a hard sell or by bearing in mind we only have 20 minutes as she said so	Practitioner's lack of time	
	because patients always say where is it and when is it and what time is it?	Insufficient information	

	And we don't know any of that so that is quite hard too and even on the form it doesn't say any of this information	held by the practitioners	
	I found the more educated and the more affluent are quite keen and ask you what is this education and yes I want to be referred and generally what you find with diabetics, they just want to get along with life	Role of social status in attendance	Motivation
	if that is what the government is thinking or looking to go it would be very sad actually as it is almost like punishing those who are already punished.	Negative view about sanction	
	I think we have referred more people than before and our referrals have significantly gone up	Increased referral rate	
	Well, I think you can't refer someone if they don't want to be referred but that is not to say you stop trying to say they should be referred.	Practitioner's perception to education	
	if they have good standing and they go and actually research the information themselves they may feel that they don't actually need an education programme	Patient's perception to other sources of information	
	is it because they have done a lot of research and have a good understanding themselves and worked out what their diet needs to be and they have used the internet and things like that so they have a good understanding and that actually is good for them at that moment	Patient's perception to other sources of information	
	is it because they think there are more important things that they want to do at the moment	Denial	Coping
	they haven't accepted their diabetes and realise it is a progressive problem	Patient's perception about the disease	
	we need to make sure and try to explain and make it as easy as possible to access it	Accessibility	
	there is no point of saying to the Doctor I have a pain on my chest but still smoking 40 cigarettes a day.	Patient's taking more responsibility for their health	Motivation
	need to have accessible locations	Location	

	because he was trying to feel that it was out of his hands	Patient's perception about the disease	
	they don't care they perhaps lost a partner and this is just another long thing that they are trying to get through and they are not perhaps interested in education but they are not motivated and preparing them enough and perhaps it's an underlying thing in preparation as part of grief.	Denial	Coping
	quick to go through the information but it is taking it in and they may just need a lot more time and a lot of time we don't have to really understand what they think about the diabetes and the progressiveness of it and what they can do to help themselves and get their heads around it.	Practitioner's lack of time Patient's perception about the disease	Health belief
	The education of practice nurses is important but it is very hard for the GPs to fund any training.	Practitioner's training and development	Staff development
	I really see my GP here, you come and get in your own room till the end of the shift and that's it.	Working practices	

Appendix 19

Sub-themes

Clustering of codes into categories

Codes	Sub-themes
Distance Location Location Timing and location Time and place Location Location Location Location Distance Location Location of the education Distance Venue of the education Inconvenient time Distance Distance Timing and duration of the education Timing of the education Timing, convenience and location of the education Timing of the education Distance Distance Timing of the education Unsuitable time of the education Timing of the education Location	Inconvenient time and location
Practitioner's lack of time Practitioner's lack of time Practitioner's lack of time Practitioner's lack of time Practitioner's lack of time and training Practitioner's lack of time Practitioner's lack of time Practitioner's lack of time Practitioner's lack of time Practitioner's lack of time Inadequate information given to patient Inadequate information given to patient	Practitioner lack of time Inadequate information Working practices Poor referral system

<p>Language problem Language problem Language problem Language problem Language problem Language problem Language problem Language problem</p>	
<p>Government regulations and incentives Government regulations and incentives Government regulations and incentives G Government regulations and incentives Government regulations and incentives Government incentives Government regulations Government regulations Government regulations and incentive Government regulations Government regulations and incentives Government regulations Government regulations Government directives Government regulations</p>	<p>Resources Importance of meeting government targets</p>
<p>Staffing issue Staffing issue Work overload Staffing issue Staffing issue Staffing issue Staffing level</p>	<p>Resources Lack of follow-up</p>
<p>Longer waiting period Longer waiting time Long waiting period Waiting period Waiting period Longer waiting period Longer waiting period</p>	<p>Waiting time</p>
<p>Negative view about the use of sanction Negative view about the use of sanction Negative view about using sanction Negative view about sanction Negative view about sanction Negative view about using sanctions Negative view on the use of any form of sanction Negative view about sanction Negative view about sanctions Negative view about using sanctions</p>	<p>Sanctions</p>

<p>Patient's perception about diabetes Patient perception about diabetes Patient's perception about diabetes Perceptions toward preventive care Patient's understanding Patient's level of awareness about diabetes complications Perceptions of patients about diabetes education Patient's perception Patient's perception Patient's perception Patient's perceptions and belief Patient's perception towards the diagnosis Patient's perception about the disease Patient's perception and belief about diabetes Patient's perception about the disease Patient's perception about self-care Patient's perception about group education Practitioner's attitude towards diabetes education Patient's attitude Patient's attitude Patient's perception Patient's perception about group education Patient's perception about group education Patient's perceptions and belief Patient's perception about the disease Patient's perception and understanding of the disease Patient's perception and understanding of the disease Patient's perception about education Perceptions of patients to education Patient's perception to other sources of information Practitioner's perception to education Patient's perception to other sources of information Patient's taking more responsibility for their health Patient's perception about the disease Practitioner's perception about diabetes education Patient's opinion about using public transport</p>	<p>Perceptions and belief about diabetes</p> <p>Perceptions about self-care</p>
<p>Forgetting Forgetting the problem Patients may forgot Forgot</p>	<p>Forgetting</p>

Voluntary service	Resources
Introduce GP practice-based education Introduce GP practice-based education Flexibility of delivery Flexibility of delivery Flexible delivery Accessibility Early educational intervention Improve accessibility Flexible delivery	Flexibility of delivery
Practitioner's attitude towards education Practitioner's view about the policy Practitioner's perception about age Practitioner's perception about age Job satisfaction Accessing information through other sources Practitioner's view on non-attendance	Practitioners attitude
Training of practitioners Practitioner's training and development	Training and development
Personal difficulties Transport problem Employment Employment Childcare issue Childcare issue Patient's busy schedule Patients having other commitments Patient's life pressure Transport and mobility issue Childcare issue Busy lifestyle of patient Ethnicity Role of social status in attendance Patient's level of education Fear of understanding the content Contingencies Sickness Language barrier Patient's lack of time Patient's interest and lack of time Accessibility Social deprivation Patients who are studying	Employment Education Childcare issue Personal disposition
Denial Patient's autonomy Denial Denial	Motivation

<p>Patient's attitude Patient's attitude Denial Denial Patient's autonomy Denial Patient's lack of motivation Psychological impact of the diagnosis Psychological impact of the diagnosis Anxiety Patient's perception about the disease Psychological impact of the diagnosis Psychological impact of diabetes Patient's attitude towards the disease</p>	
<p>Practitioner's lack of adequate information Inadequate information for practitioners Practitioner's lack of adequate information Practitioner's oversight Information delivery Information delivery Information delivery Information delivery Insufficient information given to patients Improve awareness Practitioner's attitude towards referral Inadequate practitioner's knowledge of the programme Inadequate practitioner's knowledge of the programme Raising awareness Enhanced information for patients Insufficient information held by the practitioners Practitioner's attitude Practitioner/Patient interaction</p>	<p>Attitude of practitioners Information delivery</p>
Sustaining patient's interest	Motivation
Recently diagnosed and foreigners	
Process of identifying new cases	Asymptomatic nature of diabetes
Motivation	
Patient's feedback	Previous experience
Practitioner's perception about elderly patient	Ageism
Early delivery of education	
Accessing other sources of information	
Patient's lack of time	
Prompt patient contact Sustaining patient's interest	Motivation

Trust and confidence in the system Patient's commitment Patient's taking ownership of the disease	
Frequent organisational changes Frequent organisational changes Increased referral rate Official protocol Government assistance Government assistance Funding Finance Staffing level Limited resources Finance Inadequate leaflets	Administration Resources
Shorter delivery of education Access to various other sources of information	
External agency support	Resources

Appendix 20

Themes

Sub- themes:	Major themes:
<ul style="list-style-type: none"> - Importance of meeting government targets - Service overload/waiting time - Working practices - Practitioner's lack of time - Inadequate information - Poor referral system - Lack of follow-up - Perceptions and attitude of practitioners towards diabetes education - Introducing sanctions - Inter-professional working - Inconvenient time and location of the session - Administrative errors 	<p>Organisation of care</p>
<ul style="list-style-type: none"> - Employment and education related barriers - Child care issues - Personal dispositions - Forgetfulness - Language barrier 	<p>Personal circumstances of the patient</p>
<ul style="list-style-type: none"> - Perceptions and belief about diabetes - Perceptions and beliefs about self-care management and diabetes education - Preference for group education - Motivation 	<p>Perceptions and attitudes of patients to diabetes education</p>
<ul style="list-style-type: none"> - Flexibility of delivery - Resources - Training and Development - Collaborative practice 	<p>Strategies to aid attendance</p>

Appendix 21

RELATED ACADEMIC OUTPUTS

RELATED PUBLICATIONS:

Lawal, M. (2014) Barriers to attendance in diabetes education: A systematic review. *Diabetes & Primary Care*, 16 (6), 299-306

Lawal, M. (2014) Non-attendance in diabetes education centres: perceptions of patients and education providers. *Diabetic Medicine*, 31 (S1), P102-103.

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CONFERENCE PRESENTATIONS:

11-13/3/15 – “A systematic review of literature on non-attendance in diabetes education centres” at the Diabetes UK 2015 Conference, ExCel, London.

20/21/11/14 – “Barriers associated with uptake of diabetes group education: a survey of patients' opinion” at the 10th National Conference of the Primary Care Diabetes Society,

National Motorcycle Museum, Birmingham NEC.

07/11/13 – 08/11/13 – “Beliefs and attitudes of type 2 diabetes patients’ towards education for self-care: perceptions of patients and education providers” at the 9th National Conference of the Primary Care Diabetes Society, National Motorcycle Museum, Birmingham NEC.

22/4/13 – 24/4/13 “Diabetes Essentials” at RCN Congress 2013, Hall 1B Liverpool Arena and Convention Centre (ACC), Liverpool.

13/3/13 -15/3/13 Presentation: “Telephone interviews of patients on factors affecting attendance in multi-disciplinary diabetes education centres” at the Diabetes UK conference, Manchester Central Convention Complex, Manchester.

16/11/12 – 17/11/12 – “Non-attendance in diabetes education centres” at the 8th National Conference of the Primary Care Diabetes Society, The Hilton Birmingham Metropole, Birmingham NEC.

25 April 2012 Presentation: ‘Barriers associated with uptake of diabetes group education: examining policy implementation’ at College of Nursing, Midwifery and Healthcare Research Seminar, University of West London, London.

07/03/12 – 09/03/12 Presentation: ‘Barriers associated with uptake of diabetes multi-disciplinary group education: A survey of patients’ view in a PCT in Southeast of England’ at the Diabetes UK Conference, Scottish Exhibition & Conference Centre (SECC), Glasgow, Scotland.

16/05/12– Presentation: ‘An investigation into diabetic education: Exploring barriers and facilitators’ at UWL 2012 Annual MPhil/PhD conference

11/05/11– Presentation: ‘Barriers associated with uptake of diabetes group education: A survey of patients’ opinion’ at TVU 2011 Annual MPhil/PhD conference

30/03/11 – 01/04/11 Presentation: ‘A narrowly explored phenomenon: Identifying ways to address the challenges of non-attendance in diabetes education centres.’ at the Diabetes UK Conference, International Convention Centre (ICC), ExCel, London.

03/03/10 – 05/03/10 Presentation: ‘Implementation of diabetes education policy in a PCT in South East of England: exploring barriers and prospects’ at the Diabetes UK Conference, Arena and Convention Centre (ACC), Liverpool.

18/11/11 – 19/11/11 – Presented a poster title ‘Barriers associated with uptake of diabetes group education: examining policy implementation’ at the 7th National Conference of the Primary Care Diabetes Society, The Hilton Birmingham Metropole, Birmingham NEC.

20/11/09 – 21/11/09 – Presented a poster title ‘Exploring barriers associated with uptake of diabetes education: examining policy implementation’ at the 5th National Conference of the Primary Care Diabetes Society, The Hilton Birmingham Metropole, Birmingham NEC.

5/2/09– Presented a paper title ‘Exploring barriers associated with uptake of diabetes education: examining policy implementation’ at TVU 2009 Annual MPhil/PhD conference

9/4/08 – Presented a paper title ‘Methodological analysis of a proposed mixed method

research' at Centre for Narrative Research, University of East London.

7/2/08 – Presented a paper title 'Reconciling methodological approaches of survey and focus group' at TVU 2008 Annual MPhil/PhD conference.

Barriers to attendance in diabetes education centres: A systematic review

Muili Lawal

The use of structured patient education is widely acknowledged as one of the strategies for diabetes management in the UK. Nevertheless, the delivery of education programmes such as DAFNE (Dose Adjustment For Normal Eating) and DESMOND (Diabetes Education and Self-Management for On-going and Newly Diagnosed) in the primary care setting is often challenged by decreasing attendance over time (known as attrition). The aim of this systematic review is to identify the reasons and barriers associated with non-attendance in diabetes education centres by examining the empirical evidence.

Studies have identified the beneficial effects of diabetes education in promoting self-care knowledge and improvements to diabetes management. Structured diabetes education programmes can improve diabetes knowledge among those who have the condition (Deakin et al, 2006; Rygg et al, 2012) and reduce complications and hospital admissions (Cinar et al, 2010; Karakurt and Kasikci, 2012). Tang et al (2006) have also shown that diabetes self-management education can have a positive health outcome, particularly in improving knowledge, blood glucose monitoring, attitudes towards diet and exercise, glycaemic control, adherence to medication and coping abilities, and a study by Khunti et al (2012) based on data from the DESMOND (Diabetes Education and Self-Management for On-going and Newly Diagnosed) programme concluded that diabetes education led to improvements in some illness beliefs.

NICE guidelines (2003; 2009) recommend structured patient education (SPE) for every newly diagnosed person with diabetes with an annual update. Similarly, Standard 3 of the *National Service Framework for Diabetes* emphasises the importance of education and empowerment for people with diabetes (Department of Health [DH], 2001). However, despite the evidence supporting the benefits

of SPE and the government directive, uptake among people with diabetes still varies across the country (DH, 2007). I aimed to identify the barriers associated with attendance to diabetes SPE through a systematic review of the literature.

Methodology

The health-related databases searched were EBSCOhost, CINAHL, Medline, Ovid, EMBASE, PubMed and the Cochrane Library. In addition to using various electronic databases, articles were selected manually from the references of key articles.

The search terms used were “diabetes self-management education”, “attrition”, “drop-out”, “missed appointment”, “did not attend”, “barrier to attendance”, “non-attendance” and “diabetes education”. The Boolean operators “and” and “or” were used to join the key words such as “diabetes” with “self-care management”, “attrition” or “missed appointment” to broaden the search, while “not” was used to narrow and exclude some resources.

Table 1 shows the eligibility criteria for the current systematic review. The criteria included articles that investigated non-attendance in people with diabetes and the barriers to attending SPE. The articles had to be published in English, be peer-reviewed and could be primary research papers or systematic reviews. Studies on non-

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Article points

1. Structured diabetes education is a useful strategy to achieve positive patient outcomes.
2. There are numerous barriers that lead to non-attendance in diabetes education centres, such as personal circumstances, perceptions and attitudes, and communication and motivation problems.
3. Non-attendance in diabetes education centres has negative resource implications for clinical commissioning groups and service providers in the UK.
4. The instigation to sustain a healthy behaviour requires individual motivation.
5. There is limited documentation on the phenomenon of non-attendance in diabetes education centres in the UK, but solving this problem remains a global challenge.

Key words

- Barrier to attendance
- Diabetes education
- Non-attendance
- Self-management

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Page points

1. Inclusion criteria for the systematic review included English language publications, peer-reviewed primary and secondary research articles and studies on non-attendance associated with diabetes education.
2. Fourteen articles from the initial search met the inclusion criteria, and all the articles were either qualitative or quantitative research articles published in a peer-reviewed journal.

Table 1. Eligibility criteria for articles.

Inclusion criteria
English language publications
International studies
Publications from database inception to 31 July 2013
Systematic reviews
Primary research articles
Full-text peer-reviewed articles
Studies on non-attendance associated with diabetes education

Articles were excluded if they were based on non-attendance for other medical conditions, if they were related to non-education settings or if they were not research papers, e.g. literature review, general information paper, opinion-based documents.

attendance in relation to other disease conditions or settings (e.g. non-attendance to routine appointments with healthcare professionals) were excluded. Comprehensive searches from the earliest possible date to 31 July 2013 were conducted.

Results

The initial searches identified 1704 publications (EBSCOhost 386; CINAHL 538; Medline 311; Ovid 224; EMBASE 233; PubMed 12) that were informative but not appropriate for the review based on the inclusion criteria. No publications were identified through the Cochrane Library. Fourteen articles from the initial searches met the inclusion criteria (Table 2), and all the articles were either qualitative or quantitative

research articles published in a peer-reviewed journal. The Critical Appraisal Skills Programme (CASP) tool (Public Health Resource Unit, 2008) was used as a framework to judge the validity and relevance of the shortlisted articles. The key features of each article that met the inclusion criteria are displayed in Table 3.

The 14 articles consisted of nine survey studies, three retrospective studies (Articles #1, #2, #4), one controlled experimental study (Article #14) and one systematic review (Article #5). The majority of the studies adopted a descriptive approach and used various data collection methods such as questionnaires, interviews and retrospective studies of medical records. Six of the 14 studies were conducted in Canada, five in the USA, one in Germany and one in Turkey. The systematic review by Gucciardi (2008) selected 14 research articles from the US, Japan, New Zealand, the Netherlands, Canada and the UK.

