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AN EVALUATION OF PATIENT ENGAGEMENT WITH DIABETES OUT-PATIENT SERVICES IN AN ETHNICALLY DIVERSE URBAN AREA IN THE UK

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Declaration

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Abstract

Diabetes has been described as an epidemic with a significant global burden of illness. This burden is associated with poorer engagement with services and the cost of managing avoidable complications. One outcome measure of engagement in the national health service (NHS) in the United Kingdom (UK) is attendance at appointments. The cost implications (direct and indirect) of non-attendance are significant, with empirical evidence consistently demonstrating higher than average non-attendance rates for out-patient appointments and education sessions by minority ethnic and socio-economically deprived individuals.

A gap was identified whereby a comprehensive understanding of non-attendance which moves beyond clinical and technical aspects such as capacity and demand is still required. This thesis provides a fresh approach and granular understanding of patient engagement which can influence clinical care, service delivery and policy.

The main research questions in this thesis were:

1. What are the predictors of out-patient attendance?
2. What are the barriers and enablers to attendance?

To answer these questions, a retrospective geo-demographic trend analysis, critical narrative literature review of Community Health Worker (CHW) and peer support interventions and a research study were conducted.
The case study is based on a dataset which comprised of 35,597 appointments. Its findings highlighted that factors such as age, gender, ethnicity, local geography and deprivation were significant predictors of out-patient attendance.

A critical review of CHW and peer support interventions demonstrated that despite the heterogeneity of programme designs, duration of interventions, follow up and healthcare systems in which they were used, they were assessed to be both clinically and cost effective. There was limited evidence on the sustainability of these interventions due to a lack of longitudinal studies.

The research element was conducted in two stages and utilised multi methods (focus groups, semi-structured interviews and questionnaires) to evaluate the barriers and facilitators to attendance. Key findings included the need for effective and on-going education, better alignment of health and social care due to the impact of the wider determinants of health but more interestingly, the influence of family on the concept of ownership for one's health by some individuals whose self-determination is limited by language and health literacy. The relationship between patient activation (knowledge, skills and confidence) and attendance was also evaluated. This evaluation demonstrated that the more activated individuals are, they are significantly more likely to attend appointments. However, to maximise care planning and operational effectiveness, activation should not be assessed in isolation.

The findings of this thesis highlighted the influence of individual, organisational and structural factors on patients' engagement with out-patient services and the need for a synergistic approach involving service users, clinicians, organisations and policy makers to minimise patient dis-engagement with healthcare services.

Abbreviations and Glossary

Abbreviation	Meaning
APPG	All Party Parliamentary Group
BAME	Black, Asian minority ethnic groups
CASP	Critical appraisal skills programme
CEG	Clinical effectiveness group
CHW	Community Health Worker
CQC	Care Quality Commission
CRD	Centre for Reviews and Dissemination
DES-20	Diabetes enablement scale-20
DESMOND	Diabetes education and self-management for ongoing and newly diagnosed
DIAMOND	A diabetes specific database used in some National Health Service organisations
DSME	Diabetes self-management education
DUK	Diabetes UK
DWP	Department for works and pensions
EDS	Equality Delivery System
EPR	Electronic Patient Record
EQ-5D	EuroQol- 5D
GDM	Gestational diabetes mellitus
GLA	Greater London Authority
GP	General Practitioner
GPSI	General Practitioner with special interest
HbA1C	Glycated haemoglobin
HBM	Health Belief Model
HRA	Health research authority
ICER	Incremental cost effectiveness ratio. ICER is measured against a fixed budget with the measure of effectiveness being either QALY gained or health years' equivalents (HYE) earned. ICER thresholds are

	relative to countries and relative to the country's Gross Domestic Product (GDP). An ICER is deemed to be very cost-effective if it is less than one times the capita Gross Domestic Product (GDP) or cost-effective if it's less than three times the per capita GDP (WHO)
IMD	Index of Multiple Deprivation (Noble 2007)
IRAS	Integrated Research Approval System
JSNA	Joint strategic needs assessment
LBN	London Borough of Newham
LSOA	Lower level super output areas. Lower layer super output areas (LSOA) were created by automatically aggregating the 2001 Census output areas and have a minimum population size of between 1,000 and 1,500 persons (400 households).
MSOA	Mid-level super output areas. A middle layer super output area (MSOA) has a population size of 5000 persons or 2000 households
MVA	Multivariable analysis
NCD	Non-communicable diseases
NEL	North East London
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NSF	National service framework
NUH	Newham University Hospital
ONS	Office of National Statistics
PAM	Patient activated measure
PICO	Patient, Intervention, Control, Outcome
QALY	Quality adjusted life years. A QALY is a combined single measure of reduced morbidity (quality gains) and reduced mortality (quantity gains).
QIPP	Quality, Innovation, Productivity and Prevention
QISMET	Quality institute for self-management training

QOF	Quality outcomes framework
R&D	Research and Development
RCT	Randomised Controlled Trial
SOA	Super Output Areas
SPSS	Statistical package for the social sciences
STATA	Statistics and data
T1	Type one diabetes mellitus
T2	Type two diabetes mellitus
WHO	World Health Organisation
X-PERT	Expert patient education
YHPHO	Yorkshire and Humberside Public Health Observatory

CHAPTER 1

Introduction to thesis

1.1 Outline

This thesis is submitted as a PhD (Professional Practice) which was formally known as the Doctorate in Health. Submission guidelines for this type of Doctorate indicate that the thesis must contain one or more reflective accounts of case study work, a critical review of literature, a main research area and a dissemination plan and artefact.

This thesis examined the concept of patient engagement in a diabetes out-patient service in an Inner London UK borough in its widest context using non-attendance as the central form of enquiry. It aimed to:

- Quantify the problem
- Explore trends in relation to demographic characteristics of service users
- Examine the influence of factors such as geography, service locations and deprivation on non-attendance
- Explore barriers and enablers to attendance

The purpose of this introduction is to provide an outline of the individual components of the thesis in addition to a background, rationale, underpinning frameworks and policy context.

1.2 Personal interest

The idea for this course of study arose whilst being a member of a research study which was conducted between 2006 and 2010. During the research study, a high non-attendance rate of approximately 40 percent was observed for all face to face appointments despite telephone reminders. Following discussions with the clinical team, the observed non-attendance was not limited to research but was also evident in out-patient appointments. Clinicians attributed this phenomenon to limited English proficiency, poor health literacy and the impact of deprivation on health seeking behaviours within the local community. However, there was little evidence to validate the perceived relationship.

As a practitioner researcher, I felt I was well placed to explore this phenomenon to primarily provide evidence and a comprehensive understanding which could inform non-attendance reduction strategies. It is recommended that prior to undertaking practitioner research, there must be a clear intent for the study in addition to an understanding of the shadow side of an organisation which is concerned with politics and organisational culture (Fox et al.,2007). Mindfulness of the shadow side is deemed an important factor at all stages of evaluation particularly in relation to commissioning, designing and reporting of research.

My intent was to examine the very pervasive, complex and costly phenomenon of dis-engagement as identified by high non-attendance rates in a diabetes out-patient service located in an area with a high prevalence of diabetes and poorer health outcomes. The health and social profile for the London Borough of Newham (LBN) presents a worrying picture and the impact of poor engagement with services is seen daily within the diabetes services in the form of avoidable complications. NHS London (2009) highlighted that poor diabetes service provision and its management within the local borough contributed to a reduction in quality of life and life expectancy as well as the increased use of emergency and inpatient services. In addition, understanding and addressing this phenomenon is crucial because all National Health Service (NHS) Trusts are assessed by Department of Health (DH) on service utilisation with one component being their non-attendance rates (Care Quality Commission, 2003). Addressing non-attendance is should therefore be a strategic priority for all NHS organisations.

Non-attendance is costly to both the health economy and patients' health. The national non-attendance rate for all outpatient clinics during 2008 was approximately 11% (HSJ 2009) which was only a one percent reduction when compared to the period 1996 to 1997 (DH 1997). In 1996-1997 six million appointments were missed at an estimated cost of £300 million (DH 1997).

Four years on, the estimated cost to the National Health Service (NHS) in 2001 due to outpatient non-attendance was consistent at £300 million (Tham et al., 2002). A subsequent report indicated that non-attendance rates were variable between 5 and 34 percent and depended on speciality and area (HSJ, 2009). Non-attendance rate is measured in two ways: either from the Department of Health's quarterly activity return or by using aggregated data from secondary use of service, for example outpatient encounters. Outpatient data is felt to provide a more accurate picture of non-attendance than quarterly returns. This historic non-attendance trend and its cost implications highlight the pervasive and problematic nature of the phenomenon of non-attendance at both organisational and societal levels.

1.3 Diabetes overview

Diabetes is a long term non-communicable diseases (NCD) which has a significant global burden of illness particularly due to the cost associated with treatment and the management of avoidable complications.

Diabetes is characterised by elevated blood glucose levels which requires effective clinical and self-management to prevent avoidable micro or macro-vascular complications. There are two main types of diabetes: Type 1 and Type 2. Type 1 diabetes accounts for approximately three percent of all cases and is primarily due to an auto-immune response. Type 2 however, is more prevalent and has a causal relationship with diet and lifestyle factors (Drury and Gatling 2005). Every day, there are 400 new diagnoses of diabetes with 90 percent of cases classified as T2 with the estimated diabetes prevalence in the UK population ranging between 4-7 percent (DUK 2010).

T2 diabetes is characterised by the sub-optimal production or utilisation of insulin with causality attributed to factors such as heredity, diet and lifestyle choices. T2 is therefore the most common form of diabetes with a multi-faceted epidemiological profile. There is a higher prevalence of T2 diabetes amongst South Asians, Afro-Caribbeans and individuals who are socio-economically deprived. South Asians are six times more likely and Afro-Caribbeans four times more likely to develop diabetes than Caucasians (DUK

2006). Complications of diabetes such as heart disease, stroke and kidney damage are three and a half times higher in the lower socio-economic groups (DUK 2006).

Globally, the estimated figure of adults with diabetes aged 20 to 79 years was 382 million (DUK 2012) which was a significant increase from 246 million reported in 2006 (DUK 2006). The current projected increase by 2035 is 592 million (DUK 2014) as opposed to the previous estimate of 380 million by 2025 (Diabetes UK 2006). Amos (1997) highlighted that diabetes was reaching epidemic proportions and it was later described as an emerging pandemic (Narayan et al., 2000). Diabetes is therefore viewed as a major public health problem due to its significant global burden of illness. A significant factor which constitutes the burden of illness is the management of avoidable complications which is attributed to sub-optimal self-management and lack of engagement with diabetes healthcare services (Harris, Salway 2008, Peek et al., 2007). There is a wealth of empirical evidence which demonstrates the relationship between poor self-management and lack of engagement.

In the UK, the Yorkshire and Humberside Public Health Observatory (YHPHO) diabetes Prevalence Model's key findings (2010), forecasted a diabetes prevalence rise among adults of 8.5% in 2020 and 9.5% by 2030. Diabetes has been identified as the only long-term condition which showed a significant predicted increase in the prevalence rate as well as an absolute increase in numbers of cases (NHS London, 2007). This rise has been accounted for by changes in age, ethnicity and increasing obesity. The cost implications for the NHS are significant as it is currently estimated that 10% of the NHS budget is spent on diabetes.