From the initial database search, four articles were of UK studies conducted between 1983 and 1992 (Scobie et al, 1983; Hammersley et al, 1985; Lloyd et al, 1990; Archibald et al, 1992). However, these studies did not meet the inclusion criteria for the current systematic review because they focused on non-attendance to hospital clinic appointments instead of non-attendance to SPE for diabetes. The four UK studies were conducted before the advent of key policy documents such as the *National Service Framework for Diabetes* (DH, 2001) and NICE guidelines (2003; 2009), which recommend SPE in England. The search results from this systematic review show that non-attendance is not a new phenomenon as studies on the subject date back over two decades in America (e.g. Graber et al, 1992). There is limited documentation on this particular phenomenon in the UK.

Participant sample

The participant sample sizes of the studies in the 14 articles varied widely. Rhee et al (2005) had the largest study population (605 people with diabetes attending a diabetes clinic for an initial visit) while Uitewaal et al (2005) had the smallest sample size (45 attendees with

Table 2. Database search results.

Database	Date covered	Number of selected articles
CINAHL	1984 – 31 July 2013	1
Medline	1984 – 31 July 2013	2
Ovid	1946 – 31 July 2013	1
Cochrane Library	2005 – 31 July 2013	0
EMBASE	1980 – 31 July 2013	2
PubMed	Inception to 31 July 2013	0
EBSCOhost	Inception to 31 July 2013	4
Supplementary search*	Reference sources	4

*Supplementary search involved manual searches of published research papers for relevant literature cited in the selected articles.

diabetes). With the exception of the systematic review by Gucciardi (2008), which had 1704 participants, the total participant sample size for this systematic review was 3926: 3527 (89.8%) people with diabetes who attended the hospital for diabetes education sessions, 256 (6.5%) non-attenders and 143 (3.6%) practitioners.

Twelve of the articles solely sampled participants of diabetes SPE programmes, while Temple and Epp (2009) surveyed attenders and non-attenders of diabetes and heart education programmes. One American study (Article #12) surveyed the perspectives of practitioners with membership to a diabetes educators association.

Barriers to attendance

All the studies explored the reasons for non-attendance to diabetes SPE; some focused on the association between baseline characteristics of the non-attenders, while others investigated attendance barriers in general.

The reasons people with diabetes gave for not attending diabetes education programmes were reported in the 14 articles eligible for this systematic review. The most common reason for non-attendance was a low perception of the seriousness of diabetes, which was reported by half of the articles (Articles #3, #5, #6, #7, #9, #12, #14). Another common barrier for attendance was a low perception of the benefits of attending diabetes education sessions (Articles #3, #5, #6, #9, #11, #12).

Multiple studies found that logistical factors such as transportation (Articles #3, #5, #13), distance to venue (Articles #2, #5, #11) and travel expenses (Articles #3, #5, #11) were a hindrance to attendance. An inconvenient time and location of SPE sessions were reasons for non-attendance in the survey carried out by Gucciardi et al (2012). The results of three studies indicated that the type of medical insurance cover and the financial implications of attending the education sessions were also potential barriers (Articles #3, #5, #11). Three studies reported that participants stated there had been a lack of adequate publicity for the sessions, which was why they had not attended (Articles #3, #5, #13). Gucciardi (2008) identified an

inability for participants to contact the clinic as a barrier for attendance, and Schafer et al (2013) reported that some participants had negative feelings about the education sessions being conducted in a group environment, such as some people finding the group environment intimidating. A number of studies identified work-related problems as a factor contributing to non-attendance to diabetes SPE, such as not being able to take time off (Articles #5, #11, #13).

Previous exposure to diabetes education (Article #6), insensitive interaction with healthcare professionals providing the education class (Article #9) and a long waiting list (Article #9) were also barriers for people to attend diabetes SPE.

Participant baseline characteristics

Some of the articles investigated whether there was an association between participant baseline characteristics and non-attendance. Male gender and smoking (Articles #1, #2, #8), being over 65 years of age (Articles #4, #6, #10), inability to adhere to weight loss (Article #8) and having diabetes for over 5 years (Article #14) were reported as contributory factors to non-attendance. Graber et al (1992) and Benoit et al (2004) suggested that some smokers dropped out of diabetes education programmes perhaps because the session encouraged smoking cessation. Rhee et al (2005) and Schafer (2013) both reported poor vision and hearing as a barrier to attendance. Two studies also stated that family problems (Articles #5, #11), forgetting to attend (Articles #5, #13) and the feeling that seeing a family physician provided the same level of diabetes education (Articles #5, #6) prevented some respondents from attending the diabetes SPE. Other barriers reported by a single study included when participants did not have English as a primary language (Article #4). Three of the 14 research articles reported that participants preferred for physicians to manage their medical condition (Articles #5, #6, #11), while three studies found that a low level of education was associated with a higher rate of non-attendance (Articles #3, #10, #11). Failure to attend the session due to ill health (Articles #5, #9, #10) was identified by three studies.

Page points

1. With the exception of the systematic review by Gucciardi (2008), the total participant sample size for this systematic review was 3926: 3527 (89.8%) people with diabetes who attended the hospital for diabetes education sessions, 256 (6.5%) non-attenders and 143 (3.6%) practitioners.
2. All the studies explored the reasons for non-attendance to diabetes structured patient education; some focused on the association between baseline characteristics of the non-attenders, while others investigated attendance barriers in general.
3. Male gender, smoking, being over 65 years of age, inability to adhere to weight loss and having diabetes for over 5 years were reported as contributory factors to non-attendance.

Table 3. Characteristics of the 14 articles included in the systematic review.

Source	Location	Aim	Sample	Design and method	Key findings	Limitations
[#1] Benoit et al (2004)	USA	To investigate factors that are associated with attrition from a diabetes education project	573 in total: 504 people who stayed for at least 6 months and 69 who dropped out	Case-control retrospective study using medical charts	The predictors of drop-out were insurance status, high blood pressure or HbA _{1c} and smoking.	<ul style="list-style-type: none"> Retrospective data analysis Focused on participants' characteristics Failure to assess participants' perceptions, beliefs and other attributes such as distance and work schedules
[#2] Graber et al (1992)	USA	To determine the reasons why patients drop out from ongoing diabetes medical care, education and nutritional counselling	422 people with type 1 and type 2 diabetes	Retrospective survey using medical records	Drop-out rate was influenced by distance of over 100 miles to the education centre, non-insulin treatment and cigarette smoking.	<ul style="list-style-type: none"> Retrospective analysis Limited information about follow-up care Failure to distinguish between the various insurance coverage
[#3] Graziani et al (1999)	USA	To examine the use of diabetes education programmes	Convenience sample of 150 people with type 1 and type 2 diabetes who attended a non-acute clinic	Descriptive survey of one open-ended question	The reasons for non-attendance were lack of time, lack of transportation, low level of education of the participant, stress, being unaware of the programme, low perception of the seriousness of the disease, denial/fear, lack of interest and no perceived benefits of the session. Another contributory factor for non-attendance was the perceived cost caused by a lack of awareness that insurance premiums covered the session.	<ul style="list-style-type: none"> Small sample size with convenience sampling technique Sample population was largely African-American females from a university-based family practice (limited generalisation)
[#4] Gucciardi et al (2007)	Canada	To assess utilisation pattern and identify factors that are associated with attrition in diabetes self-management education	536 people with type 2 diabetes who attended a diabetes education centre for the first time	Retrospective study using medical charts of first-time visitors	Factors associated with attrition from recommended education programme were over 65 years of age, working full or part time and primarily speaking English.	<ul style="list-style-type: none"> Retrospective analysis Difficult to conclude what factors are responsible for the outcomes Possibilities of incomplete data on clinical and contextual factors Limited generalisation
[#5] Gucciardi (2008)	Several countries	To examine the factors that are responsible for attrition in either diabetes clinics or diabetes education centres	14 research studies	Systematic review comprising 1704 people with diabetes	Reasons for defaulting were feeling unwell, inability to take time off from work, being too busy, having a family physician, not being interested, forgetting the appointment, being unable to contact the clinic, family problems, finance, transportation, distance and the programme not providing new information.	<ul style="list-style-type: none"> Thirteen of the 14 studies were conducted retrospectively Most studies related to clinic appointment as opposed to diabetes education Most studies surveyed the opinion of people after they had attended an initial visit to the centre Focus of most studies was on socio-demographic and clinical factors, with limited attention to psychosocial and contextual reasons Most studies performed descriptive analysis Studies using diverse methodologies with small sample sizes
[#6] Gucciardi et al (2008a)	Canada	To determine whether men and women with type 2 diabetes have different behavioural, psychosocial and clinical characteristics during first contact with diabetes education centre	275 men and women with type 2 diabetes attending first appointment	Cross-sectional study using medical charts and questionnaires	Men and women have different psychosocial and behavioural characteristics that can affect attitudes and behaviours towards diabetes education. These include differences in previous exposure to diabetes education and expectations of the benefits.	<ul style="list-style-type: none"> Participants were users of diabetes education centres The differences between both sexes were observed at a single point
[#7] Gucciardi et al (2008b)	Canada	To examine the factors that are associated with attrition behaviour in diabetes self-management programmes	267 people with type 2 diabetes who attended a diabetes education centre; 11B who dropped out	Retrospective, cross-sectional study consisting of a review of medical charts and a telephone interview	Factors contributing to attrition behaviour in the study were full or part time work, aged over 65 years, fewer diabetes symptoms, confidence in knowledge and ability to self-manage, regular physician consultation, low perceived seriousness of diabetes and lack of familiarity with the centre and services.	<ul style="list-style-type: none"> A single open-ended question was asked Quantitative data were collected retrospectively

Table 3 (continued). Characteristics of the 14 articles included in the systematic review.

Source	Location	Aim	Sample	Design and method	Key findings	Limitations
(#8) Gucciardi et al (2009)	Canada	To identify factors associated with attrition in diabetes self-management education services	268 people with type 2 diabetes who attended a diabetes education management centre	Descriptive prospective study using a questionnaire	Failure to attend the sessions was due to inability to adhere to weight loss, recent diagnosis of diabetes, male gender and smoking.	<ul style="list-style-type: none"> • Items focused on psychosocial and behavioural measurement as opposed to assessing the barriers to attendance • Analysis was based on the number of contacts made in the hospital
(#9) Gucciardi et al (2012)	Canada	To explore participants' utilisation of diabetes education centres and the barriers to attendance	221 people with prediabetes, type 1 or type 2 diabetes in total: 159 attenders and 62 non-attenders	Internet survey and hard copy questionnaire	Failure to attend the sessions included the condition not being considered as serious, diabetes education not being a priority, perceived futility of the service, insensitive interaction with the professionals and inconvenient timing and location. Other factors included parking issues, language problems and illness.	<ul style="list-style-type: none"> • Small sample size • Convenience sampling technique • Lack of qualitative data to provide comprehensive information
(#10) Rhee et al (2005)	USA	To explore patients' perceptions of barriers to diabetes education	605 people (95% with type 2 and 5% with type 1 diabetes) who attended a diabetes clinic for an initial visit	Cross-sectional survey using a questionnaire	The potential barriers reported were poor vision, inability to read well, problems with hearing, English language problems, older age, employment status and low level of education.	<ul style="list-style-type: none"> • Self-developed questionnaire • A cross-sectional study that reported anticipated barriers
(#11) Schafer et al (2013)	Germany	To describe the reasons for non-participation in type 2 diabetes education programmes	297 people with type 2 diabetes: 165 attenders and 132 non-attenders	Cross-sectional observational study using results from a postal survey and medical chart review	Factors influencing non-participation were a belief of sufficient knowledge of diabetes, a feeling that the physician is responsible for diabetes management, the purpose of diabetes education not being clear and negative feelings about the course and groups of people. Barriers were also due to distance and travel expenses, physical and excessive demands of the education (e.g. difficult contents, occupation-related time pressure or working schedule, family-related time pressure and problems with vision and hearing).	<ul style="list-style-type: none"> • Small sample size • Retrospective data collected through medical chart • Inclusion of self-developed instrument
(#12) Sprague et al (1999)	USA	To assess the perspectives of diabetes educators on potential barriers to successful diabetes education	1996 members of the Washington Association of Diabetes Educators were invited to participate; 143 practitioners responded	Descriptive study using a mailed questionnaire	Barriers to attendance relate to lack of understanding of the nature of diabetes and the need for educational support, unaffordable follow-up care and lack of insurance cover for education.	<ul style="list-style-type: none"> • Self-developed questionnaire • Responses are perceptions of practitioners, which may not directly represent patient views
(#13) Temple and Epp (2009)	Canada	To evaluate the characteristics of attendees and non-attendees and their reasons for non-attendance at diabetes/heart health education programmes	A convenience sample of 124 people with type 1 and type 2 diabetes (62 attendees and 62 non-attendees)	Cross-sectional descriptive study using a telephone questionnaire	Barriers to attendance were due to participants being busy, transportation, work-related problems and other health issues that were more important. Other barriers included forgetting, needing the doctor to manage their disease, the participant not needing help or never having heard of the service.	<ul style="list-style-type: none"> • Self-developed questionnaire • Low response rate due to futile repeated phone calls • Low sample size with convenience sampling technique
(#14) Uitewaal et al (2005)	Turkey	To assess the association between patient characteristics and compliance	45 people with type 1 or type 2 diabetes who attended a diabetes education session	Controlled experimental study consisting of interviews	The characteristics of participants that influenced attrition from the education facilities were having diabetes for over 5 years and relatively poor knowledge of the seriousness of diabetes.	<ul style="list-style-type: none"> • Small sample size

Page points

1. Based on the results, the author conceptualised the reported barriers under four broad areas: personal difficulties, perceptions and attitudes of people with diabetes, communication and motivation.
2. The majority of the articles reported that personal difficulties were a barrier to attendance.
3. Some participants in the current systematic review failed to attend the education sessions owing to their perceptions about the nature of diabetes, their perceived benefits of the session and their belief about the level of knowledge they possessed.

Table 4. Emergent themes.

Themes	Articles
Personal difficulties	Graber et al (1992); Graziani et al (1999); Sprague et al (1999); Benoit et al (2004); Rhee et al (2005); Gucciardi et al (2007); Gucciardi et al (2008a); Gucciardi et al (2008b); Temple and Epp (2009); Gucciardi et al (2012); Schafer et al (2013).
Perceptions and attitudes of people with diabetes	Graziani et al (1999); Sprague et al (1999); Uitewal et al (2005); Gucciardi (2008); Gucciardi et al (2008b); Temple and Epp (2009); Gucciardi et al (2012); Schafer et al (2013).
Communication	Graziani et al (1999); Gucciardi et al (2007); Gucciardi (2008); Temple and Epp (2009).
Motivation	Graziani et al (1999); Gucciardi (2008); Gucciardi et al (2008b); Temple and Epp (2009); Schafer et al (2013).

Discussion of findings

Based on the results, I conceptualised the reported barriers under four broad areas: personal difficulties, perceptions and attitudes of people with diabetes, communication and motivation (*Table 4*).

Theme 1: Personal difficulties

The majority of the articles reported that personal difficulties were a barrier to attendance. Almost all of the studies identified personal difficulties such as work-related problems, family problems, illness, access to transportation, distance to SPE centre, travel expenses and the sessions occurring at an inconvenient time or location. Several other authors have identified similar personal difficulties as a barrier to attendance in general clinical practice, such as forgetfulness, being too busy, language problems and poor vision and hearing (Stone et al, 1999; Hamilton et al, 2002; Zailinawati et al, 2006).

Three US-based studies from this systematic review (Graziani et al, 1999; Sprague et al, 1999; Benoit et al, 2004) identified insurance status as a barrier to accessing and attending education sessions. This is not a major barrier in the UK as the healthcare system is different to the US (Kenny, 2014). The NHS is largely funded by national taxation (Baggott, 2010) rather than by individuals, so non-attendance at UK diabetes SPE centres has negative resource implications for clinical commissioning groups and service providers.

Theme 2: Perceptions and attitudes of people with diabetes

Helman (2007) acknowledges the influence of individual perceptions and beliefs on people's

choice of health intervention, and this extends to perceptions and attitudes towards health education. Some participants in the current systematic review failed to attend the education sessions owing to their perceptions about the nature of diabetes, their perceived benefits of the session and their belief about the level of knowledge they possessed. The impact of negative perceptions on seeking and attending health education sessions has been long-established (Hammersley et al, 1985; Glasgow et al, 1997).

Another perception and attitude that was reported to affect attendance of self-management education sessions was the perception that it is the physician that manages an individual's diabetes with little or no input from the person with diabetes (Schafer, 2013). Metcalfe (2005) stated that the traditional paternalistic approach to care by the NHS is outdated for people with long-term conditions in terms of preventing unnecessary admissions and improving quality of life and independence. Rana and Upton (2009) also stated that patient empowerment entails involving individuals in the management of their care, which is a key factor in providing good care and engaging with the patient.

Theme 3: Communication

The current systematic review found that some respondents did not attend the education session because of poor communication. These barriers included the participants' inability to speak or read English very well, an inability to contact the clinic, participants not being aware of the service and reported insensitive interactions with the healthcare professionals running the sessions. In

some cases, the participants appeared to have been absent owing to the appointment having been booked a long time ago (Gucciardi et al, 2012).

The benefit of prompt and effective communication between patients and care providers is well documented in the literature (Collin, 2009; Webb, 2011). While barriers to attendance relating to communication may vary, the onus is on the healthcare professionals to enhance effective communication to aid attendance.

Theme 4: Motivation

Individual motivation impacts on attendance: some participants forgot the appointment, some people were too busy to attend and some were simply not interested in the education programme. Others cited lack of time or lack of familiarity with the centre or the service as factors that prevented them from attending the sessions. A well-motivated learning experience may alter individual behaviour; however, Schafer et al (2013) emphasised the importance of motivation in diabetes education by saying that the success of the programme depends on the willingness of the individuals to engage with the education. Self-care management requires willpower; therefore, motivation is crucial to diabetes education programmes.

Limitations of the review

A key methodological weakness of this systematic review is that the majority of the participants studied were people who attended diabetes education centres rather than those who did not. It is possible to understand the reasons for missed appointments among attenders; nevertheless, the motivation for attendance in this group versus non-attenders may differ. The 14 studies selected for the systematic review had low sample sizes, lacked probability sampling of participants and included retrospective data. Therefore, focusing on attenders and methodological limitations reported makes it difficult to draw firm conclusions.

A major limitation was that most of the available studies were from countries outside the UK. These countries have a different funding approach (mostly private health insurance,

based on single practice and of short duration) and education systems. Therefore, considering whether the barriers to attendance are relevant to the UK is difficult. A recent UK study which aimed to identify the barriers associated with attendance in diabetes education centres presented at the *10th National Conference of the Primary Care Diabetes Society* in Birmingham in November 2014 had similar findings (Lawal, 2014). The poster presentation illustrated how the study used a postal questionnaire to elicit data from 105 defaulted patients who were referred for structured patient education in four diabetes education centres in the South East of England. The findings of the study also identified perceptions and beliefs of patients, personal problems, inconvenient location and time as barriers, among others.

Implications for practice and research

Although there are several international research studies on non-attendance to diabetes education, a significant number of studies surveyed attenders while very few surveyed the views of non-attenders. The paucity of studies in this area may be attributed to the fact that people who fail to attend hospital appointments are difficult to access. According to a systematic review carried out by Ajay and Rubin (2003), investigating reasons for non-attendance in a primary care setting presents some obvious methodological issues because this group of people might not be willing to participate in research and may see it as being confrontational if not handled with care.

Based on the results of this systematic review, the key barriers to attendance are work, illness, language problem, distance, finance, lack of interest, low perception about the seriousness of the medical condition and the benefits of the session. Consequently, strategies to promote attendance include offering the education service in the community nearer to the patient and offering various choices of time such as evenings and weekend sessions. Also, the patients need to assume more responsibility for their health and the healthcare practitioners need to influence patients' beliefs and attitudes that are necessary to promote motivation and commitment.

Page points

1. Communication barriers included the participants' inability to speak or read English very well, an inability to contact the clinic, participants not being aware of the service and reported insensitive interactions with the healthcare professionals running the sessions.
2. Individual motivation impacts on attendance: some participants forgot the appointments, some people were too busy to attend and some were simply not interested in the education programme.
3. Although there are several international research studies on non-attendance to diabetes education, a significant number of studies surveyed attenders while very few surveyed the views of non-attenders.

“Understanding the barriers to attendance for people with diabetes is crucial in developing ways to improve care and engagement with people who have diabetes.”

Conclusion

An ageing population and lifestyle changes have caused an increase in the prevalence of long-term conditions, of which diabetes is one. This has led to a growing pressure on the NHS. Equally, the challenge to achieve good health has caused a paradigm shift from the traditional paternalistic approach to long-term condition management to one of patient empowerment and self-management. This can be achieved through education sessions; however, this can be problematic when the attrition rate to SPE is high. Understanding the barriers to attendance for people with diabetes is crucial in developing ways to improve care and engagement with people who have diabetes. This review has established the need for further work and discussion to promote attendance to diabetes education sessions. ■

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parents, (1d) 'we do try to set a good example'; (2) 'the biggest thing that you lose as a child with Type 1 diabetes is independence'; and (3) physical activity with other children with Type 1 diabetes. Five themes and two sub-themes were identified in healthcare professionals' transcripts: (1) comparable physical activity levels to children without Type 1 diabetes; (2) potential barriers – (2a) fear of hypoglycaemia, (2b) testing blood glucose; (3) impact of pump; (4) 'nice convenient excuse'; and (5) current education and resources.

Conclusion: A physical activity promotion intervention would be beneficial for children with Type 1 diabetes.

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Get on your bike: group based exercise workshop improves exercise confidence for people with Type 1 diabetes

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Background/aims: The benefit of exercise is wide ranging and includes improved quality of life, cardiovascular fitness and weight management. People with Type 1 diabetes are less likely than their peers to engage in regular exercise which in part may be due to a fear of hypoglycaemia. In an effort to help reduce this fear and encourage exercise we designed a ½ day exercise workshop which delivered a mix of didactic teaching, group discussion and then a 1h class on a static bike. We were interested to see if this improved confidence and resulted in acceptable glucose control.

Methods: The class involved a 1h session on exercise and insulin/carbohydrate adjustment followed by a group discussion over lunch and then a 1h session on a static bike facilitated by an exercise coach. We recorded the percentage insulin reduction at lunch and participants monitored glucose at 10 min intervals during the class and frequently for the following 24h. After the session we had a debrief and shared results and experience. The following day participants were asked to feedback using an online questionnaire.

Results: We ran two pilot sessions with 28 participants. 22 completed the post-event questionnaire. All felt that their confidence was improved (45% agreed and 55% strongly agreed), 85% had better blood glucose results than they expected, 95% felt motivated to do more exercise and only 5% had hypoglycaemia in the 24h post session.

Conclusion: We have demonstrated that a practical group session results in improved confidence and better blood glucose than expected.

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A systematic review of the literature on non-attendance in diabetes education centres

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Background: The use of structured patient education is widely acknowledged as one of the strategies for diabetes management in the UK. Nevertheless, the delivery of education programmes such as DAFNE (Dose Adjustment for Normal Eating) and DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) in the primary care settings is often challenged by the attrition rate.

Objective: The aim of this review was to identify barriers associated with attendance in diabetes education centres.

Research design and methods: This secondary research used a systematic literature review approach to examine the empirical evidence relating to non-attendance in diabetes education centres. A comprehensive search of CINAHL, MEDLINE, OVID, PubMed, EMBASE and the Cochrane Library was conducted from inception to July 2013. In addition to using various electronic databases, hand search of key articles was performed to retrieve relevant research papers.

Results: A total of 14 international research studies excluding the UK met the inclusion criteria. The findings of this study indicated various barriers ranging from personal problems and beliefs to lack of motivation and communication problems. Also, the findings revealed a continuous need for ongoing education and support for patients affected by diabetes, regardless of the challenges posed by non-attendance.

Summary: Although there is limited documentation on the phenomenon of non-attendance in diabetes education centres in the UK, solving this problem remains a global challenge. In conclusion, transferring the findings to the UK setting has its limitations; therefore, there is a need to further explore the phenomenon, particularly in the UK.

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Randomised controlled trial of peer support in Type 2 diabetes (RAPSID)

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Aims: We have tested whether diabetes peer support, where one person with diabetes helps guide and support others, can improve metabolic and/or psychological outcomes.

Methods: We performed a 2 × 2 factorial randomised cluster controlled trial among people with Type 2 diabetes, who were invited, predominantly by post through general practices, to participate as either 'peer' or 'peer support facilitator' (PSF). Clusters (parish council areas) were randomly assigned to either group, 1:1, both groups and 1:1 or control interventions. Trained PSFs delivered the intervention over 8–12 months. Outcome assessors/investigators were masked to arm allocation. Primary end-point was HbA1c. Main factors were either 1:1 or group intervention. Analysis was by intention to treat (ITT) adjusting for baseline (ISRCTN66963621).

Results: Invitations were sent to 21,961. Participants (n=1,299) were consented across 130 clusters. The four arms were well matched; 1,035 (79.7%) completed the mid-point postal questionnaire and 1,064 (81.9%) had a final HbA1c. Mean baseline HbA1c was 57mmol/mol (7.4%) with no significant change. Systolic blood pressure was –2.3mm Hg (–4.0 to –0.6) among those allocated group peer support and –3.0mm Hg (–5.0 to –1.1) among those who attended group peer support at least once. There was no impact on other outcomes by ITT or in self-reported adherence or medications. Waist circumference was [–0.71 (–1.42 to –0.01) cm] among those attending at least once for group peer support.

Conclusions: We conclude that group diabetes peer support over 8–12 months was associated with a small improvement in blood pressure. Long-term benefits should be investigated.

Reconciling methodological approaches of survey and focus group

Muili Lawal explains how to use two research methodologies with different philosophical underpinnings

The aim of research, be it qualitative or quantitative is either to predict, describe or explain a phenomena and add to the body of knowledge within the context of a philosophical belief. Each study generates knowledge in line with a chosen paradigm, and uses appropriate data collection methods. Two such methods are surveys and focus groups, each of which will be chosen according to the aim of the research.

key words

- ▶ surveys
- ▶ focus groups
- ▶ research paradigms
- ▶ diabetes

Introduction

Diabetes represents a significant world health problem (World Health Organization 2006) and its incidence is increasing (Department of Health (DH) 2005). As a result, government policy supports and encourages patient self-management. This article will explore two methodological approaches that aim to elicit the attitude of patients with diabetes to self-management of their disease, and identify factors that may help them to develop positive self-care abilities.

Research paradigm

Research methodologies in qualitative and quantitative research are guided by a research paradigm. Guba and Lincoln (2005) identified four paradigms: positivism, post-positivism, critical theory and constructivism. Conversely, Crossan (2003) suggested only two broad categories: positivism and

post-positivism. Parahoo (2006) added interpretive, modernism and post-modernism to those identified by Crossan, but claimed that the two main paradigms in social and healthcare research are positivism and interpretivism. The debate is further confused by the fact that authors tend to categorise paradigms differently and that the post-modern movement assumption of 'no single truth' may suggest future paradigm controversies and new textual forms (Guba and Lincoln 2005).

Positivism and post-positivism

The philosophical paradigm, positivism, is the traditional scientific or quantitative approach, often referred to as the gold standard (Denzin and Lincoln 2005, Polit and Beck 2006, Parahoo 2006). A positivist researcher generally uses quantitative approaches to study phenomena of interest, while a post-positivist investigator will employ qualitative methods to describe and explore a phenomenon in depth (Crossan 2003). The tenets of positivism are standardised subjects, statistical analysis, and scientific explanation of cause and effect (Hammersley 1995). A typical example of this approach is the randomised controlled trial and the quasi experimental approach. In the positivist paradigm, effort is geared toward building scientific knowledge through objective, systematic observation and control.

Positivism assumes that reality is independent of human behaviour (Crossan 2003), whereas the non-positivist paradigm, generally used in qualitative research, uses phenomenological interview or ethnography, induction and analysis based on themes and concept. This approach may lead to subjectivity, and raise issues of transferability and reliability (Carolan 2003, Walliman 2005). However, a number of authors suggest that positivism may have disadvantages. Alick (2002), for example, attributed the increased use of inductive approaches to the failure of deductive methodologies, while Parahoo (2006) argued that positivists study human beings as inanimate objects and do not make allowances for human uniqueness and complexity.

The proponents of the post-positivist paradigm argue against rigid rules for enquiry methodology and one single approach to truth, embracing post-structuralism which challenges positivist assumptions (Travers 2001). According to Crossan (2003), in contrast to the positivist assumption that

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truth can only be established through generalisation and laws, the post-positivist paradigm offers another dimension to the research that acknowledges the uniqueness of human beings.

Mixed methodologies

Qualitative and quantitative research methods tend to be distinct to that particular paradigm. However, the concept of mixed methodologies is becoming viable, perhaps due to the emerging idea that research methods do not carry a completely fixed epistemological and ontological assumption (Bryman 2004). Similarly, Guba and Lincoln (2005) also suggested an interbreeding of paradigms, where two previously opposing theories are re-contextualised and inform each other. Such an approach can 'fill in the gaps' when one methodology cannot sufficiently answer the research question.

This is not without disadvantages, however. It has been argued that mixed methods research is not feasible because each methodology originates from a separate paradigm, and because qualitative and quantitative research has different epistemological assumptions (Bryman 2004). For example, undertaking a survey or focus group interview would be based on the epistemological assumption of the research rather than simply viewed as data collection tools. Guba (1985) argued that when mixed methods are used, each is used only superficially in a single paradigm. Bryman (2004) suggests that this approach could lead to inconsistent results.

Survey versus focus group approach

According to Masters *et al* (2006), the research approach to be used depends on the aim of the enquiry and the questions to be answered. A positivist epistemological assumption emphasises the pursuit of objective truth through investigation. Survey, as a form of positivist research, is informed by empiricism; the facts are said to speak for themselves, by presenting standardised information obtained through value-free methods (Polit and Beck 2006). However, Denzin and Lincoln (2005) and Travers (2001) have argued that this form of enquiry can not be value-free because the researcher introduces their epistemological assumption into the study. Therefore, regardless of

being a positivist paradigm, it is possible to influence the findings, based on the type of questions asked.

By comparison, a focus group is a systematic questioning of many people to obtain qualitative data. It originated from a non-positivist paradigm and uses an inductive approach (Babbie and Mouton 2001, Fontana and Fray 2005). In contrast to positivist epistemology, which assumes that the researcher can be separated from the object under study, the role of the facilitator presents a methodological issue as he or she can influence the direction of the group (Hand 2003, Carolan 2003, Marks and Yardley 2004). Thus, to improve rigour, appropriate facilitative skills and the use of reflexivity are essential (Morales and Kaitell 2001, Marks and Yardley 2004).

Sampling and ethical consideration

One purpose of positivist research is to generalise its findings to the population. To achieve this, the sample must represent the total population that meets the study criteria. To sample for a survey, systematic sampling, a form of probability sampling, will be used by picking every sixth name from a computer generated list of 600 names to arrive at a sample size of 100. This method offers, for example, every patient who meets the inclusion criteria an equal chance of being selected. Sample sizes are generally large to minimise bias.

A focus group uses a non-probabilistic sampling technique: a convenience sample. Gillham (2000) argued against accessible participants as a representative sample and cited the example of journalists who sometimes interview available subjects. Higginbottom (2004) also sees small, non-probabilistic sampling as a weakness of qualitative paradigm. Nevertheless, it collects in-depth information for the data and the intention is not to generalise the result to the entire population. As Crossan (2003) states, the post-positivist assumption relates to multiple reality, subjective and personal to the individual.

The ethical issues of significance for these approaches are honesty, informed consent, voluntary withdrawal and confidentiality.

Data collection method and nature of data

From a positivist point of view, it is possible to survey the diabetic patients' attitude to self-care management. The aim will be to obtain objective and

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quantifiable information uninfluenced by the researcher. Two data collection methodologies could be used: a reliable, sensitive and valid questionnaire based on literature review, piloting and the use of measurement scales such as the five point Likert scale (Table 1); or a focus group interview, using a question guide (Box 1) to collect in-depth information to explore patients' attitude towards self-care management.

Using open-ended questions in the focus group interview will give participants the opportunity to express their feelings. This descriptive study is capable of gathering qualitative data and to describe a phenomenon from the participants' points of view (Polit and Beck 2006). Ashby *et al* (2005) and Mansell *et al* (2004) state that the use of focus groups allows group discussion that may lead to in-depth information, while Babbie and Mouton (2001) argue that individual dominance, non-participants and group think can affect the quality of data collected in focus group interviews.

Table 1. Sample of survey questionnaire

Please tick your response	SA	A	N	D	SD
Health is wealth is a golden statement					
Self-care management is an important aspect of my care					
It is always possible to manage my diabetes through self-care effort					
I engage with self-care in order to conform with the diabetic group norm					
The healthcare professionals should take full responsibility for diabetic patients' care					
Strongly agree (SA), Agree (A), Neither agree nor disagree (N), Disagree (D), Strongly disagree (SD)					

Box 1. Examples of question guide for focus group discussion

- What is your perception about self-care management?
- What factors aid you to engage with self-care?
- What is your opinion about the role of healthcare professionals in diabetic management?

As Polgar and Thomas (2000) suggest, qualitative research approaches usually attempt to investigate personal understanding and therefore are concerned with interpretation rather than quantification. This is contrary to the positivist view which embraces verifiable truth but not belief. A survey approach, will produce objective, quantifiable data that can be replicated by following the same technique, but not in-depth data about participants' feelings toward self-care management. Thus, exploring human behaviours is outside the field of positivism (Crossan 2003) and would not be applicable for this study.

Data analysis

Positivists believe in objective reality and use deductive processes to study the phenomenon and lay emphasis on measurement, quantitative information and statistical analysis to seek generalisation (Polit and Beck 2006). On the other hand, Gerrish and Lacey (2006) argue that qualitative analysis is geared towards identifying themes, concepts or to develop theory.

Unlike quantitative data, which deal with numerical quantification, qualitative data consist of detailed description of events, situations or observed behaviour (Polit and Hungler 2001). Although analysis is seen as a major weakness of qualitative data (Higginbottom 2004), there are several ways to analyse the qualitative information, including thematic analysis and content analysis (Marks and Yardley 2004, Walliman 2005). Focus group data will therefore be analysed using thematic analysis.

According to Marks and Yardley (2004), thematic analysis is similar to content analysis but more exploratory, seeking themes rather than the frequency of occurrence of a data. Thematic analysis allows data to be organised and provides in-depth information about the subject under investigation. However, it may be difficult to demonstrate reliability of the data (Marks and Yardley 2004). Ashby, however, argues that it is possible to enhance reliability of the data by recording it before transcription and analysing the data. Gillham (2000) also suggested presenting a summary report of the focus group to the participants for validation. Whatever the argument, it is essential to think through how to demonstrate the reliability of the findings. As a result of this, the focus group interview data will be cross-checked with the participants.

Conclusion

Although there is a distinction between the aims of qualitative and quantitative paradigm, both are valuable depending on the aim of the study and the nature of data to be generated. Surveys tend to fit more conveniently into positivist research approaches, although they may be designed to generate qualitative and quantitative data, irrespective of underlying paradigms. On the other hand, focus groups are a naturalistic methodology that are only capable of gathering qualitative in-depth data. According to Crossan (2003), the weakness of the post-positivist approach strongly relates to researcher bias, lack of replication and generalisation. Denzin and Lincoln (2005) argued in favour of both paradigms and identified some contending issues in terms of ontological bases of all paradigms as the aim of the enquiry, nature of knowledge to be generated, method of achieving the aim and the rigour of the process.

Generally, paradigms should be seen as a guide to the method of study and Crossan (2003) argued that the philosophical distinction between quantitative and qualitative methodology is sometimes over-emphasised, with multiple paradigms commonly used. Travers (2001) also argued against being overwhelmed by a debate about methods driven by philosophy.