Based on the London poverty profile (2009), the borough of Newham which is located in North East London had the second most diverse population in the UK with greater than 70% of residents being non-white. Ethnicity figures as reported in Newham's Joint Strategic Needs Assessment (2010) demonstrated the distribution to be: 21.6% Pakistani or Bangladeshi, 26% Black and 11.7% Indian. The Greater London Authority (GLA) in the UK has forecasted that, based on age, gender and ethnicity, the number of people with predominantly Type 2 diabetes in LBN will be more than 20,000 by the year 2026. More recent data has shown a steady increase in the prevalence of diabetes in the LBN between 2011 (6.9%) and 2014 (7.6%) (GLA 2015) in addition to the second highest percentage (25%) population growth in England (ONS 2016). An overview of key statistics of LBN is illustrated (see Table 1.2)

Table 1.2

Key statistics for the London Borough of Newham (LBN)

LBN Key Statistics 2011	LBN Key Statistics 2017
• 246,000 population (GLA 2009) • Youngest age structure in England and Wales (London Poverty Profile 2009) • 70% non-white. Second most diverse population in the UK. (London poverty profile 2009) • 86% of residents live in areas classed amongst the fifth most deprived areas in England (Health Profile 2010) • 3rd highest estimated total diabetes prevalence (YHPO 2010) • Diabetes mortality and emergency admission rates higher than the England average (Health Care Commission 2008)	• 332,817 population (GLA 2015) • 73.5% non-white population • Prevalence of T2 diabetes of 7.6% in individuals 17 years and older

1.4 Rationale for thesis enquiry

Diabetes has been described as one of the greatest health challenges facing the United Kingdom (UK) today and has been identified as the only long-term condition which showed a significant predicted increase in the prevalence rate as well as an absolute increase in numbers of cases (NHS London, 2007).

Diabetes constitutes not just a significant financial burden on the UK's National Health Service (NHS) but also has profound human and society costs. The direct and indirect cost implication of diabetes in England and Wales for the period 2010/2011 was calculated at £23.7 billion with a predicted increase to £39.8 billion by 2035/36 (Hex et al., 2012). Direct cost was associated with the management of avoidable complications however indirect costs included sickness, loss of productivity and informal care. The diabetes prevalence and socio-economic profile of LBN (see Table 1.2) provides a worrying landscape for health and social care. To mitigate against what appears to be a diabetes related 'ticking time-bomb' a local understanding of factors which influence engagement with diabetes services and health related outcomes (morbidity, mortality and cost) is essential.

Non-attendance is a manifestation of dis-engagement with healthcare. It has been reported that evaluation of non-attendance tends to have an individual (demographic), clinical (outcomes) or service delivery (accessibility, administrative and communication) focus (Patterson et al., 2009, Gucciardi 2008, Lawson et al., 2005). However, what is lacking is a critical analysis and understanding of why people do not attend appointments as this knowledge is needed to develop effective non-attendance reduction strategies (Heneghan et al. 2007). With the increasing prevalence of diabetes in the local borough, high non-attendance rates and poorer health outcomes, a comprehensive enquiry is required to inform non-attendance reduction strategies which are effective and receptive to the need of the local population.

1.4.1 **Engagement**

The term engagement has various definitions in the context of healthcare with no universal definition (Barello et al., 2012). One definition of patient engagement includes an individual perspective whereby the individual has healthy behaviours that facilitate compliance with healthcare (Lehman et al., 2002). Another definition which provides a broader context of engagement refers to not just individual behaviour but the relationship with healthcare organisations or clinicians that fosters patient interaction (Schoenbaum and Audet 2005). This description recognises the reciprocal relationship that is needed facilitate engagement. Schoenbaum's comprehensive definition is supported by a review of literature which reports that core elements of engagement are equity, empowerment, participation and self-determination (Wallerstein et al., 2006, Chavez et al., 2007, Salway et al., 2007). These core elements are subject to individual, societal and structural influences which are interdependent and as such should not be viewed in isolation.

Individual influences are rooted in an individual's sense of identity which may be determined by factors such as family structure, cultural origin, language, religion and political beliefs. Societies are structured in variable ways and each communities' social structure may determine how and with whom individuals interact. The level of interaction is subject to influences such as social, cultural, religious and political networks. Structural influences include and are not limited to education, employment, social care, transportation and policy. It is suggested that a critical understanding of all factors (individual, societal and structural) is required if meaningful and effective engagement is to be achieved. Relationship building between patients and organisations in addition to the cultivation of effective multi-sectorial partnership is suggested as a means of improving engagement (Sapir et al., 2017).

Empirically, the extent of engagement with healthcare services in localities which have high levels of socio-economic deprivation, is influenced by key factors such as the ease of access and utilisation of services and health inequalities which will be discussed sections 1.4.2 and 1.4.3.

1.4.2 Access and utilisation of services

Empirical evidence has identified poor engagement (access and utilisation of services) of Black and Minority ethnic (BAME) and vulnerable groups with healthcare services (Goddard 2001, Dixon-Woods 2005). The definition of access is relative to some countries (Goddard 2001) and is influenced by factors such as quality, information, personal inconvenience and cost. Access in the United States tends to refer to whether a person has health insurance whereas in Europe, access refers to the "ability to secure a specified range of services" (Goddard, Smith 2001, p.1151). Utilisation is a defined unit of measurement and varies for example number of contacts with a General Practitioner, waiting times for appointments or attendance at appointments.

Despite extensive literature on inequality in access and utilisation of services amongst disadvantaged groups (Gray et al., 2006, Walker et al., 2011, Cauch-Dudek 2013), there are still gaps in the understanding of the causes of disengagement with healthcare services. Organisational barriers to the access and utilisation of services have been highlighted in empirical research. The concept of porosity and permeability of services as enablers or barriers to accessing services has also been explored (Dixon Woods 2005). Services which require minimal effort and negotiation to use are deemed to have high permeability whereas services which require greater effort and negotiation to enter and maintain engagement with are deemed to be less permeable. High non-attendance rates are a reflection of services which are less permeable and require qualitative evaluation.

Locally, a survey commissioned by Newham Primary Care Trust and conducted by IPSOS MORI (2009) identified poor engagement with services and lack of flexibility of services as key factors which contributed to poor self-management and outcomes for the patient with diabetes. The impact of poorer health outcomes is increased health expenditure due to the inappropriate use of services and management of avoidable complications of ill-health.

1.4.3 Health inequalities

Health inequalities are measurable and have been defined as "population-specific differences in the presence of disease, health outcomes or access to health care" (Goldberg et al, 2004). Health inequalities are multifactorial and complex and are evaluated in the context of mortality, morbidity and healthcare access (Goldberg et al., 2004).