Therefore, for the purpose of this study, it is possible to use surveys in a positivist paradigm through a structured close-ended questionnaire. Alternatively, it is possible to use focus group interviews to collect descriptive in-depth information about participants' attitudes towards self-care.

The main difference is that each approach will address different aspects of the topic and produce different forms of data that may complement each other in terms of developing knowledge about their attitude ■

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Self-monitoring of blood glucose: making an economical decision

Self-monitoring of blood glucose represents the largest component of costs associated with glycaemic control in the UK. Muili Lawal discusses the clinical benefits and cost-effectiveness of this treatment in people with type 2 diabetes

Diabetes is a long-term condition that is becoming a growing global concern. The rising prevalence of diabetes in the UK and its impact on patient wellbeing have been raised in the *National Diabetes Audit* (Health and Social Care Information Centre, 2012) and by Diabetes UK (2012a).

Defined simply, diabetes refers to the presence of abnormal blood glucose levels which, if poorly managed, may lead to diabetes-related complications resulting in blindness and amputation (National Institute for Health and Care Excellence (NICE), 2011; World Health Organization (WHO), 2013). The goal of diabetes management is to maintain the patient's blood glucose levels within the normal range of 4–8 mmol/litre, and one of the approaches to improving glycaemic control is self-

monitoring of blood glucose (SMBG) (Canadian Agency for Drugs and Technologies in Health (CADTH), 2010; Diabetes UK, 2013).

This article will look at the current debate about balancing the economic cost of blood glucose monitoring with clinical need, particularly in the management of patients with type 2 diabetes.

Blood glucose monitoring

Blood glucose monitoring refers to measuring the level of glucose in the blood (Lawal, 2009). There are various ways to measure blood glucose levels, including urinalysis and glycosylated haemoglobin (Alexander et al, 2000). Evidence shows that the use of glucose meters is the most common and accurate method used by patients (Dougherty and Lister, 2008) (Figure 1).

According to Alexander et al (2000), blood glucose monitoring offers a simple and reliable method to monitor a patient's glycaemic control. Jansen's (2006) comparative study also suggests that SMBG is likely to be more effective than self-monitoring of urine glucose, which is often unacceptable to patients and also carries a time lag of what is accurately happening with the patient's glucose levels (Diabetes UK, 2012b; LeMone et al, 2008).

Maintaining tight glucose control

There is evidence to support the benefits of SMBG in maintaining tight glucose control in people with type 1 and type 2 diabetes who are on insulin therapy (Malanda et al, 2012; Diabetes UK, 2013). SMBG can help patients to adjust their insulin dosage accordingly and serve as a safety check if they are unwell or prone to hypoglycaemia or hyperglycaemia for any reason (e.g. vigorous exercise or diet). SMBG can also aid the adjustment of food intake, physical activity and/or medication in response to blood glucose test results (CADTH, 2010).

Hall (2013) recognizes that SMBG is beneficial to certain categories of type 2 diabetes, while NICE (2009) emphasizes the importance of effective blood glucose monitoring in reducing diabetes-related

complications. Additionally, SMBG is crucial to self-management of diabetes and is associated with reductions in long-term complications of diabetes (Diabetes UK, 2013).

Despite the benefits of SMBG, Hall (2013) and Diabetes UK (2013) suggest that patients do experience difficulties in accessing test strips for various reasons. For example, some patients are limited to only two testing strips per week. This suggests an economic undertone, which is further discussed later in the article.

Cost-effectiveness

The resource implications of diabetes for clinical commissioning groups and service providers are huge, and SMBG is an expensive form of diabetes care (Simon et al, 2008; Yeaw et al, 2012). The growth in the number of items and cost for blood

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Figure 1. Blood being placed on the test strip of a glucometer

LUCIE CARLIER

glucose monitoring agents and devices are summarized in *Table 1*.

SMBG represents the largest component of costs associated with blood glucose control in the UK, with the cost of test strips rising from £85 million to £118 million from 2001 to 2003 (Simon et al, 2008). Further evidence shows that the overall cost of blood glucose monitoring agents and devices represented 7.7% of the cost of prescribing in primary care in 2009/10 (NICE, 2011).

An economic analysis of SMBG conducted by Farmer et al (2009) suggests that SMBG increases health care costs and that its routine use does not appear to be cost-effective. A systematic review of 33 studies conducted by CADTH (2010) suggests that additional clinical and economic evidence is required to inform the use of SMBG in patients with type 2 diabetes. Simon et al (2008) also indicates that there is no convincing evidence to recommend routine SMBG for people with non-insulin treated type 2 diabetes.

Although prescribing routine SMBG is a debatable issue, particularly in non-insulin treated patients with type 2 diabetes (Simon et al, 2008; Lawal, 2009; CADTH, 2010; Malanda et al, 2012), its use can be recommended based on individual circumstances. In patients with type 2 diabetes, NICE (2009) recommends using SMBG on the following grounds:

- ▶ As an integral part of self-management education for newly diagnosed patients
- ▶ For patients who are on insulin therapy

- ▶ During intercurrent illness
- ▶ For patients who are treated with oral glucose-lowering medication
- ▶ To ensure safety during various daily activities, including driving.

Additionally, Diabetes UK (2013) state that patients' accessibility to test strips should be based on individual assessment, and that all options should be jointly explored by the patient and their clinician to ensure effective use of scarce resources.

Health systems under financial pressure

Economics and politics play a vital role in the health care delivery of a nation, and the UK is no exception. Lister (2005) and Baggott (2010) argue that the NHS, which is largely funded by national taxation, continues to face financial pressures due to rising public expectations, an ageing population and new clinical, pharmacological and information technologies. Importantly, SMBG is widely used by people with diabetes in countries with different funding systems. A nationwide study of non-institutionalized people in Norway found that approximately 70% of people with diabetes purchased their own test strips at an estimated annual cost of €446 (£370.51) per individual (Kjome et al, 2010).

Saltman and Cahn (2013) argue that restructuring health-care sectors in Europe to reduce unsustainable cost is inevitable and that it is vital for policymakers to minimize undesirable inequality. Davies et al (2000) also suggest that health care policy changes in

the UK cross party lines with discernible differences.

Notably, the latest reform by the coalition government has brought many changes into effect with the Health and Social Care Act 2012.

Since the birth of the NHS on 5 July 1948, its founding principle has been to improve health and prevent disease—not only to treat ill people (DH, 2004). Since then, patients in the UK have become more active, empowered and encouraged to take more control over their health (DH, 2008).

However, more needs to be done in relation to supporting patients who wish to use SMBG. According to the DH (2008), prevention will continue to be high on the health agenda, with the NHS promoting good health as opposed to treating ill health. This could serve as a justification of the policy of offering equitable access to test strips based on needs, treatment regimen or individual circumstances.

Access to glucose test strips

In 2012, Diabetes UK proposed that restrictions on the number of test strips being prescribed and a lack of choice of glucose meters seemed to be

driven by financial constraints. Diabetes UK (2012a) also found that difficulty in gaining access to test strips caused distress and anxiety to patients, thereby reducing their willingness to take responsibility for self-care.

In the following year, a survey conducted by Diabetes UK (2013) found that policies and guidance on prescribing test strips across the UK varies considerably in terms of content, format and the level of flexibility allowed in a patient's application. Notably, although most policies cover both type 1 and type 2 diabetes, the guidance varies more widely in type 2 diabetes management. For example, there are inconsistencies as to whether driving is taken into consideration and the way in which treatment regimes are grouped (Diabetes UK, 2013). The survey also found that there was an increase in the number of people with type 1 diabetes who have restricted access to test strips.

In response to the uneven distribution of test strips in the UK, Hall (2013) argued that the cost of effective SMBG amounts to less than the cost of treating diabetes-related complications.

Table 1. Items and net ingredient cost for blood glucose monitoring agents and devices

Financial year	Blood glucose monitoring items (millions)	Cost (millions)	Percentage change from previous year (%)
2005/6	5.6	£142.3	8.7
2006/7	5.7	£137.8	-3.1
2007/8	5.7	£133.1	-3.4
2008/9	5.7	£137.7	3.4
2009/10	5.9	£145.8	5.9
2010/11	6.0	£152.6	4.7
2011/12	6.1	£158.4	3.8

From: The Information Centre for Health and Social Care, 2012

Delivering evidence-based practice

Evidence-based practice is defined as clinically sound and cost effective care that provides the best outcome for patients (DH, 2013). The five domains of *The NHS Outcomes Framework 2013/14* focus on measuring health outcomes in order to improve clinical practice and ensure a positive patient experience (DH, 2012) (*Table 2*).

Although it can be argued that the resultant wastage from distributing test strips to all patients is unnecessary and an unacceptable practice when attempting to provide an economical and high quality health service to the entire population, evidence-based practice should be based on the delivery of high quality care. This means that considerations are made according to the individual needs and preferences of patients within the limit of the health budget.

Undoubtedly, there are situations where prescribing SMBG may not be appropriate. Examples include type 2 diabetes patients who are not on sulphonylureas or insulin. However, it remains important for the health professional to consider circumstances where there is a valid indication for SMBG in patients with type 2 diabetes who are not treated with insulin (*Case Study 1*).

Diabetes UK (2013) argued against blanket policies of prescribing test strips or glucose meters, and stated that patients with type 2 diabetes who find SMBG useful should be provided with clinical support to do so regardless of whether they are treated with insulin.

Conclusions

The rising prevalence of type 2 diabetes and the resultant economic cost of SMBG can be challenging. While routine SMBG may not be economically justifiable in non-insulin treated people with type 2 diabetes whose hypoglycaemic risk is low, individuals who are taking medication with some hypoglycaemic risk, such as John in *Case Study 1*, should not be excluded from using SMBG as their medical condition is not static. Therefore, prescribing SMBG

for individuals with type 2 diabetes should be based on individual need in order to minimize the impact of and effectively manage the patient's diabetes. To conclude, evidence-based economic evaluations of SBGM in patients with type 2 diabetes requires more attention.

Conflict of interest: none declared.

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Table 2. Domains of the NHS Outcomes Framework 2013/14

1	Preventing people from dying prematurely
2	Enhancing quality of life for people with long-term conditions
3	Helping people to recover from episodes of ill health or following injury
4	Ensuring that people have a positive experience of care
5	Treating and caring for people in a safe environment, and protecting them from avoidable harm

From: Department of Health, 2012

CASE STUDY I

John is a 45-year-old businessman with a 3-year history of type 2 diabetes which is maintained on diet, exercise, metformin and gliclazide tablets. He is overweight, with a body mass index of 29 kg/m² and a waist circumference of 102 cm. John's glycaemic control is poor. His recent blood glucose level was 22 mmol/litre, with a HbA_{1c} reading of 77 mmol/mol (9.2%).

John has a family history of diabetes and both his parents are living with chronic vascular complications from their diabetes.

What should you consider when prescribing self-monitoring of blood glucose?

- ▶ John meets the NICE (2009) criteria to access blood glucose meters. Sulphonylureas such as chlorpropamide, glibenclamide or gliclazide work by stimulating the cells in the pancreas to produce more insulin. A possible side effect is hypoglycaemia (Joint Formulary Committee, 2013). John's risk of hypoglycaemia may be reduced through self-monitoring of blood glucose (SMBG).
- ▶ Diabetes UK (2012a) recommends that SMBG should be made available to patients receiving sulphonylurea and prandial glucose regulators owing to the potential risk of hypoglycaemia.

Managing risk factors:

- ▶ NICE (2011) suggests that people with type 2 diabetes often have multiple risk factors and are at a higher risk of complications such as retinopathy and neuropathy.
- ▶ Due to his poor glycaemic control, John has multiple risk factors and is prone to complications. NICE (2011) guidelines state that the cause of type 2 diabetes is more complex than that of type 1 diabetes, and management is not always easier.

Other considerations:

- ▶ NICE (2011) stresses the importance of self-monitoring and education for people with type 2 diabetes because of the life changes involved, complexities of management and the side effects of medication. Being a busy man, John may enjoy greater autonomy and better glycaemic control through SMBG.
- ▶ Although the exact role of SMBG for people with type 2 diabetes is unclear, Diabetes UK (2013) suggests that many health professionals support its use because self-monitoring empowers the patient and aids the patient's satisfaction
- ▶ Thus, measures to lessen complications and aid prompt management such as offering an adequate number of test strips to John may enhance his quality of life.

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KEY POINTS

- Blood glucose monitoring is a simple, common and reliable method to assess the glycaemic control of patients with diabetes
- Effective blood glucose monitoring helps to reduce the risk of long-term complications of diabetes
- Blood glucose monitoring has resource implications for NHS commissioners and service providers
- Decisions to offer self-monitoring of blood glucose and choice of testing equipment should be based on individual need and circumstance
- Health professionals play a pivotal role in ensuring effective, patient-focused blood glucose monitoring

Yeaw J, Lee WC, Aagren M, Christensen T (2012) Cost of self-monitoring of blood glucose in the United States among patients on an insulin regimen for diabetes. *J Manag Care Pharm* 18(1): 21–32

Conclusion: What emerged from the study is a substantive theory in which absence of information regarding the menopause and its impact on Type 1 diabetes was identified as the main problem facing women with Type 1 diabetes during their menopausal transition. The findings may enable practitioners to identify the types of information, advice and support that should be made available to these women and contributes to the limited knowledge base currently available. The findings indicate also that further research into this under-studied but important area of diabetes care is required.

P251

Barriers associated with uptake of diabetes multidisciplinary group education: a survey of patients' view in a PCT in southeast England

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Aims: The paradigm shift in management of diabetes from the basic disease model of the 1930s which centred exclusively on treatment by healthcare professionals to the recent integrated healthcare approach involving the patients (Diabetes UK 2008) stresses the importance of patient empowerment. The aim of this study was to explore the barriers and facilitators to patient attendance in group education designed to promote self-care.

Method: A questionnaire survey which contains both closed and open-ended questions was administered to elicit data from 207 (105 non-attenders and 102 attenders) newly diagnosed diabetes patients who were referred for structured patient education.

Results: The patient's views were analysed by using SPSS software and the qualitative comments were categorised into themes. In comparison to 94 (45 per cent) attenders, 35 (17 per cent) non-attenders either strongly agree or agree that attending the session is important to develop self-care ability. This result shows a significant difference among the two groups (0.000, $P < 0.05$). A substantial number of respondents among the non-attenders ($n = 43$, 21 per cent) did not have flexible working arrangements compared with the attenders ($n = 24$, 12 per cent). Although more than half of the total number of respondents have a family history of diabetes ($n = 112$, 54 per cent), the majority of them are non-attenders ($n = 73$, 35 per cent) showing a significant difference (0.000, $P < 0.05$) between the two groups. Key themes from qualitative data included personal difficulties, lack of motivation and healthcare practitioners' influence.

Conclusion: The results were consistent with the findings of previous studies and suggest that patients' perceived benefits of structured education may influence attendance.

Acknowledgements: J Magill-Cuerden, T Olden, D Sookhoo, J Durrant, A Debowy.

P252

Successful weight reducers in the workplace: experiences of men and women who participated in the Prosiect Sir Gâr lifestyle intervention programme

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Aim: The objective of this qualitative study was to evaluate participants' experiences associated with maintained weight loss at 6 months following the Prosiect Sir Gâr (the Carmarthenshire project) 10-year cardiovascular disease (CVD) risk assessment and lifestyle intervention programme.

Methods: The lifestyle intervention programme (LIP) consisted of eight 75min group sessions, delivered once weekly by a dietitian (seven sessions) and an exercise specialist (one session) with an emphasis on behaviour change. At 2 weeks post LIP 1 h semi-structured face-to-face interviews were conducted and body weight data were tracked over 6 months. Eight successful weight reducers (defined as an individual who had lost and sustained ≥ 5 per cent body weight over 6 months) were targeted for thematic analysis by applying the constant comparison method. Four male blue collar workers and four female health workers aged 40–57 years with a body mass index range of 30–39 kg/m² took part in the study.

Results: All participants reported a 'change of mind' regarding their attitude toward weight loss. Some attributed this to a 'wake-up call' following the CVD risk assessment; others believed it to be a more gradual process during LIP. Accepting lapses of undesirable behaviours as normal was a common theme in both genders, as too was a focus and commitment to goals. Both genders described the group environment of LIP as humorous at times, yet supportive.

Conclusions: These findings suggest that in successful weight reducers a combination of health risk assessment and lifestyle intervention programme may have added value in evoking motivation to commit to weight management.

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Do we care about the road safety of people living with diabetes?

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Aim: Currently there are 2.8 million people in the UK living with diabetes. Several studies have demonstrated a link between hypoglycaemia and driving mishaps. The aim of the study was to assess patient awareness of recently imposed changes to driving regulations relevant to diabetes.

Methods: A 37-point anonymous structured questionnaire was distributed amongst 47 registered drivers attending a secondary care diabetes clinic in Birmingham. Information concerning diabetes treatment and knowledge of Driver and Vehicle Licensing Agency (DVLA) regulations, including recognition of hypoglycaemic episodes, in addition to general precautions regarding hypoglycaemia, was sought.

Results: Despite finding that 72.3 per cent of participants had received information concerning DVLA regulations and advised precautions, the present study showed a surprising lack of awareness of details important for safe driving. Amongst those surveyed, only 73.3 per cent were always aware of when they were becoming hypoglycaemic, an absolute licence stipulation according to DVLA regulations. With regard to advised precautions, 29.8 per cent of patients were unable to identify a capillary blood glucose level of 5 mmol/l or greater as a safe level for driving. Interestingly, only 14.9 per cent of patients understood the recommendation of a 45min wait after achieving this recommended safe capillary blood glucose level.

Conclusions: Whilst the majority of people living with diabetes have received information concerning the driving regulations, there is a worrying lack of understanding of safe driving practices, indicating that

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Quality assurance across the oceans: assessing the quality of delivery of structured self-management education using a virtual approach from the UK to Gibraltar and Australia

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Aim: To assess the feasibility of 'virtual' quality assurance processes in the delivery of the DESMOND module for those with newly diagnosed Type 2 diabetes in Western Australia and Gibraltar.

Methods: Following the training of 14 educators (Australia 12, Gibraltar two), a system of assessing educator delivery was planned and delivered by using video, online viewing of recordings and feedback by Skype video calls. Adaptation of the current face-to-face assessment was reviewed as the study progressed. The views/experiences of educators and assessors were assessed by interviews.

Results: Nine of 14 virtual 'mentoring' (initial assessment) visits were completed. Two of 14 educators (from Gibraltar) required a face-to-face 'assessment' (second assessment) due to technical difficulties. Five of 14 completed a virtual (second) 'assessment' process and were accredited as DESMOND educators within a year from initial training. To support the importance of assessing the quality of the actual delivery of a DESMOND module across the oceans, an alternative approach to face-to-face observation was required. Our study demonstrated that virtual quality development processes are possible and have benefits for being more objective/focused for both the assessor and the educator. The challenges appear to be related to recording of delivery, downloading onto a 'globally accessible' secure website and ensuring a reliable internet connection to both review the recordings and undertake feedback. This is a system worth considering further for areas where access by assessors is either costly and/or difficult to arrange for other reasons and a UK based pilot is being developed.

Acknowledgements: Jan Durrant, Community Lead/Diabetes Specialist Nurse, King Edward VII Hospital, Windsor and Anne Debony, Community Diabetes Co-ordinator, Berkshire East PCT Diabetes Centre, King Edward VII Hospital, Windsor for their support in practice.

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Telephone interviews of patients on factors affecting attendance in multidisciplinary diabetes education centres

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Background: Missed hospital appointments remain a national and global problem. DH (2009) states that 57,083 outpatients referrals were missed in South East Coast Strategic Health Authority in the third quarter of 2008. In a similar way, one of the challenges associated with patients' multidisciplinary education programmes is the rate of non-attendance.

Aim: The aim of this study was to explore the barriers associated with non-attendance in group education designed to promote self-care.

Methods: A qualitative approach was adopted using telephone interviews (n = 24) of newly diagnosed Type 2 diabetes patients who failed to attend their appointments following referral from the GP surgeries. Thematic analysis was used to analyse the data.

Results: The findings yielded two main themes: barriers associated with the patient and barriers related to service delivery. The respondents identified various personal reasons such as work-related barriers, childcare problems, forgetfulness, bad weather, away on holiday, ill-health, lack of interest and inconvenient date, location and time of the session. Some organisational issues such as lack of clarity in the process of invitation, a rigid appointment system and administrative errors were also identified. Whilst some of the reasons require a simple solution, it is difficult to mitigate some of these barriers.

Conclusions: The results were consistent with the findings of some previous studies and suggest that barriers to attendance are multifactorial; therefore, interventions will vary and be diverse.

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First impressions: implementation of insulin passports in East London

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Aims: Insulin administration is an integral component of self-management for people with diabetes. However, errors in prescription, administration and the associated clinical risks were highlighted by the NPSA. In order to reduce the incidence of errors the NPSA (2011) recommended the introduction of insulin passports. East London is one of the most ethnically diverse regions in England. Due to its demographic profile and diabetes health outcome challenges, collaboration was sought in implementing the use of insulin passports. The primary aims of collaboration were to unify implementation and audit the experiences of healthcare professionals in order to refine further implementation.

Methods: Three diabetes care providers in East London collaborated in order to assess feasibility and agree an implementation strategy and evaluation process. Following implementation, questionnaires were circulated and individual interviews were conducted in order to establish acceptability and usability of insulin passports.

Findings: Analysis of surveys and interviews showed predominantly positive feedback following implementation of insulin passports. Usability by non-English speakers was identified as a key factor. However, concerns were identified by the use of the word 'passport' as a barrier to acceptance by some patients due to misinterpretation of its meaning. Time, work constraints, potential increase in clinical risks due to multiple forms, uncertainty about ownership and accountability for ongoing documentation were other concerns expressed.

Conclusion: Conducting this review has provided an insight into the practicalities and clinical implications of insulin passports. Due to the infancy of this implementation phase, a further review is planned which will include auditing of clinical incidents.

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Experiences of preparation for pregnancy in women with pre-gestational diabetes: a systematic review of qualitative studies

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Aim: Many women with diabetes do not seek preconception advice. We aimed to synthesise available qualitative evidence of women's and healthcare professionals' experience of preparation for pregnancy and preconception care.

Incorporating psychosocial characteristics into cost-effectiveness modelling of Type 1 diabetes

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To incorporate psychosocial and behavioural patient characteristics into an economic model of Type 1 diabetes in order to account for heterogeneity in cost-effectiveness outcomes.

Methods: Patient behaviour is linked to a long-term patient-level decision model of Type 1 diabetes to evaluate the cost-effectiveness of Dose Adjustment for Normal Eating (DAFNE) educational intervention. Most cost-effectiveness models of Type 1 diabetes have a clinical rather than behavioural focus; they model the progression of diabetes and its complications with clinical and socio-demographic characteristics as their inputs. This study comprises a new approach: variation in patients' attitudes, beliefs and self-care behaviours is modelled to construct composite behavioural inputs for predicting outcomes of clinical markers (HbA1c) and the frequency of acute diabetic complications such as hypoglycaemia.

Results: The behaviour-focused model allows estimation of change in patients' self-care behaviours following DAFNE, and direct estimation of the cost-effectiveness of this behaviour change. The model has the ability to aid clinical decision making by predicting long-term costs and outcomes of patients with Type 1 diabetes from their baseline psychosocial and demographic characteristics. It also allows for prediction of the types of patients likely to need follow-up support following the DAFNE course and can help inform the type of support required.

Conclusion: The novel approach to integrating psychosocial and economic modelling demonstrates potential for informing clinical decision making by identifying those patients likely to have positive outcomes from the DAFNE educational intervention and those patients who might require follow-up support.

Narrowly explored phenomenon: Identifying ways to address the challenges of non-attendance in diabetes education centres

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Background: The problem of non-attendance in hospital continues to receive increasing attention from healthcare professionals, policymakers and media. Several interventions have proved to ease the problem, e.g. telephone and sending email reminders. Nevertheless, this problem of enquiry is still problematic and it remains a huge financial loss to the NHS.

Aims: The aims were to identify the reasons why some patients do not attend diabetes structured patient education and explore the drivers for increasing attendance.

Method: A twofold approach to data collection was undertaken. A focus group study of health professionals delivering the education and a mailed questionnaire survey of defaulted patients were used.

Results: The findings of the focus group interview indicated that the practitioners agreed on the need for an improved appointment system,

better resources such as more secretarial support to follow up cases and offering different times of attendance to the patients. For the second phase, 70 respondents (67.3 per cent) stated that other sources of information such as the internet are adequate. Almost half, 50 (46.7 per cent) believed that their diabetes was mild and they did not require additional information. Although the education was offered in the morning, 32 (32 per cent) preferred evening, 28 (28 per cent) preferred afternoon and 17 per cent preferred weekend. The questionnaire results suggested that paying more attention to a flexible choice of time and giving additional information during referral may further enhance uptake of group education.

Conclusion: Tackling non-attendance has been extremely difficult and this study identified some interventions to break down the barriers of non-attendance.

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Implementing a community-based diabetes prevention programme

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Aims: To provide a comprehensive community-based diabetes prevention programme in a rural setting.

Methods: All members of the primary care team carried out Findrisk [1] assessments. Those at high risk of developing Type 2 diabetes were referred to the diabetes prevention team for one-to-one intensive counselling over six sessions. Those found to be at moderate or high risk were offered the 'Walk Away from Diabetes' programme developed by the DESMOND organisation. This is a 3-h group session offering lifestyle counselling and education to support behaviour change.

Results: From January 2010 to October 2010, 125 people have taken part in the Walk Away programme and 44 in the intensive counselling. A telephone follow-up of the Walk Away participants found that 48 per cent of those surveyed were reaching the recommended 30 min of exercise on most days of the week 5–9 months later.

Conclusion: Feedback obtained after the sessions would support the continued use of this programme. Using both the one-on-one sessions and the group work enables us to focus the high cost intervention on those at most risk while providing a sound educational programme for those at a lesser risk.

Reference: [1] Lindström J & Tuomilehto J (2003). The diabetes risk score: a practical tool to predict Type 2 diabetes risk. *Diabetes Care* 2003; 26:725–731.

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Patients' experiences of, views about and perceived needs for support when implementing flexible intensive insulin treatment: a qualitative longitudinal study

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Aims: Flexible intensive insulin treatment (FIIT), involving multiple daily injections, is increasingly used in the management of Type 1

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Ketone education: at diagnosis and beyond

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Refer to Oral number A41.

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Audit on driving awareness in patients with diabetes

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Aim: To find out patients awareness regarding diabetes and driving. Reason for choosing this audit: diabetes carries similar risk of accident as epilepsy (relative risk 1.23–1.24). Hypoglycaemia and decreased visual acuity can impair the drivers ability to drive and increases the risk of accidents.

Methods and patients selection: Patients on insulin, exenatide ± oral anti diabetic medications were given the questionnaire in the OP clinic. Total number of patients participated in the audit was 50. **Results:** Only 43(85%) patients have informed DVLA regarding their diabetes. 20 out of 50 patients gets frequent hypoglycaemia. 42 patients have 3 years licence. Nearly half of them do not check their blood sugars before driving. In managing hypoglycaemia while driving, only 20 patients (40%) know how to manage appropriately. Only 80% of patients carry some form of carbohydrates with them. Unfortunately only 23 patients (46%) have been told regarding driving and diabetes by a healthcare professional. Only 3 patients (6%) have received written information about driving and diabetes. **Conclusions and comments:** From this audit, we have found that new patients with Type 1 and Type 2 were not given much needed and important informations regarding diabetes and driving. As a healthcare professional (includes doctors, diabetic nurse specialists and GP's) it is our duty to inform all the patients with diabetes about driving. In our trust we have formulated information leaflet about diabetes and driving which will be given to all new patients with diabetes.

P261

Structured education in Type 1 diabetes: a five year audit of a locally developed education programme for people with Type 1 diabetes

J Jackson and S Faulkner

District Diabetes Centre, District General Hospital, Eastbourne, UK

Aim: To determine whether people with Type 1 diabetes participating in an intensive structured education programme benefit both quantitatively and qualitatively.

Methods: SADIE (Skills for Adjusting Diet and Insulin in East Sussex) was first delivered in 2004 and by May 2009 64 patients had completed the full SADIE programme. The programme is based on participants attending an individual appointment prior to the start of the course followed by five consecutive Thursdays, each lasting six hours. Post course, each participant receives a follow up joint appointment with the Diabetes Specialist Nurse (DSN) and the Diabetes Specialist Dietitian (DSD) at three months, six months and one year. SADIE educators are supported by the national Diabetes Education Network (DEN) and have audited according to DEN's guidance. NICE recommends audit as an integral part of structured

education and in April 2009 SADIE data was audited to examine the changes in HbA1c, body weight and PAID score (Problems and Associated Issues in Diabetes).

Results: 64 patients completed SADIE to the end of the five days. Of this number 12 patients were lost to either non attendance or moving away. Statistical significance was assessed using the paired t-test HbA1c: Pre SADIE, ranged from 6.0–11.5% and post SADIE 6.1–11.7, statistically significant $p < 0.001$ Weight changes: Pre SADIE, mean weight of 74.3 kg and post SADIE mean weight of 74.2 kg no statistical significance PAID scores: Pre SADIE 27/80 and Post SADIE 11/80, statistically significant. $p < 0.05$

Conclusion: The SADIE approach to supporting people with Type 1 diabetes is conducive to both a reduction in HbA1c and an improvement in individual's quality of life.

P262

Implementation of diabetes education policy in a PCT in South East of England: exploring barriers and prospects

M Lawal and J Maggil-Cuerden

Faculty of Health and Human Sciences, Slough Campus, Thames Valley University, London, UK

Background: The national policy and guidance, for example, the National Service Framework for diabetes and NICE (2009) emphasises patient education and empowerment (DH 2001, NICE 2009). However, implementation of policy in the context of healthcare delivery may be challenging at times and the delivery of multidisciplinary education is not an exception. A major challenge to be addressed in this study is the degree of non-attendance in diabetes education clinics.

Objective: To explore practitioners' views about causes of non-attendance and identify ways to reduce some of the barriers to advancing government policy of education for all people with diabetes.

Method: A qualitative approach was adopted using a focus group interview ($n = 7$) and semi-structured individual interviews ($n = 10$). It involves Diabetes Specialist Nurses, Podiatrists and Dieticians from four localities of a PCT in the South East of England. The 90 minute focus group was audio-taped, recorded on a flip chat by the moderator and a field note kept by the researcher. Thematic analysis was used to analyse the data. **Findings:** six main themes emerged (1) Perceptions of patients about their health and the benefits of education (2) Inappropriate referral systems and a rigid appointment system (3) Insufficient resources (4) Increased patient responsibility (5) Patient life-style reasons such as, lack of time, feelings about group education session and (6) effect of cultural differences.

Conclusions: The findings indicated that there is a need for improvement in the appointment system, better resources and offering more choice to the patients. Also each locality needs to consider the cultural background of their patient. The authors acknowledge Jan Durra, Community Lead/Diabetes Specialist Nurse, King Edward VII Hospital, Windsor and Sat Nagra, Diabetes Specialist Nurse, Up Hospital, Slough for their support.

Ethical clearance was obtained from Berkshire Research Ethics Committee, Reading (REC reference 08/H0505/73).

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Non-attendance at diabetes education centres

Published: 25 April 2012

Muili Lawal, Senior Lecturer at University of West London, shares the findings of his study on non-attendance in diabetes education centres

Hospital non-attendance has been a recognised problem for a long time. To show the magnitude of the problem, nowadays it is common for health workers to display the number of failed appointments on the walls in casualty and other clinics.

Background

The paradigm shift in management of diabetes has moved from the basic disease model of the 1930s, which centred exclusively on treatment by health care professionals. Today, there is an integrated health care approach involving the patients (Diabetes UK, 2008), which stresses the importance of patient empowerment. Standard 3 of the National Service Framework for diabetes emphasises patient education and empowerment (DH, 2001).

Aims

The aim of this study was to explore the barriers and facilitators to patient attendance in group education designed to promote self-care.

Method

A questionnaire, which contained both closed and open ended questions, was administered to elicit data from 207 newly-diagnosed diabetes patients who were referred for structured patient education. The patients were made up of 105 non-attendees and 102 attendees.

Results

The patients' views were analysed by using SPSS software and the qualitative comments were categorised into themes. In comparison to 94 (92 per cent) defaulters, 35 (33 per cent) patients who attended the session either strongly agreed or agreed that attending the session was important to develop the ability to self-care. The results show a significant difference among the two groups ($.000, p < 0.05$). A substantial number of respondents among the non-attendees $n=43$ (41 per cent) did not have flexible working arrangements compared to the attendees ($n=24$, 24 per cent).

Although more than half of the total number of respondents have family history of diabetes ($n=112$, 54 per cent), the majority were non-attendees ($n=73$, 65 per cent) showing a significant difference ($.000, p < 0.05$) among the two groups. Key themes from qualitative data included personal difficulties, lack of motivation and health care practitioners' influence.

Conclusion

The results were consistent with the findings of previous studies and suggest that the way an individual perceives the nature of diabetes and the proposed benefits of structured patient education does influence attendance.

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Non-attendance in diabetes education clinics

Published: 27 October 2010

Newsletter Editor Muili Lawal, Senior Lecturer at Thames Valley University, London, reveals his study to explore barriers associated with patient uptake of diabetes education. The postal of the study was exhibited at the Diabetes UK conference in Liverpool in November 2009 and was published in Diabetic Medicine's 2010 conference supplement.

Background

National policy and guidance, for example, the National Service Framework for Diabetes and NICI (2009), emphasises patient education and empowerment (DH 2001, NICE 2009). However, implementation of policy in the context of health care delivery may be challenging at times and the delivery of multi-disciplinary education is not an exception. A major challenge to be addressed in this study is the degree of non-attendance in diabetes education clinics.

Objective

To explore practitioners' views about causes of non-attendance and identify ways to reduce some of the barriers to advancing government policy of education for all people with diabetes.

Method

A qualitative approach was adopted using a focus group interview (n=7) and semi-structured individual interviews (n=3). It involved diabetes specialist nurses, podiatrists and dieticians in four localities of a PCT in the South East of England. The focus group of 90 minutes duration was recorded on a tape, facilitated by a moderator and the interviewer wrote a field note. Thematic analysis was used to analyse the data.

Findings

Five main themes emerged:

1. perceptions of patients about their health and the benefits of education
2. inappropriate referral systems and a rigid appointment system
3. insufficient resources
4. increased patient responsibility
5. patient lifestyle reasons such as lack of time, feelings about group education session and cultural background.

Conclusions

The findings indicated that the practitioners agreed on the need for an improved appointment system, better resources such as more secretarial support to follow-up cases and offering more choice to the patients. Also, each locality will consider the cultural needs and background of their patient. However, while some participants felt that non-attendance should attract a sanction, suc

as a fine, others disagreed. Another point of disagreement identified by the findings was to display shocking pictures of complications to send serious messages to the patient as a way to alter their perception. These areas of disagreement require further exploration.

Acknowledgments

The author wishes to acknowledge Jan Durrant, Community Lead/Diabetes Specialist Nurse, King Edward V11 Hospital, Windsor, and Sat Nagra, Diabetes Specialist Nurse, Upton Hospital, Slough, for their support.