There are inherent biological differences between individuals such as genetic determinants which influence susceptibility to diseases and ill-health. The World Health Organisation (WHO) states that it may be impossible or ethically or ideologically unacceptable to change biological health determinants and so in this instance, health inequalities are unavoidable. However once biological factors and the aetiology of illness are excluded, health and illness become the social products of society due to social, economic and cultural characteristics of the society (WHO 2009).

The disparities seen within diabetes such as a higher prevalence rates and poorer outcome amongst minority ethnic groups and people in areas of high deprivation are a result of health inequalities. Conceptual frameworks utilised in health inequalities demonstrate the inter-relationship between three core dimensions (Dalgreen and Whitehead (1991), Solar & Irwin (2007), Hankivsky et al. (2011). These core dimensions of health inequalities have been identified as being structural, organisational and individual. Structural drivers involve the stratification of society and are driven by global, national and local economic and social policies. Organisational drivers are directly influenced by national and local policies and provide the interface with the local population. Individual drivers have been identified as being psychosocial in nature but are also directly influenced by both organisational and structural factors. Recommendations to address health inequalities have included: improving daily living conditions, tackling the inequitable distribution of power, money and resources, measuring and understanding the problem and assessing the impact of action Marmot (2005). Marmot highlighted that the major determinants of health are social therefore the remedies must be social. In a subsequent review, Marmot (2012) stated that health inequalities are actually widening instead of reducing. This follow up review demonstrates the complex and challenging nature of addressing health inequalities.

Health inequalities have been described as pervasive, difficult to address and expensive (DUK 2006). Reducing health inequalities is a mammoth task however researchers have identified factors such as improving health literacy and access to services as means of making steady progress. Sorensen et al. (2012) elaborated that health literacy needs to be linked to economic growth and socio-cultural and political change. Research conducted within the London Borough of Newham (LBN) highlighted the impact of health literacy on engagement with services and health outcomes (Greenhalgh et al 2011). Factors such as the ability to navigate through healthcare services and transform information to action were identified as determinants of access. Within the local context health inequalities have been characterised as being location, gender, socio-economically and ethnicity based. For example, men and women from the most deprived group have a four-year shorter life expectancy than those in the least deprived group (Health Profile 2008). Health inequalities are routinely examined within the confines of several framework.

1.5 Theoretical Frameworks

Van Ryn and Heaney (1992) defined theory as: “systematically organized knowledge applicable in a relatively wide variety of circumstances devised to analyse, predict or otherwise explain the nature or behaviour of a specified set of phenomena that could be used as the basis of action.”

Due to health inequalities being described as social products of society, a sociological framework was firstly examined. Health inequalities pertain to not just morbidity and mortality but extends to access and utilisation of services. Health inequalities can be examined from the sociological perspective of structuralism which is rooted in the Marxist theory which focuses on the interplay between the socio-economic, legal and political (macro) elements of society and social relationships/construct within the society. Marx argued that the organisation of the macro elements in society creates disparities in power and social relationships thereby creating social inequalities (Marx 1978) Structuralism therefore focuses on "how people's social behaviour, values and attitudes are largely determined by the organisation and structure of the society in which they live and more particularly, the social groups to which they belong in their society" (Larking, 2011, p. 19). Another health inequalities framework which was examined for use is this thesis was the Intersectional Theory. This theory provides a framework that takes account of the personal, societal, economic and political interplay and its impact on health inequities (Hankivsky et al 2011). However, this theory was not deemed to be appropriate as it's a feminist construct and not commonly used in the context of access and utilisation of health care services. Fundamentally, most theories or health conceptual frameworks which focus on inequalities have highlighted the need for social and structural cohesion and reform as a means of reducing the disparities that persist.

Due to the multifactorial and complex nature of health inequalities of which dis-engagement is a manifestation, two further frameworks were examined and chosen to underpin this thesis as they provide a robust structure for the evaluation of all components of the determinants which are known to influence dis-engagement (individual, organisational and structural).

1.5.1 Health inequalities framework

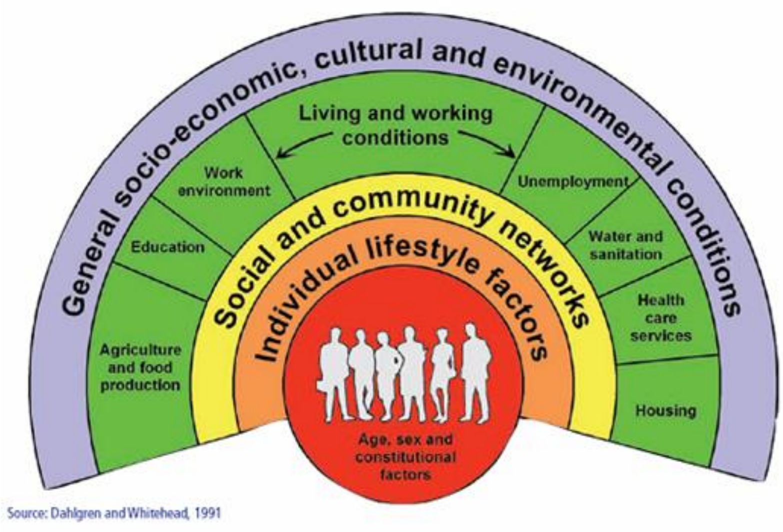
This framework examines the micro and macro influences on health and focuses on the social, economic and ecological theory of health. It highlights the influences on health which are subject to modification either on a personal, community or structural level. This framework contextualises the inter-relationship between people, social determinants and the government and rationalises the need for a cohesive, seamless and efficient health and social care policy if health inequalities are to be redressed both locally and nationally.

Health inequalities are evident within the local borough and are attributed to both its demographic and socio-economic profile. Because of the demographic, socio-economic and health outcomes profile of the local borough, Dahlgren and Whitehead's Social Model of Health (1991) was considered useful for framing this case study (see Figure 1.1). Core elements of this framework are also used to categorise and discuss findings in the research element of this thesis.