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Glasgow

Diabetes: a guide to glucose meters

Muili Lawal, Senior Lecturer in Adult Health, Faculty of Health and Human Sciences, Thames Valley University

Diabetes is a growing global concern and careful monitoring of blood sugar levels is essential in diabetes care (Lawal, 2008). Despite the high prevalence of diabetes, it is often detected during routine medical investigation. Diabetes UK (2008a) states that 2.3 million people are diagnosed with diabetes in the UK and more than half a million also have diabetes without knowing. According to Diabetes UK (2008a), this poses a serious health challenges, therefore, awareness and prevention are crucial to avoid a future health crisis. The Medical Research Council Epidemiology Unit (2004) states that the rising prevalence of diabetes and its associated complications in some patients when they are diagnosed presents a major health challenge. Therefore, as diabetes is a serious long-term medical condition, it requires prompt diagnosis and regular monitoring to assess the effectiveness of treatment to prevent complications.

Standard 10 of the National Service Framework (NSF) for diabetes focuses on reducing the risk of long-term complications and blood glucose monitoring is essential to achieve this standard (Department of Health (DH), 2001). According to Dougherty and Lister (2008), regular blood glucose monitoring lowers the risk of long-term complications in diabetes. Similarly, Clement et al (2004) argue that a well-controlled glucose in the hospital environment has potential to reduce the mortality and morbidity rate, and improve the healthcare outcomes. The National Institute for Clinical Excellence (NICE) (2002) emphasizes the importance of effective blood glucose monitoring and states that lack of good glucose control increases the risk of developing diabetic complications such as nephropathy and retinopathy. Regardless of the benefits of blood glucose estimation, a study of nurses' rationale for blood glucose monitoring in critical care identified some knowledge gaps such as the normal blood glucose level; this has implications for glucose test and care management (Crosser and McDowell, 2008).

Box 1. Factors affecting sugar level readings

- Timing of meals
- Fasting, e.g. Muslim during Ramadan period
- Drugs, e.g. corticosteroids
- Underlying disease
- Hyperlipaemia.

Abstract

Standards 4 and 5 of the National Service Framework for diabetes put an emphasis on blood glucose control. Among other things, the two standards aim to improve the care of patients with diabetes by facilitating optimum glycaemic control. No doubt, blood glucose monitoring plays an important role in the control of blood sugar level. It helps to identify new cases, detect abnormal values, minimize long-term complications and promotes the quality of life for patients. This article illustrates the assessment, planning, implementation and evaluation of glucose estimation. The aim is to inform all members of the multi-professional diabetes team about effective glucose estimation, particularly those who have responsibility for day-to-day monitoring of blood glucose levels.

Key words

- Diabetes mellitus ■ Blood sugar monitoring
- Glucose estimation ■ Glucose meters ■ Clinical skills.

Blood glucose monitoring

Blood glucose monitoring is the measurement of blood glucose level in the body and it is an essential aspect of diabetes care. Accurate blood glucose monitoring is the key to identifying that blood glucose levels are within normal range. A normal blood glucose level is between 3.5 – 8mmol/litre (63 – 144mg/100ml) (Waugh and Grant,

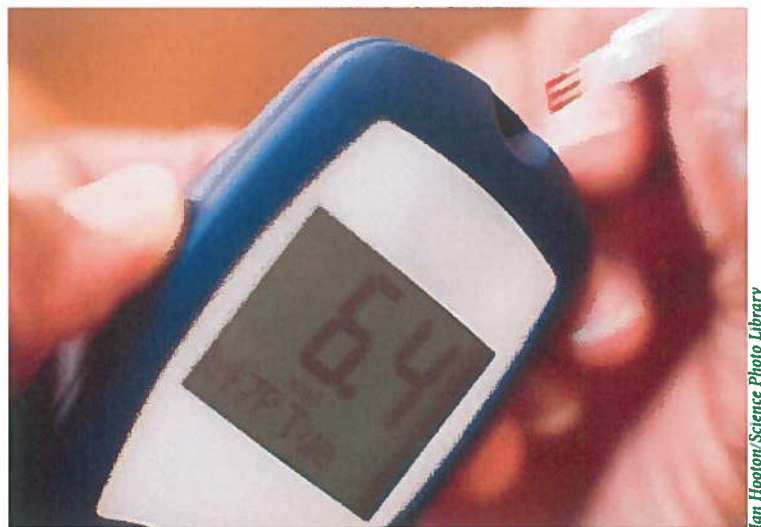


Figure 1: Inserting the strip into the meter

Ian Hooton/Science Photo Library

2006). Jamieson et al (2007) state that the target for people affected by diabetes is a pre-prandial level of 4-6mmol/l (before meal) and a maximum of 2 hours post-prandial level of 10mmol/l (after meal). They also added that the acceptable level for patients with long-standing diabetes may vary slightly and the interpretation of results may be affected by other problems (*Box 1*). Alexander et al (2006) identify that some patients with unstable blood glucose levels may require continuous monitoring by inserting a sensor under the abdominal skin, but for routine monitoring the recommended frequency would be four times a day. Wallymahmed (2007) suggests before each meal and before going to bed. However, it is recommended that the patient's GP would identify the required frequency of testing in the patient's record.

The indications for measuring blood glucose levels include assessing the level of glucose in the blood to ascertain that it is within the normal range, pre- and post-operatively and in diabetes emergencies such as hypoglycaemia (see *Box 2*).

The levels of glucose in the blood can be monitored by urinalysis, blood glucose monitoring and glycosylated haemoglobin (Alexander et al, 2006). Whatever the

clinical procedure employed, the individual is personally responsible for their practice. Therefore, it is important for the practitioner carrying out the monitoring to be competent in performing this procedure before undertaking it (Nursing and Midwifery Council (NMC), 2008). In practice, glucose is monitored by using urine or a blood sample.

Methods of glucose monitoring

Urine testing

This simple procedure is often performed during routine admission and it involves putting a test strip in the urine for a few seconds and comparing the colour of the strip with the chart on the container of the strip and recording it on an appropriate chart (Diabetes UK, 2008b; Alexander et al, 2006). Urine testing is a non-invasive technique and is used in clinical practice to detect the presence of glucose, ketones or protein in case of suspected renal complications of diabetes mellitus. However, it is not an accurate method because a positive result only indicates the current level and delayed micturition may give rise to a high glucose level. Similarly, it cannot detect hypoglycaemia (Alexander et al, 2006). Diabetes UK (2008b) argues that the urine of people with low renal threshold for glucose may contain glucose at lower levels.

Haemoglobin A1c (HbA1c)

The NICE (2002) guideline recommends measurement of Hb1Ac at every 2- 6 monthly intervals and sets a target level of 6.5 – 7.5 %.

A glycosylated haemoglobin test measures the amount of glucose bound onto haemoglobin, and is used to monitor glycaemic control. It gives an indication of the blood glucose level for a period of 8-12 weeks. The normal HbA1c is 4-6% and a level above 7% increase the risk of diabetes complications (Marie and Whitaker, 2004). This is an effective laboratory test but it is more expensive than a urine and blood glucose monitoring test.

Blood glucose monitoring

Measuring blood glucose level shows how the blood is controlling glucose metabolism. In comparison to urine tests, the use of glucose meters to measure blood glucose level is more accurate and indicates both low and high level (Dougherty and Lister, 2008). This is the commonest method of testing blood glucose levels and often done at the patient's bedside. This technique also allows competent people to measure their blood glucose at home. It is important to use the correct equipment and obtain accurate readings and staff should receive appropriate training in both the theoretical and practical aspects of blood glucose monitoring. The issue of appropriate training is emphasized by NICE (2002) as blood glucose testing must conform to safety standards. There are various blood glucose monitoring devices available, some of which have computer software packages that offer the benefit of monitoring the trends in blood

Box 2. Indications

- For initial diagnosis of diabetes.
- Monitor patients receiving insulin or hypoglycaemic drugs to adjust the treatment.
- To regularly assess patients with metabolic disorders e.g. hyperinsulinaemia
- To detect abnormal levels -hypoglycaemia, hyperglycaemia and ketoacidosis
- Assess suitability of diabetic patients for surgery and to monitor blood glucose level post-operatively
- In pregnancy, it helps to diagnose gestational diabetes
- Identify and monitor changes in blood sugar level of a known diabetic patient particularly during illness.

Box 3. Equipment

- Tray for equipment
- Finger pricking device such as lancets
- Blood glucose meter
- Test strips
- Control solution
- Disposable gloves
- Piece of gauze
- Patient documentation
- Sharp disposal bin
- Container for soiled material

glucose levels. The procedure may be different depending on the type of monitor used, and staff must always read the product manual and follow hospital regulations. The quality control testing should be done before using the meter for the first time or using a test strip from a new container. The procedure for blood sugar measurement requires assessment, planning, implementation and evaluation (see *Table 1*).

The paradigm shift in management of diabetes from the basic disease model of the 1930s which centred exclusively on treatment by healthcare professionals to the recent integrated care approach involving the patients (Diabetes UK, 2008c) stress the importance of patient empowerment. Standard 3 of the NSF for diabetes emphasizes patient education for self-monitoring and patient empowerment (DH, 2001). According to Alexander et al (2006), the use of glucose meters has helped to increase patient involvement in their glycaemic control. Although self-monitoring of blood glucose (SMBG) is still a debatable issue in diabetes care, NICE (2002) cautiously recommend SMBG as part of the broad empowerment process based on individual circumstances when it is assessed as providing a useful option for the patient. Diabetes UK (2008) sees SMBG as a beneficial aspect of the day-to-day management of diabetes. Therefore, it is the responsibility of the health professionals to teach the patient how to monitor their blood glucose level when necessary.

Accurate monitoring of blood glucose is essential for appropriate intervention in diabetes management. However, in order to be accurate and effective it requires some degree of normal visual and intellectual ability, coupled with self-motivation (Alexander et al, 2006). There are various inexpensive monitoring devices, and patients can often obtain free monitors from certain diabetes clinics. Choosing a glucose meter may be difficult owing to the wide variety of choice and healthcare professionals should ideally be able to offer advice on the most appropriate one; for example, the Sensocard Plus is a meter designed for people with visual impairments as it is a talking blood glucose meter (Diabetes UK, 2008b). NICE (2002) stress the need for quality assurance and adequate training for patients in relation to blood glucose monitoring.

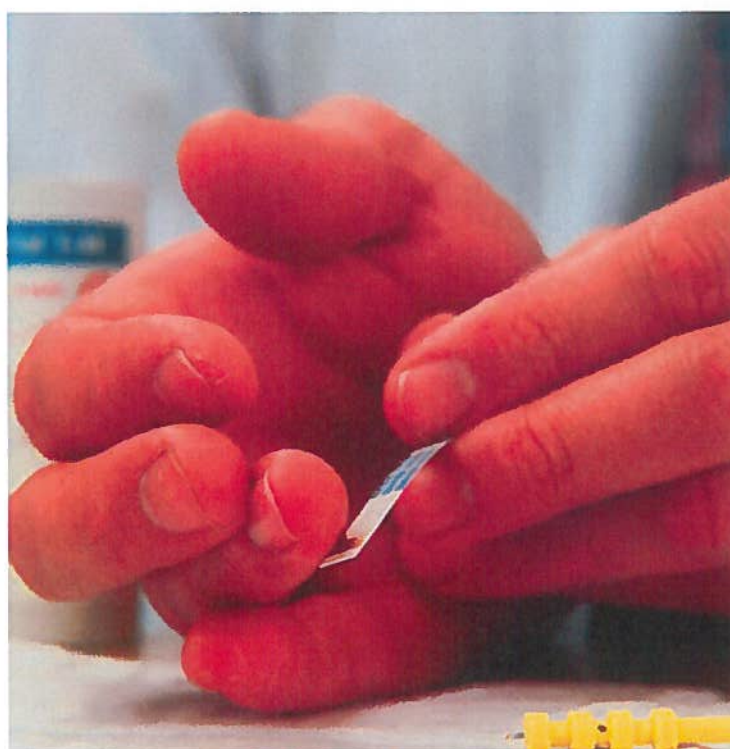
Conclusion

Diabetes remains a growing international concern and blood glucose monitoring forms an essential part of its management (Lawal, 2008). The NSF for diabetes (2001) sets out standards for twelve areas of practice. The initiative proposed by this document emphasized service improvement. The standards 3, 4, 5 and 10 are linked to promoting glycaemic control, prevention of complications and patient empowerment. Alexander et al (2006) state that blood glucose estimation offers a simple and reliable method of monitoring glycaemic control if performed accurately. Nevertheless, a gap in

Figure 2: Piercing the finger tip with a lancet



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Figure 3: Applying the blood directly onto the strip

Education and Training

Table 1. Performing a blood glucose test

Action	Rationale
Assessment	
Assess the patient's overall condition including risk factors of developing hypoglycaemia and readiness to undertake the procedure. There is a need to assess the psychological effect of lifelong blood glucose tests on the individual.	To prevent undue risk, protect the right of the patient and foster partnership in care.
Planning	
Check that the equipment is functioning properly. Check that the test strips have not expired or been exposed to the air. Check that the monitor and the test strips have been calibrated together. Check the log book to ensure that the internal quality control test has been performed. Prepare the equipments (Box 3). Read the instructions of the device you are using carefully.	To ensure accuracy and conform to the safety standard of the manufacturer.
Implementation	
Explain the reasons, duration, implication of the result and seek the consent of the patient.	This is to aid patient understanding of the procedure, reduce fear, and ensure cooperation Similarly, seeking consent is a legal requirement.
Advise the patient to wash their hands with soap and water and dry with a clean paper towel before taking the blood sample. The use of alcohol wipes is contraindicated because they act as a contaminant and hardens the skin with frequent use (Jamieson et al, 2007)	To ensure that the result is free from contamination
Ask the patient to sit or lie comfortably in supine position.	To ensure patient's comfort and safety
Wash your hands and put on gloves.	To avoid any contamination of the test strips and prevent risk of blood-borne infection.
Ensure that the right strip is correctly inserted into the meter (see Figure 1)	To obtain accurate results.
Select a puncture site which is often either side of the top of the finger. This should be rotated for prolonged testing and avoid frequent use of the index finger and thumb.	To minimize pain and it is easier to obtain a hanging droplet of blood sample. To prevent the area becoming sore from repeated stabbing.
Use the correct disposable lancet for the device. Adjust the depth of the lancet, prick as appropriate to the thickness of the skin.	To reduce the risk of cross infection, pain and accidental needle stick injury
Pierce the side of a fingertip with the lancet to obtain sufficient blood and precisely follow the manufacturer's directions (Figure 2)	To minimize the patient discomfort and maximize the sample volume.
Apply the blood directly onto the test strip and ensure the sample covers the target area on the strip (Figure 3).	To prevent inaccurate results.
Apply a clean piece of gauze to the site and apply firm pressure.	To prevent unnecessary blood loss through bleeding and prevent haematoma formation.
Dispose of lancet in a sharp container.	To minimize the risk of needle stick injury.
Read and record the results displayed on the meter on an appropriate chart immediately or use the monitor memory system.	To obtain the blood glucose level and prevent incorrect result.
Dispose of all waste appropriately, remove and dispose of gloves.	To minimize the risk of cross-infection
Ensure that the patient is comfortable and observe site of test for bleeding	To promote patient's comfort and prevent unnecessary blood loss.
Wash and dry hands.	To minimize the risk of cross infection.
Clear the tray and return the equipment to the appropriate place.	To facilitate the next user.
Evaluation	
Assess whether the value is within the normal range. Compare the results with the previous readings and target level. Inform the medical staff, adjust if this should be high or low and take action. Discuss the result and its implications	To initiate appropriate management in case of a low or high value.

Source: Dougherty and Lister, 2008; Jamieson et al, 2008

knowledge still exists and this article aims to provide the reader with an understanding of how to measure blood glucose levels, recognize abnormal values, and be aware of actions to be taken in case of abnormal readings. In conclusion, it is thought that effective blood glucose monitoring may aid identification of new cases and helps to prevent diabetes emergencies.

BHCA

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Key Points

- Diabetes is an international public health problem and early diagnosis is essential.
- Blood glucose monitoring helps to minimize long-term complications and promote patients' quality of life.
- Glucose is monitored in clinical practice by using urine or blood samples.
- There are different versions of monitor on sale and it is essential to read the product manual and local policy.
- The staff should be properly trained to undertake the clinical procedure.

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Management of diabetes mellitus in clinical practice

Muili Lawal

Abstract

Diabetes is a global health problem, with a challenging epidemiology. It is one of the major health problems affecting countries around the world, particularly the UK (World Health Organization [WHO], 2006; Department of Health [DH], 2006b). It is also a growing public health threat in the US (Mokdad et al, 2001). As a result, diabetes has become an important public health issue, prompting the WHO and International Diabetes Federation (IDF) to adopt the theme 'Diabetes for Everyone' for World Diabetes Day 2006. In 2007, on World Diabetes Day, the United Nations also launched its 'Living with Diabetes at School' campaign, in response to the growing diabetes 'epidemics' (Diabetes UK, 2007). This article provides an overview of diabetes mellitus and its acute- and long-term management, including definition, aetiology, pathophysiology, classification, signs, symptoms and complications. The role of the nurse in providing patient-centred care for people with diabetes is emphasized.

Key words: Diabetes management ■ Diabetes mellitus ■ Hypoglycaemia ■ Insulin therapy

Diabetes is an endocrine disorder resulting from disorder of the hormones produced by the beta cells of the islets of Langerhans in the pancreas. The World Health Organization (WHO) (2006) defines diabetes as a chronic disease resulting from failure of the pancreas to produce adequate insulin or the body's ineffective use of the insulin produced. Similarly, Waugh and Grant (2006) define diabetes as a metabolic disorder of carbohydrate and fat resulting from a deficiency or absence of insulin.