Figure 1.1

Dahlgren and Whitehead, 1991

Social Model of Health



Source: Dahlgren and Whitehead, 1991

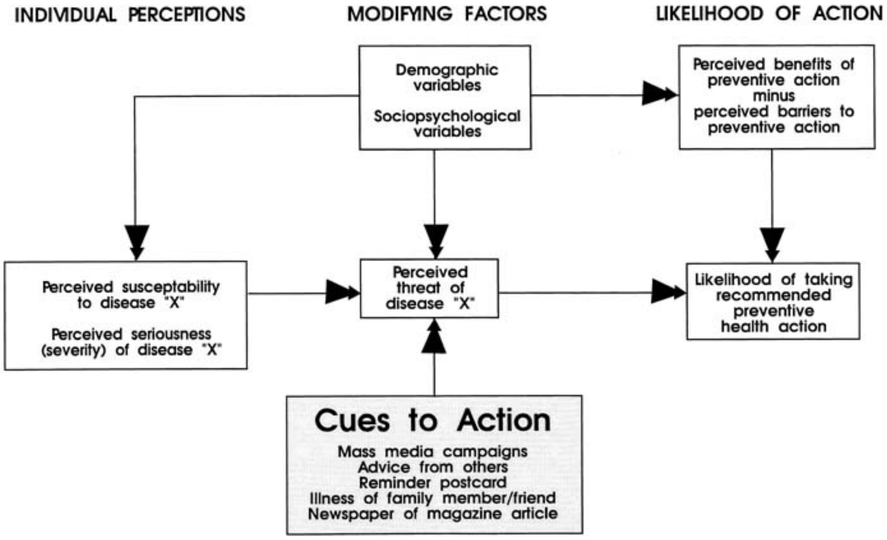
1.5.2 *Psychosocial framework*

Patient-centred evaluation of health seeking behaviours is commonly conducted in the psycho-social context as opposed to socio- economic context. Factors such as lack of motivation, self-determination and empowerment are significant barriers to engagement and are heavily influenced by psychological and social influences. Therefore a psycho-social framework was deemed necessary for analysis and interpretation of the research component. A common model which was developed in the 1950's and used to evaluate the interplay between psycho-social elements and their influence on health-related decision making is the Health Belief Model (Hochbaum 1958). The HBM was first developed to explain the poor uptake of medical screening programmes by the US Public Health Service and provided a template for evaluating health seeking behaviours on an individual level and as such examines issues such as motivation, understanding and the level of importance an individual attach to their health and engaging with health services (see Figure 1.2). There have been adaptations to the model (Rosenstock et al, 1988) since it's development, however, its principles are relevant and applicable to understanding the disengagement identified in this thesis which is manifested in non-attendance.

Figure 1.2

The Health Belief Model

Rosenstock et al. 1988



Nationally and internationally, there are key policy drivers in relation to health inequalities which are discussed.

1.6 Policy context

In 1980, the causes and impact of health inequalities in the UK was brought to the forefront (Black 1980). The Black report highlighted the need for the examination of health in a wider context particularly the relationship between health and the wider social determinants. In the UK; there have been several key health inequalities policy documents since the Black report, which have served to inform strategies aimed at reducing health inequalities. Globally, the reduction of health inequalities is a key priority for the WHO hence the commissioned report 'Social Determinants of Health' (Marmot 2005).

Key health inequalities are summarised in Table 1.1. Over time, these policies have illuminated the underlying determinants of health inequalities and the actions required to redress inequalities. The complexity and pervasiveness of health inequalities is evident due to little improvement as reported in the Fair Society Healthy Lives – 2 years on report (Marmot 2012). More recently, it was reported that there has been little improvement in health inequality indicators such as life expectancy, life satisfaction, work and income and early years development with deprivation related variations (Marmot 2017).

Table 1.1

Health Inequalities policy documents

Policy	**Author**	**Year**	**Summary**
The Black Report	D. Black	1980	Introduced a framework highlighting the layers of influence in the context of health. It highlighted both the structural and behavioural components of health inequalities
Independent inquiry into health inequalities	D. Acheson	1998	Highlighted the profound effects of the wider determinants such as poverty and social exclusion on health inequalities
Tackling health inequalities: A programme for action	Department of Health	2003	Highlighted the impacts of health inequalities and the need for local and sustainable approaches to reducing health inequalities. These approaches should be an integral part of policy development and change.
Social Determinants of Health	M. Marmot	2005	Examined the global context of health inequalities and its impact; highlighting that health status is of concern to all policy makers not just those involved in health policy. It stressed the need to “turn public–health knowledge into political action”.

Fair Society Healthy Lives	M. Marmot	2010	UK examination of health inequalities. Six key policy objectives were identified as the measure for evaluating health inequality reduction
Fair Society Healthy Lives – 2 Years On	M. Marmot	2012	The indicators show an increase in life expectancy. However there continues to be variations in life expectancy between communities with different deprivation profiles. The report recommends that the government needs to level the social gradient to reduce health inequalities.

The core components of the thesis will be outlined in section 1.7.

1.7 Thesis components

A summary of each component of this thesis is discussed in the sections below:

1.7.1 Case study (service audit)

The case study examined non-attendance at the diabetes out-patient service and utilised routinely collected data. The case study aimed to firstly quantify the extent of the problem (non-attendance) and evaluate the trends based on geo-demography and deprivation to understand the likelihood of attendance.

1.7.2 Literature Review

A critical narrative review of community health worker (CHW) and Peer support interventions was conducted to systematically evaluate their effectiveness, cost-effectiveness and sustainability.

These interventions were chosen because better self-management by patients has been identified as a key factor which improves health outcomes by positively impacting on both disease specific clinical outcomes such as HbA1C, self-reported outcomes such as improved health literacy and empowerment and engagement with services (Jack 2003). Therefore, from a clinical perspective the decision was made to review these two educational interventions which are underpinned by psycho-social frameworks. This review aligns with the third standard of the National Service Framework (NSF) for diabetes (DH 2001) which highlighted the importance of empowering patients with diabetes and encourages partnership in decision making and support to enable more effective lifestyle choices and self-management.

1.7.3 Research study

The research element of this thesis was conducted in two phases.

Phase one was conducted during the period May to October of 2013 and utilised the findings of the case study as its foundation. It aimed to qualitatively explore the factors influencing diabetes out-patient attendance by patients categorised as African, Bengali and Pakistani. These three ethnic groups were identified from the case study analysis as being significantly less likely to attend appointments when compared to patients from other ethnic groups.