Epidemiology

Diabetes is a significant global health problem (Dixon and Salamonson, 2006). Its prevalence is increasing worldwide (Waugh and Grant, 2006), and so the economic cost of diabetes management continues to rise (Smeltzer and Bare, 2004; WHO, 2006). There are an estimated 2.35 million people with diabetes in England (DH, 2006b), and this figure is expected to rise to more than 2.5 million by 2010. WHO (2006) highlights the increasing incidence of diabetes and

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the need for urgent action, e.g. early detection and prompt management (Table 1).

There is evidence to suggest a link between diabetes and ethnicity; in a study by Newnham et al (2002), type 2 diabetes was found to be more common in adults of Asian and African Caribbean ethnic origin. The prevalence of type 2 diabetes is increasing, particularly in African, black Caribbean, South Asian, Middle Eastern people and those of Chinese origin (National Institute for Health and Clinical Excellence [NICE], 2008b). According to Diabetes UK (2008), African-Caribbean and South Asian people living in the UK are five times more likely to have diabetes than the white population.

Overall, type 2 diabetes is more prevalent, accounting for 90% of people with diabetes worldwide (WHO, 2006). Reasons for the increase in prevalence include dietary habit, lack of exercise and increasing age (glucose tolerance declines with age). Newnham et al (2002) argued that the increased prevalence of diabetes may be due to better treatment, which probably results in longer survival. The American Diabetes Association (2008) attributed increased prevalence to improved diagnostic techniques, enhanced detection methods, decreasing mortality, increasing numbers of elderly people and increased prevalence of overweight and obese people.

Aetiology

Classification of diabetes

Diabetes may be classified into two major types: diabetes mellitus and diabetes insipidus (Dixon and Salamonson, 2006). Although the two conditions are very different, they

Table 1. Facts about diabetes

- More than 180 million people worldwide have diabetes
 - This figure is likely to more than double by 2030
 - In 2005, an estimated 1.1 million people died from diabetes-related complications
 - Almost half of diabetes deaths occur in people under 70 years of age, and 55% of diabetes deaths occur in women
 - Almost 80% of diabetes deaths occur in low- and middle-income countries
 - The World Health Organization estimates that diabetes deaths will increase by more than 50% in the next 10 years without urgent action
 - Diabetes deaths in upper middle-income countries are projected to rise by more than 80% between 2006 and 2015
- Source: World Health Organization (2006)

are both caused by hormonal deficiency or resistance: diabetes insipidus is rare and results from deficiency of antidiuretic hormone (vasopressin) leading to fluid loss through diuresis, while diabetes mellitus is more common and results from deficiency of insulin.

Types of diabetes mellitus

There are various classifications of diabetes mellitus based on treatment, period of occurrence or other associated conditions (Marie and Whitaker, 2004). In this article, the WHO (2006) classification, based on the disease process, will be used. Accordingly, diabetes mellitus is grouped into three main categories: type 1, type 2 and gestational diabetes. WHO (2006) also identified an intermediary group of people who are susceptible to type 2 diabetes. This group includes people with impaired glucose tolerance (IGT) or impaired fasting glycaemia (IFG), who are therefore at high risk of developing type 2 diabetes.

Pathophysiology

The pancreas is an elongated flattened organ situated in the epigastric and left hypochondriac regions of the abdominal cavity (Waugh and Grant, 2006). This organ is closely associated with the small intestine and located behind the parietal peritoneum (Figure 1).

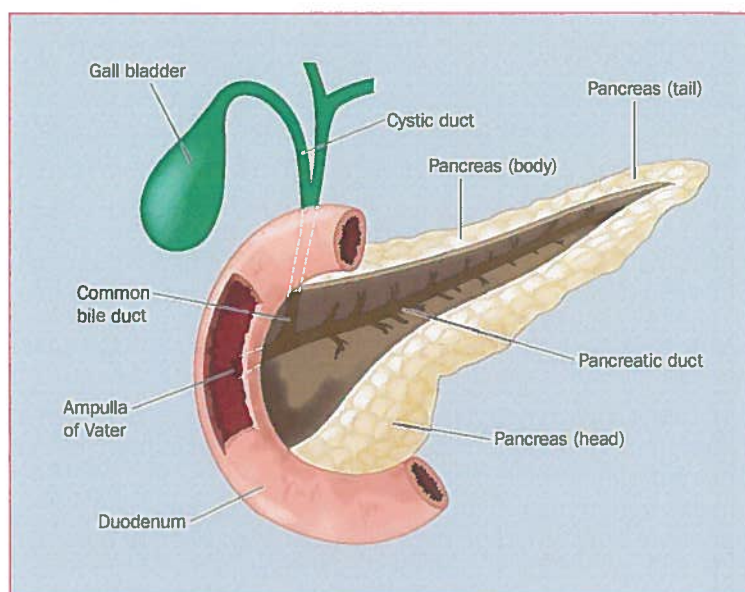
The pancreas is both an exocrine and an endocrine gland: it contains two major types of secretory tissue, reflecting its dual role of performing both hormonal and digestive functions (Hole, 1993). The exocrine portion secretes pancreatic juice into the intestine through a duct, which aids the digestion of carbohydrates, proteins and fats. The endocrine portion is a ductless gland which contains specialized cells known as the islets of Langerhans. The islets of Langerhans produce three types of cells, termed alpha, beta and delta cells (Figure 2). The alpha cells secrete glucagon, the beta cells secrete insulin and the delta cells secrete somatostatin. These groups of cells secrete their hormones directly into the blood. The opposing actions of insulin and glucagon regulate the glucose concentration in the blood (Hole, 1993; Waugh and Grant, 2006): glucagon raises the blood glucose level, and insulin lowers the blood glucose level (Table 2; Waugh and Grant, 2006).

This hormonal secretion is finely balanced through sympathetic and parasympathetic stimulation to prevent the development of endocrine disorders (Dixon and Salamonson, 2006). The secretion of insulin is stimulated by high blood glucose levels and to a lesser extent by raised amino acid and fatty acid levels in the blood. The production of glucagon is stimulated by low blood glucose levels, exercise and decreased somatostatin and insulin levels. The normal range of blood glucose concentration is 3.5–8 mmol/litre (63–144 mg/100 ml) (Waugh and Grant, 2006). A deficiency of insulin leads to a type of diabetes, depending on the aetiology of the condition (gestational diabetes included).

Type 1 diabetes

Formerly referred to as insulin-dependent or juvenile-onset diabetes (WHO, 2006), type 1 diabetes accounts for 5–10% of people with diabetes mellitus (Smeltzer and Bare, 2004). It

Figure 1. Diagram showing the location of the pancreas.



is characterized by sudden onset and is common in children and young adults (Table 3). The primary cause of type 1 diabetes is immune-mediated destruction of the beta cells of the islets of Langerhans in the pancreas, leading to reduced or lack of insulin secretion; affected people therefore require insulin treatment (Dixon and Salamonson, 2006).

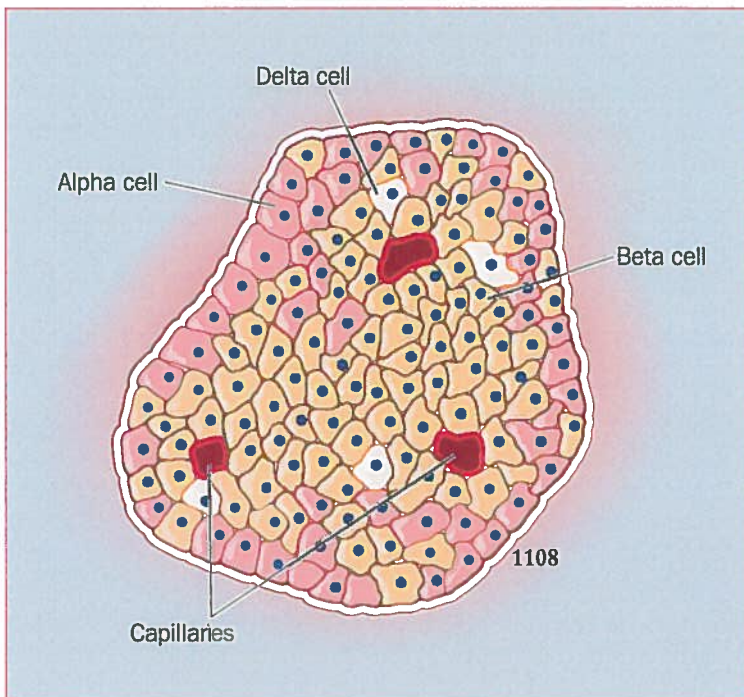
Genetic predisposition, immunological factors and environmental factors such as viral infection (Smeltzer and Bare, 2004; Waugh and Grant, 2006) are thought

Table 2. Hormonal secretions of the islets of Langerhans and their roles

Hormone	Role
Insulin	Decreases high levels of blood nutrients, especially glucose but also amino acids and fatty acids, by: <ul style="list-style-type: none"> • Stimulating the uptake and utilization of glucose by muscle and connective tissue • Increasing the rate of conversion of glucose to glycogen (glycogenesis), mostly in the liver and skeletal muscles • Increasing the uptake of amino acids by cells • Increasing the synthesis of fatty acids and fat storage in adipose tissue (lipogenesis) • Reducing the breakdown of glycogen into glucose (glycogenolysis) • Preventing the breakdown of protein and fat
Glucagon	Increases the blood glucose level by: <ul style="list-style-type: none"> • Converting glycogen to glucose in the liver and skeletal muscles (glycogenolysis) • Converting non-carbohydrates, such as amino acids, to glucose (gluconeogenesis)
Somatostatin	• Inhibits the secretion of insulin and glucagon from the pancreas and the secretion of growth hormone from the anterior pituitary gland

Source: Waugh and Grant (2006)

Figure 2. Diagrammatic representation of a cross-section through an islet of Langerhans.



to contribute to the destruction of beta cells, and hence the development of type 1 diabetes. Although type 1 diabetes is not inherited, a genetic predisposition to the condition may be inherited. Human leucocyte antigen (HLA) is hereditary and it has been found to play some role in the development of type 1 diabetes. Lic et al (1999) found that HLA type DR3 haplotype is associated with reduced susceptibility for the development type 1 diabetes. Also, autoimmune antibodies against islet cells and endogenous insulin have been found in certain people with type 1 diabetes (Smeltzer and Bare, 2004). Studies by Yoon et al (1998) and Thomas and Kay (2000) suggest that CD8 (+) T-cells is one of the cells implicated in the autoimmune destruction of beta cells and development of type 1 diabetes. Although the specific aetiology of beta-cell destruction is not fully understood, it is well established that beta-cell destruction leads to a raised fasting blood glucose level (hyperglycaemia) due to a reduction in the level of insulin produced (Smeltzer and Bare, 2004).

Table 3. Characteristics of type 1 diabetes

- Formerly known as insulin-dependent or juvenile-onset diabetes
- Sudden onset
- Common in children and young adults
- Destruction of beta cells leading to lack of insulin (Waugh and Grant, 2006)
- Contributing factors include autoimmune response, genetic predisposition and environmental factors (Smeltzer and Bare, 2004; Waugh and Grant, 2006)
- Requires lifelong insulin treatment (Dixon and Salomonson, 2006)
- Inherited human leukocyte types DR3 and DR4 increase the risk (Smeltzer and Bare, 2004)

Type 2 diabetes

Type 2 diabetes was previously known as non-insulin dependent diabetes. Formerly this condition was peculiar to adults, but it has recently been found in obese children (WHO, 2006). Most people with diabetes suffer from type 2 diabetes (Levene, 2003; Smeltzer and Bare, 2004) and it is claimed that it accounts for almost 90% of diabetes (Waugh and Grant, 2006; WHO, 2006). Type 2 diabetes is characterized by insulin resistance and impaired insulin secretion (Smeltzer and Bare, 2004). Insulin resistance occurs when the tissues become less sensitive to insulin, leading to ineffective insulin action (Smeltzer and Bare, 2004). Type 2 diabetes occurs as a result of the body's ineffective use of insulin (WHO, 2006; Table 4). In order to prevent the accumulation of glucose in the blood, the beta cells secrete more insulin to maintain normal blood glucose levels. However, if the demand for insulin exceeds secretion, type 2 diabetes will develop (Smeltzer and Bare, 2004).

Factors that predispose to type 2 diabetes include obesity, lack of exercise, increasing age and genetic factors (Waugh and Grant, 2006). Although genetic predisposition is thought to play a role in the development of type 2 diabetes, the mechanism of insulin resistance and impaired secretion is unknown (Smeltzer and Bare, 2004). However, despite impaired secretion, there is adequate insulin to prevent fat metabolism which may lead to the production of ketone bodies (Smeltzer and Bare, 2004). Type 2 diabetes may also be induced by steroid therapy and other hormonal disorders such as Cushing's syndrome. Excess release of cortisone (Cushing's syndrome) may result from a tumour of the adrenal gland, hypersecretion of corticotrophin-releasing hormone or over dosage of steroid medications (Pocock and Richards, 2006). Cushing's syndrome is characterized by changes in carbohydrate and protein metabolism and hyperglycaemia. Catargi et al (2003) showed that subclinical Cushing's syndrome caused by adrenal incidentalomas is frequently associated with overweight and insulin resistance.

The symptoms of type 2 diabetes may be similar to those of type 1 diabetes but less severe (WHO, 2006). Because of its mild presentation, type 2 diabetes is often detected during a routine investigation, e.g. a urine test at a GP visit, or a pregnancy check-up, or when there is an acute complication such as hypoglycaemia.

Gestational diabetes

This condition is characterized by the onset of high blood glucose levels during pregnancy (WHO, 2006). It develops in 1–3% of pregnancies (Pocock and Richards, 2006) and may disappear after birth, but often recurs in later life (Waugh and Grant, 2006). The aetiology of gestational diabetes is not fully understood, although placental hormones such as human chorionic somatomammotrophin (HCS), maternal serum cortisol, oestrogen and progesterone are thought to play a vital role in the disease process (Scollan-Koliopoulos et al, 2006). Gestational diabetes often develops around the 20th week of pregnancy, when blood levels of these hormones are high (Scollan-Koliopoulos et al, 2006). The secretion of placental hormones causes insulin resistance, leading to high blood glucose levels (Smeltzer and Bare, 2004).

Gestational diabetes has negative health implications for the baby (Scollan-Koliopoulos et al, 2006). For example, a high blood glucose level during pregnancy increases the risk of the baby having a high birth weight or being stillborn (Waugh and Grant, 2006). According to NICE (2008b), almost 87.5% of pregnancies complicated by diabetes are due to gestational diabetes, 7.5% to type 1 diabetes and 5% to type 2 diabetes. Risk factors for the condition include obesity and a family history of diabetes in a first-degree relative (Scollan-Koliopoulos et al, 2006). Selective screening during the sixth and seventh month of pregnancy is recommended for certain groups of women, namely those aged ≥ 25 years, obese women, and those with a family history of diabetes (Smeltzer and Bare, 2004; Table 5).

Clinical manifestations

The initial symptoms of type 1 diabetes are generally acute, whereas the onset of type 2 diabetes is more insidious and the condition may be detected incidentally during a routine medical check (Marie and Whitaker, 2004). The symptoms of all types of diabetes mellitus include the 'three Ps':

- Polyuria (increased urinary output)
- Polydipsia (increased thirst)
- Polyphagia (increased appetite).

Other symptoms that may be present include fatigue, sudden visual changes, numbness in the feet or hands, recurrent infections and delayed wound healing (Smeltzer and Bare, 2004). The clinical manifestations of polyuria, polydipsia and unexplained loss of weight are strongly suggestive of type 1 diabetes (Dixon and Salomonson, 2006). The symptoms of type 1 diabetes include excessive output of urine (polyuria), thirst (polydipsia) as a result of increased water loss, hunger, loss of weight, fatigue and visual changes. The symptoms of type 2 diabetes may be similar to those of type 1 diabetes but less severe (WHO, 2006). People with type 2 diabetes may present with mild symptoms, such as fatigue, polyuria, polydipsia, delayed wound healing, vaginal infections or blurred vision in the case of a very high blood glucose level (Smeltzer and Bare, 2004; Table 6).

Complications

The complications of diabetes are classified as acute or chronic (Waugh and Grant, 2006). The acute complications of diabetes are diabetic ketoacidosis (DKA) and hypoglycaemic coma (Marie and Whitaker, 2004).

The chronic complications of diabetes occur as a result of impairment of the macrovascular and microvascular circulation. Microvascular complications, such as diabetic nephropathy, retinopathy and peripheral neuropathy, result from damage to the tiny blood vessels of the kidneys, retina and nerves, respectively. Macrovascular impairment results in cardiac, cerebral and peripheral vascular disease due to damage to the large vessels of the brain, heart and legs respectively (Hill, 2004). Microvascular complications manifest as blindness or tingling sensations, while peripheral complications may include leg cramp with intermittent loss of sensation after walking (Dixon and Salomonson, 2006). The risk of developing atherosclerosis is increased by diabetes, and the risk of developing macrovascular disease, such as stroke, coronary heart disease and peripheral

Table 4. Characteristics of type 2 diabetes

- Previously known as non-Insulin dependent diabetes
- Formerly peculiar to adults, but recently found in obese children
- Accounts for about 90% of cases (World Health Organization, 2006)
- Insulin resistance and impaired insulin secretion (Smeltzer and Bare, 2004)
- Predisposing factors include obesity, lack of exercise, increasing age and genetic factors
- Mild symptoms, which are often detected during routine investigation (Waugh and Grant, 2006)

vascular disease, is increased two- to five-fold in people with diabetes compared with the general population (Marie and Whitaker, 2004). Peripheral vascular disease may progress to gangrene and 'diabetic foot'. People with diabetes are also susceptible to bacterial and fungal infections, such as vaginal candidiasis, pyelonephritis and boils, probably due to depressed phagocytic action resulting from a lack of intracellular glucose (Waugh and Grant, 2006).

Diabetic ketoacidosis

Diabetic ketoacidosis mainly affects people with type 1 diabetes. It is characterized by the formation of excessive ketones in the urine resulting from an increased demand for insulin, inadequate adjustment of insulin injection to meet the required needs of the body, and increased resistance to insulin due to various factors such as pregnancy or infection (Waugh and Grant, 2006). Ketoacidosis may result in increasing hyperglycaemia, polyuria, dehydration, hypovolaemia, electrolyte imbalance, confusion, coma and death (Waugh and Grant, 2006). Diabetic ketoacidosis is a life-threatening complication of type 1 diabetes and accounts for up to 14% of all diabetes-related hospital admissions (Palmer, 2004).

Table 5. Characteristics of gestational diabetes

- Onset of high blood glucose level during pregnancy
- Affects 1–3% of pregnancies
- May disappear after birth but can recur in the future
- Often develops at around the 20th week of pregnancy
- Increases the risk of a large baby and stillbirth
- Risk factors include obesity and a family history of diabetes
- Screening of high-risk women may aid early detection

Table 6. Clinical manifestations of diabetes

- Polyuria (increased urinary output)
- Polydipsia (increased thirst)
- Polyphagia (increased appetite)
- Loss of weight
- Numbness in the feet or hands
- Fatigue
- Delayed wound healing
- Sudden visual changes
- Recurrent infections

Hypoglycaemia

Hypoglycaemia is a condition in which the blood sugar level is below the normal range. It may be caused by insulin overdose, a delayed meal following insulin administration, an insulin-secreting cancer, or increased metabolic rate due to unexpected exercise or acute febrile illness (Waugh and Grant, 2006). Increased and continuous low blood sugar levels may starve the brain of glucose, leading to coma and possibly death. The initial presentation is hunger and light-headedness. This may be followed by sweating, palpitations and tremor. As the condition progresses, there may be blurred vision and speech, headache, tiredness and unsteady gait. It is an emergency situation that requires the prompt administration of glucose (Marie and Whitaker, 2004).

Diabetic retinopathy

Diabetic retinopathy refers to destruction of the macular retina by diabetes mellitus, causing loss of central vision (Marie and Whitaker, 2004). It is caused by altered permeability of the blood vessels in the retina, which leads to oedema, and may initially present as blurred vision (Palmer, 2004). The incidence of cataract extraction is high among diabetic patients (Klein et al, 1995) and the prognosis of cataract extraction is worse among diabetic patients, particularly those with diabetic retinopathy compared to non-diabetic individuals (Krepler et al, 2002). Diabetic retinopathy is a major cause of blindness in adults between the ages of 20–74 years (Fong et al, 2004). In a study by Klein et al (1984) it was found that diabetic retinopathy account for the majority of impaired vision among diabetic patients.

Diabetic nephropathy

Diabetic nephropathy refers to the alteration in renal structure and function resulting from diabetes mellitus. It affects about 30% of people with type 1 diabetes and is a major cause of kidney failure and death (Marie and Whitaker, 2004). Renal failure is a common cause of death in people with diabetes, and may result from diabetic nephropathy (Waugh and Grant, 2006). Diabetic nephropathy may present in a mild form, albuminuria, caused by thickening of the glomerulus, until a significant proportion of the kidney tissue has been damaged (Palmer, 2004).

Diabetic neuropathy

Diabetic neuropathy refers to nerve damage caused by the effects of diabetes. The disease may affect the autonomic nervous system or the central nervous system, giving rise to various symptoms depending on the neurons involved (Marie and Whitaker, 2004). Autonomic neuropathy may result in impotence, bladder dysfunction and intermittent or continuous pain (Palmer, 2004). Diabetes may cause impotence in approximately 30% of affected men (Marie and Whitaker, 2004).

Diagnosis

A diagnosis of diabetes would be suspected in a person with an abnormally high blood glucose level. A random plasma glucose level of >11.1 mmol/litre (200 mg/dl) or a fasting plasma glucose level of ≥ 7.0 mmol/litre (126 mg/dl) on more

than one occasion requires further investigation (Smeltzer and Bare, 2004). Similarly, Dixon and Salamonson (2006) consider a repeated fasting plasma glucose level of ≥ 7 mmol/litre on two occasions to be indicative of diabetes.

The following investigative techniques can be used to diagnose diabetes (Table 7).

History taking: A thorough history obtained from the patient or close relative on the basis of the clinical symptoms of diabetes and hyperglycaemia is a useful technique to diagnose the disease.

Urinalysis: Urine does not normally contain detectable glucose or ketones, and the presence of either substance may indicate diabetes. A sensitive glucose-specific reagent strip can be used to test for glucose and ketones in the urine. However, this is not a conclusive test because the presence of glucose in the urine does not always indicate that a person has diabetes.

Random blood glucose test: This test is a random check of plasma glucose concentration regardless of the time of the last meal. A plasma glucose level >11.1 mmol/litre may be indicative of diabetes (Marie and Whitaker, 2004).

Fasting blood glucose test: This test involves the measurement of plasma glucose concentration in a blood sample taken after 8 hours of fasting. The normal range of plasma glucose concentration is 3.3–5.9 mmol/litre. A value of ≥ 7.0 mmol/litre may suggest diabetes (Smeltzer and Bare, 2004).

Oral and intravenous glucose tolerance test: In this test, blood glucose concentration is measured after 8 hours of fasting followed by either ingestion of 75 g anhydrous glucose dissolved in water or an infusion of 50% glucose. A blood sample is taken at intervals of 30 minutes, 1 hour, 2 hours and 3 hours following ingestion of the glucose solution. This test is considered positive when fasting plasma glucose is above 7.0 mmol or greater than 11.1 mmol when repeated after 2 hours of ingesting the glucose (WHO, 1999). This is not recommended as a routine investigation (Smeltzer and Bare, 2004) because it may cause side-effects such as weakness, dizziness and sweating during the 2–3 hours of the test (Marie and Whitaker, 2004). Also, it is not recommended for bedridden patients because lack of activity may interfere with the result.

Blood glucose level measurement: This involves pricking the finger with a lancet or special needle to obtain a drop of capillary blood. The blood is placed on a reagent strip, and the glucose concentration is determined either electronically or visually by comparison with a colour chart (Marie and Whitaker, 2004).

Glycosylated haemoglobin test: This test measures the amount of glucose bound to haemoglobin, and is used to monitor glycaemic control. It gives an indication of the blood glucose level for an average of 8–12 weeks, which is the approximate life span of red blood cells. Normal glycosylated haemoglobin (HbA1c) is 4–6%, and the goal of diabetes management is to keep HbA1c levels below 7%, as a higher value increase the risk of diabetic complications (Marie and Whitaker, 2004; Dixon and Salamonson, 2006).

National diabetic screening

The aim of screening is to aid early identification of susceptible individuals, provide appropriate diagnostic examination and

institute early treatment. However, there are arguments both for and against screening for diabetes. The rising incidence of diabetes and high prevalence of undiagnosed diabetes, and the fact that early detection may reduce the impact of the disease, strengthen the argument for screening. However, case finding must be cost-effective and without any disadvantage to other people. Wareham and Griffin (2001) state that the advantages of early detection are not well proven and disadvantages of screening should be quantified. It is still unclear whether screening for diabetes would result in appreciable health gain, therefore the money could be used for effective management of diagnosed diabetic patient.

There is also the issue of how often to screen people. Highly predictive tests, such as the glycosylated haemoglobin test and oral and intravenous glucose tolerance test, tend to be expensive compared with needle-prick testing, and involve venepuncture, which is invasive, although they pose little risk when performed by a competent practitioner. The July 2006 National Screening Committee Policy report on diabetes screening of adults concluded that general population screening should not be offered, but recommended a vascular risk management programme (National Library for Health, 2006). Levene (2003) projected that regular screening of high-risk people was feasible in primary care, depending on the availability of resources.

Management options

The goal of management is strict blood glucose control through a combination of pharmacological treatment and lifestyle modifications that focus on diet and exercise (Dixon and Salamonson, 2006). Insulin is the most effective treatment for type 1 diabetes, and oral antidiabetic drugs such as metformin and gliquidone for type 2 diabetes. Patients with type 2 diabetes who do not respond to oral hypoglycaemic agents may also require insulin therapy. According to Scollan-Koliopoulos et al (2006), the cornerstone of treatment for gestational diabetes is diet and exercise coupled with exogenous insulin when the fasting blood glucose level exceeds 5.3 mmol/litre (95 mg/dl), or 1-hour postprandial value rises above 7.2–7.8 mmol/litre (130–140 mg/dl). The aim of all forms of pharmacological therapy is to alleviate symptoms and reduce the risk of long-term complications through optimal glycaemic control.

Insulin therapy

Insulin plays a vital role in the regulation of carbohydrate, fat and protein metabolism. People with type 1 diabetes, also referred to as insulin-dependent diabetes, require the administration of exogenous insulin to compensate for the lack of endogenous insulin. Similarly, those with type 2 diabetes who have poor glycaemic control may require insulin; it may also need to be administered temporarily during pregnancy or intraoperatively (Joint Formulary Committee, 2008).

Insulin regimens vary from one to four injections daily, and the dosage depends on the glycaemic profile of the patient (Marie and Whitaker, 2004). There are three types of insulin preparation, based on their duration of action. Each may be given alone, but sometimes a mixture is required.

Table 7. Investigative techniques for diagnosing diabetes

- History taken from patient and significant others
- Urinalysis
- Random blood glucose test
- Fasting blood glucose test
- Oral and intravenous glucose tolerance test
- Blood glucose level measurement
- Glycosylated haemoglobin test

- Short-acting insulins have a rapid onset of action of between 30 and 60 minutes. Examples are soluble insulin, insulin lispro and insulin aspart. They have a maximum effect at 2–4 hours and a duration of action of up to 8 hours.
- Intermediate-acting insulins have an onset of action of approximately 1–2 hours and a maximum effect at 4–12 hours. An example is isophane insulin which is useful for initiation of twice-daily insulin regimens.
- Long-acting insulin has a slow onset of action and a duration of action of 16–35 hours. An example is insulin zinc suspension.

The duration of action of any insulin differs for each patient and individual assessment is essential. The insulin dose may need to be adjusted upwards during pregnancy and breast feeding; certain other conditions such as infection, stress, surgical trauma, puberty and the last trimester of pregnancy may increase or decrease insulin requirements. Renal or liver impairment and some endocrine disorders such as Addison's disease and hypopituitarism may reduce the insulin requirements.

Insulin may be administered by subcutaneous injection or by inhalation. It is usually injected into the upper arms, thighs, buttocks or abdomen by means of special insulin syringes graduated in units. Soluble insulin can also be given by continuous subcutaneous infusion using a portable infusion pump for patients with recurrent hypoglycaemia despite optimized multiple injection regimen, or during operation (Joint Formulary Committee, 2008).

Insulin from animal sources may be derived from beef or pork pancreas. 'Human' insulin is produced semisynthetically by enzymatic modification or biosynthetically using recombinant deoxyribonucleic acid (DNA) technology. Human insulin is very useful for patients with religious beliefs that prohibit ingestion of animal products (Marie and Whitaker, 2004).

Oral antidiabetic drugs

Although type 2 diabetes may be controlled with diet, exercise and weight control, patients with poor glycaemic control may also require oral hypoglycaemic agents and/or insulin to maintain adequate glucose levels. Oral hypoglycaemic drugs are classified into three groups: sulphonylureas, biguanides and other antidiabetic agents (BNF, 2008).

Sulphonylureas: These drugs act by augmenting insulin secretion, and are therefore only effective when some residual beta-cell activity is present. They are useful for normal weight patients, and should also be considered when metformin (a

biguanide) is contraindicated. Choice of sulphonylurea for the individual patient will depend on the side-effects and duration of action: chlorpropamide and glibenclamide are long acting, and gliclazide and tolbutamide are short acting. Sulphonylureas are contraindicated in severe liver and kidney disease and in the presence of ketoacidosis and breast feeding. Side-effects are generally mild and include weight gain and gastrointestinal disturbances such as nausea, vomiting, constipation and diarrhoea.

Biguanides: The only available biguanide is metformin. This acts by decreasing gluconeogenesis and increasing peripheral utilization of glucose, and is therefore only useful in the presence of endogenous insulin. Metformin is indicated when diabetes is inadequately controlled with sulphonylureas. It is also the first choice of drug for obese patients who have failed to achieve adequate control by dietary modification. It rarely produces hypoglycaemia when the appropriate dose is administered (Joint Formulary Committee, 2008).

Other antidiabetic drugs: These include agents that have a small but significant effect in reducing the blood sugar level and can be used alone or in combination with metformin or sulphonylureas. Examples are: acarbose, which inhibits the digestion and absorption of starch and sucrose; nateglinide and repaglinide, which stimulates insulin release; and the thiazolidinediones, pioglitazone and rosiglitazone, which reduce blood sugar levels by reducing peripheral insulin resistance (Joint Formulary Committee, 2008).

Dietary modification

Dietary management is an essential aspect of diabetes care, and the formulation of a diabetic nutritional plan is one of the roles of the multidisciplinary team. The diet plan will depend on several factors, such as the type of diabetes, sex, age, height, weight, level of patient activity, nature of job, general health, cultural beliefs and previous dietary habits (Marie and Whitaker, 2004). Dietary advice should focus on healthy eating, and comprise a balanced diet with the emphasis on a low fat, vegetables and fruits, less sugar and sugary foods, and moderate carbohydrate, especially those that are slowly absorbed such as new potatoes, pasta, porridge oats and bran flakes.

Exercise

Obesity can be defined, in simple terms, as an excess of body fat (Zaninotto et al, 2006). Some medical conditions, such as diabetes, are linked to obesity (Mokdad et al, 2003). The Department of Health (2006c) document *Your Health, Your Weight* emphasized the importance of weight control as one of the measures to prevent health problems such as type 2 diabetes. The management of obesity is partly addressed by standard 1 of the *National Service Framework for Diabetes* (DH, 2001) due to its role in the development of diabetes. Individualized exercise programmes should therefore be instituted for obese patients and sedentary adults (with or without diabetes), because obesity increases the risk of some medical conditions such as diabetes and hypertension. Regular physical exercise helps to metabolize carbohydrates, decreasing insulin requirements. Therefore, careful monitoring of blood glucose levels of diabetic patients

is essential to modify the dosage during increased activities (Marie and Whitaker, 2004).

Pancreatic transplant

A successful pancreas transplant has the potential to improve the patient's quality of life, by temporarily restoring normal carbohydrate metabolism. However, a major issue is the risk of rejection (Guyen and Kuenzi, 1998). Diabetes UK (2006) reported details of successful islet cell transplants undertaken by Canadian researchers, and the effort made to adopt the technique worldwide. The technique is still in an early stage of development and has only been used on a few patients in Britain; only one achieved insulin cessation following the procedure (Diabetes UK, 2006)

Nursing management

The nurse has a significant role to play in caring for people with diabetes. The NICE (2004) guidelines specify that management of type 1 diabetes should be patient centred and involve the multidisciplinary team. Management should include nutrition, patient education, therapeutics, foot care and psychological care. NICE (2008a) guidance on the care of people with type 2 diabetes stresses the importance of blood glucose and blood cholesterol monitoring, blood pressure measurement, diabetes education programmes and dietary advice. It covers the use of medication to control blood glucose levels, prevent vascular disease, reduce blood pressure and improve lipid levels. It also highlights the need for detection and ongoing management of eye disease (retinopathy), kidney disease (nephropathy) and nerve damage (neuropathy). Similarly, NICE (2008b) recommendations for the management of diabetes in pregnancy stress pre-conception care, monitoring of blood glucose and ketones during pregnancy, close monitoring of fetal growth and wellbeing, and tight glycaemic control during labour and birth.

The role of any nurse therefore involves regular monitoring of blood glucose level, observing for signs and symptoms of complications, preventing and treating complications and providing adequate information to help patients self-manage their diabetes. Routine assessment for complications such as retinopathy and neuropathy is the responsibility of the nurse (Burden, 2003).

There is evidence to support the benefits of education to promote self-care (Rubin et al, 1999). Uitewaal et al (2005) see diabetic education as an important part of diabetes management. The NICE (2003) guidelines recommend structured patient education for all patients with diabetes and the DH (2005) identified the criteria that such a programme should fulfil in order to meet the NICE requirements.

The nurse, as a member of the multidisciplinary team, should help the patient and his/her family to understand diabetes management by teaching them about the disease, e.g. the importance of nutrition, monitoring and compliance with the regimen. Although patients can obtain information from various sources, such as NHS Direct, the internet, interactive CD-ROMs (Burden, 2003), the nurse is required to provide patient-centred care and offer advice on issues such as home blood tests, diet, exercise, eye screening, foot care, the benefits

of carrying an ID card, annual medical review, informing the DVLA and insurance company of the patient's diabetes, and offering information about the services of Diabetes UK.

Conclusion

The increasing incidence of diabetes and the health implications for those affected make diabetes management a major public health issue. Diabetes is a chronic illness that requires ongoing care and patient education to promote self-management. The goal of management is to maintain normal blood glucose levels by regulating food intake and activity levels and possibly administering either exogenous insulin or oral hypoglycaemic medication. The DH (2006b) document *Turning the Corner: Improving Diabetes Care* claimed that diabetic services in England are improving; nevertheless, there is a need for further improvement, particularly in the area of patient education to promote self-care.

The care and management of all types of diabetes requires a multidisciplinary approach, and nurses have a vital role to play in preventing, managing and minimizing the complications associated with the disease. It is hoped that by reading this article, healthcare practitioners should be able to increase their understanding of this chronic health condition. **BJN**

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KEY POINTS

- Diabetes is a global health problem with a challenging epidemiology.
- Diabetes is treated by pharmacological agents and lifestyle modification to maintain tight blood glucose control, in order to prevent the development of complications.
- Mortality is increased in people with diabetes.
- The goal of care is to assist the patient with blood glucose control, minimize complications and empower the patient to self-manage his/her diabetes.
- Nurses are able to offer patient-centred care and general information on diet, exercise etc., and on joining organizations such as Diabetes UK (www.diabetes.org.uk).