The study aimed to answer the following questions:

- What are the barriers and enablers to diabetes outpatient attendance/non-attendance
- What approaches are needed to improve attendance?
- Are there unmet needs?

Full Ethical approval for this study was granted by Berkshire Research Ethics Committee on March 7th 2013 and NHS Trust Research and Development approval granted in May 2013.

Phase two was subsequently conducted during the period April 2016 to January 2017. This phase was deemed to be essential due to the emergent theme of ‘ownership’ and the complexity of this concept. In this phase of evaluation, ownership was examined in the context of Patient Activation.

The study aimed to answer the following questions:

- Can patient activation be used to predict the likelihood of attendance?
- Can patient activation be used to identify specific unmet needs of non-attendees?

- What sample size would be needed to detect differences in activation levels between patients who attend and do not attend appointments?

Proportional Ethical approval for Phase two of this study was granted by the Mid-West and Edgbaston Research Ethics Committee in December 2015 and NHS Trust Research and Development approval granted in March 2016.

1.7.4 Dissemination artefact

The artefact from this thesis is an article submitted for publication in a peer reviewed journal based upon the findings of the geo-demographic analysis conducted in the case study. The journal Health and Place was chosen based on its focus, audience, reach and impact factor.

1.8 Chapter summary

This chapter provided the context and purpose for this thesis with a description of its background, rationale for the work undertaken, aims and structure. The increasing global burden of illness due to diabetes in particular the personal, societal and financial implications have been demonstrated. The health profile, diabetes prevalence and poorer diabetes related outcomes of the local borough within which this thesis has been undertaken highlight the need for the enquiry posed by this thesis. The factors which influence engagement/disengagement with healthcare services have been discussed and are framed in the context of health inequalities. The historic policy context of health inequalities in the United Kingdom over time has been highlighted and demonstrates the complexity and pervasiveness of health inequalities and the slow rate of progress in addressing these inequalities. In addition, the frameworks which will be used to examine the results of the findings of this thesis have been described.

The following chapter is a detailed description of the first component of the thesis (case study) which is a quantitative retrospective analysis of diabetes out-patient attendance data for the period 2004 to 2009.

CHAPTER 2

CASE STUDY

Diabetes outpatient attendance in a U.K inner London Borough: A retrospective analysis utilising geo-demographic profiling

2.1 Introduction

The case study detailed in this chapter was conducted as a service evaluation audit of diabetes non-attendance data and undertaken during the period August 2010 to August 2011. A case study is an in-depth investigation of a single person, group, event or community with data gathered from a variety of data sources and using different methods to explain a phenomenon (Swanborn 2010). Case studies are designed to provide rich information about an individual or group and an insight for further research.

Within health and social care, there are two main categories of evaluations namely, service evaluations/clinical audits and research with distinct differences between both types of undertakings. NICE 2003 defined a service evaluation/clinical audit as “a quality improvement process that seek to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change.”

In accordance with IRAS and NHS R&D guidance, the evaluation conducted for the case study was categorised as a service evaluation therefore did not require ethical approval. Non-the less, consultation and authorisation from the Trust’s Information Governance department was required prior to undertaking this evaluation to ensure that its conduct was in accordance with data protection guidance and policy.

2.2 Background

The national non-attendance rate for all outpatient clinics during 2008 in the UK was approximately 11% (HSJ 2009) which is only a one percent reduction when compared to the period 1996 to 1997(DH 1997). Non-attendance rate is measured in two ways: from the Department of Health quarterly activity return or by using aggregated data from secondary care services for example outpatient encounters. Outpatient data is felt to provide a more accurate picture of non-attendance than quarterly returns.

The diabetes services in Newham serve one of the most culturally diverse and deprived areas in the UK. This creates multiple challenges for not only the clients but the multidisciplinary care team. Patients with diabetes who require specialist management are referred to the diabetes out-patient service at the local acute hospital by their general practitioner (GP) in accordance with local protocols. Unfortunately, there has been a high incidence of outpatient non-attendance within the diabetes service for many years with an approximate range of 25 to 41 per cent depending on age category (adult or young adult (aged 16 – 25 years)). The incidence of repeat non-attendances per patient is addressed by Newham University Hospital's policy on outpatient attendance. The Trust's guidelines specify that patients who do not attend for two consecutive appointments should be discharged back to their general practitioner.

The GLA forecasted that based on age, gender and ethnicity, the number of people with predominantly Type 2 diabetes in Newham will be more than 20,000 by the year 2026. This projected increase and associated management of diabetes will produce a significant financial burden for Newham's healthcare organisations. The National Survey of People with Diabetes (2006-2007) reported a higher rate of hospital clinic attendance within Newham Primary Care Trust (28.6%) as opposed to England's average (19%). Conversely, there is a lower rate of attendance at general practitioners in comparison to the England's average (65.9% vs. 78.3% respectively). The forecasted Figure for diabetes indicated above and the higher than average outpatient attendance has highlighted the need to develop a better understanding of local non-attendance.

2.3 Approach

This case study was a retrospective audit of diabetes outpatient attendance for Newham University Hospital (NUH) which is in the London borough of Newham (LBN) using routinely collected data for the period April 2004 to

March 2009. During the period reviewed, diabetes out-patient services within the LBN were offered at four locations throughout the local borough. An informal interview was conducted with a consultant diabetologist to establish the rationale for the configuration of services and selection of locations for delivering the current service. It was indicated by the clinician that the existing diabetes services were configured within the community based on space and capacity as opposed to need, with minimal consultation with patient groups.

This evaluation of the outpatient attendance data was two-fold as it aimed to firstly examine the overall trends in attendance based on the demographic characteristics of patients, location of clinics, clinician seen and appointment type (new or follow-up). The patients within the full dataset resided both within and outside the local borough.

The second aspect of this evaluation aimed to examine the trends in attendance based on demographic characteristics and local geography therefore all patients without a local postcode were excluded from this analysis.

Due to the socio-economic and health profile of the London borough of Newham – the population served by the Trust, (see Figure 1.1 chapter 1), it was important to investigate attendance in the context of local geography and deprivation as defined by Noble's Indices of Deprivation (2007). Newham has a mobile migrant population. However, data obtained from the Office of National Statistics (ONS 2004) indicated that irrespective of migration, there is ward based ethnicity clustering throughout the borough. Clustering of ethnic groups into deprived neighbourhoods has been attributed to racial inequalities and prejudice over generations (Barnard 2011). This study therefore aimed to examine the attendance data in a geo-demographic context to gain a comprehensive insight into local trends.

It is important to highlight that this study focused on the number of scheduled appointments per year and the outcome of either attended or did not attend as opposed to the number of appointments per patient per year. It has been reported that the manner in which the sample for investigation is defined has an influence on the interpretation of findings (Griffin 1998). In this thesis, number of scheduled appointments has been chosen because of the cost infrastructure associated with out-patient appointments. Following discussions with one of the consultant diabetologist, it was confirmed that the diabetes service level agreements with General Practitioners was based on the number of appointments per year as opposed to the number of appointments per patient per year.

2.4 Aims

The main purpose of the case study was to conduct a retrospective analysis of diabetes outpatient non-attendance at an East London acute NHS Trust to examine trends in attendance and explore factors which influence attendance.
To establish a comprehensive view of diabetes outpatient attendance during the period in question, this study aimed to examine:
Firstly

- Examine the trends in attendance for diabetes outpatient appointments
- Examine the demographic characteristics of all patients who did not attend for diabetes outpatient appointments (local/non-local residents)
- Examine the clinical context of non-attendance (clinician, clinic location and type of appointment (new/follow-up).

Secondly

- To examine the demographic and geographic distribution of non-attendance for local residents
- To evaluate whether a relationship exists between attendance, demographic characteristics and deprivation.

2.5 Methods

A quantitative research method was used to undertake this evaluation. Quantitative research is framed within the positivist paradigm as its roots are situated in natural sciences and as such, deemed to be objective. Quantitative research is deductive, involves hypotheses testing, predicts relationships between variables and its findings can be generalised (Hart, 1998: 83). Therefore, it is deemed to be a scientific method which produces valid, reliable, generalisable and replicable knowledge.

2.5.1 Data collection

The primary data source for this case study was diabetes outpatient clinic attendance figures for the period 2004 to 2009. The data was obtained from the Health Intelligence department of the local NHS acute trust and checked for accuracy by the Trust's Capacity and Information Officer. The data consisted of all patients seen in the diabetic out-patient clinics of the local acute hospital aged sixteen years old and greater. This sample population therefore included all patients with a diagnosis of Type 1, Type 2 or Gestational diabetes (GDM).

Missing data were identified (gender and ethnicity) and subsequently inserted utilising the Electronic Patient Record (EPR) system.

Demographic information in the data set included date of birth, gender and ethnicity. The geographic information included was patients' postcode and location of clinic appointments.

Advice was sought from the Trust's research and development department to determine whether ethical approval would be required for this evaluation. Based on IRAS guidance, this evaluation was categorised as an audit therefore approval was not required. Recoding of the data ensured that all personally identifiable data was anonymised and the data was stored in accordance with Information Governance data guidelines.

2.5.2 Data set

A retrospective search for the period March 2004 to March 2009 was conducted for all scheduled appointments coded on EPR as 'diabetes'. The dataset provided comprised of all scheduled appointments dating from November 2004 to March 2009 as opposed to April 2004 to March 2009. The discrepancy in timeline was due to a transitional change in the IT recording systems (PAS to EPR) during the period April 2004 to October 2004.

To provide a robust dataset, both podiatry and weight management appointments were excluded due to minimal numbers. The appointments which formed the final dataset were coded within the following categories:

- Doctor (including Registrar) - new/follow-up
- Diabetes nurse specialists - follow-up
- Dietician - new/follow-up

2.5.3 Data Exclusions

To establish the final records for only attenders and non-attenders, the following appointments were excluded from the dataset:

- Cancelled, postponed, rescheduled
- Pending
- Phone appointments
- Confirmed
- Checked out

A definitive attendance outcome could not be established for appointments coded as confirmed or checked out due to inconsistencies in recording therefore these were excluded from the dataset. A total of 1752 appointment were recorded as confirmed however in each instance, the outcome was coded as did not attend (DNA). A minimal number of appointments were recorded as checked out however in some instances the outcome was coded as attended and in others; DNA. Due to the inability to validate the accuracy of the recorded outcome, these appointments were also excluded.

2.5.4 Data handling: Demographic information

Age:

To accurately calculate the patients age at the time of their appointments throughout the time span under investigation SPSS was utilised. The patient's date of birth and date of their appointment was used to facilitate this calculation. Age in years was computed utilising SPSS functions.

Ethnicity:

Ethnicity was not recorded on the original dataset provided. Ethnicity is self-reported and routinely collected when patients book-in for an appointment. Coding is conducted in accordance with the National Codes for the UK (Table 2.1).

To complete the dataset, patient's hospital numbers were utilised to manually extract their ethnicity from the EPR (Electronic Patient Record) system. To minimise transcription errors, hospital numbers from the dataset were copied and pasted into EPR. Ethnicity codes were then copied and pasted into the dataset. The dataset was provided as a Microsoft Excel document therefore the functions of find all and replace within the workbook were selected.

To undertake the demographic analysis, all 17 (16 + 1) ethnic categories were used as determined by the ONS (2001) (Table 2.1). However, in order to undertake the geographic analysis, the seventeen ethnicity codes were aggregated into six individual categories in accordance with the Office of National Statistics ethnicity categorisation (ONS 2001) (Table 2.2). Aggregation into the six recommended ethnic categories is a common practice when examining large datasets where a broader categorisation does not minimise findings (CEG 2011). For the aggregated ethnic categories, patients whose ethnicity was recorded on EPR as not stated, not asked or refused were categorised as not stated. This category (not stated) was included in the analysis as it accounted for five percent of the overall number of appointments and provided other elements of interest.

Table 2.1

Ethnic categories (ONS 2001)

National Ethnicity codes (16 + 1)

White	
A	British
B	Irish
C	Any other White background
Mixed	
D	White and Black Caribbean
E	White and Black African
F	White and Asian
G	Any other Mixed background
Asian	
H	Indian
J	Pakistani
K	Bangladeshi
L	Any other Asian background
Black	
M	Caribbean
N	African
P	Any other Black background
Other	
R	Chinese
S	Any other Ethnic group
Z	Not stated

Table 2.2

Aggregated Ethnic categories (ONS 2001)

Category	**Composition**
White	White British, White Irish, Scottish, Welsh, Eastern European, White other
Black	African, Caribbean, Black British, Somali, Black other
Asian	Indian, Pakistani, Bangladeshi, Other Asian
Mixed	Black/White, Asian/White, Other Mixed
Other	Arab, Middle Eastern, Chinese, Vietnamese, Other,
Not stated	Not stated, Not asked and Refused

Geographic information

The postcodes for the London Borough of Newham and their associated Super Output Areas (SOA) were obtained via the UK Borders (**edina.ac.uk/ukborders).** This organization falls within the remit of the Office of National Statistics (ONS). However, the governance of this data lies with the University of Edinburgh**.**

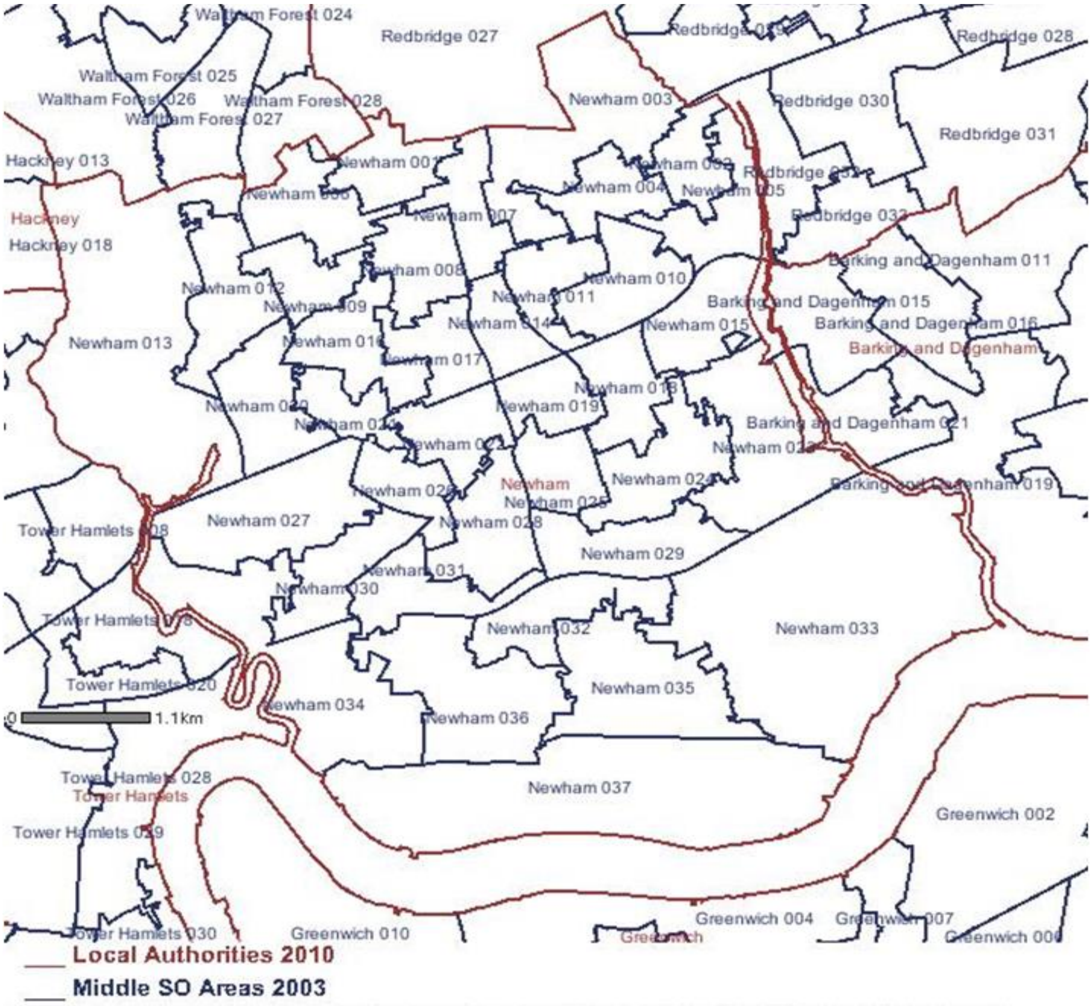
Super output areas (SOA) are a statistical geography published by the Office for National Statistics (ONS). ONS introduced SOAs to replace electoral wards as the standard geography for the collection and dissemination of small area statistics. They are made up of three hierarchical layers: lower, middle and upper that all fit within the borough boundary. In comparison to electoral wards, they are more consistent in size with each layer having a specified minimum population in order to avoid the risk of data disclosure. Due to the consistency in size, SOAs are utilised for conducting comparison over time. Unlike wards they are not subject to frequent boundary changes and are very useful for small area statistics which enable data to be built upon.

Lower layer super output areas (LSOA) were created by automatically aggregating the 2001 Census output areas and have a minimum population size of between 1,000 and 1,500 persons (400 households). A middle layer super output area (MSOA) has a population size of 5000 persons or 2000 households (ONS 2004).

Within LBN, there are 159 LSOAs and 37 MSOAs. For the purpose of the geo-demographic analysis, the MSOA codes were selected in order to simplify the graphical representation of the results. Once exported into SPSS, the MSOAs were recoded numerically; 1-37 (see Appendix 1). The numeric coding was done in parallel with LBN geographic locators (E02000714 to E0200750) as per the Office of National Statistics (see Figure 2.2). However for the analysis of geography and deprivation LSOAs were used due to their associated deprivation ranks and scores as provided by the ONS. The 159 LSOAs for Newham were further recoded into deprivation quintiles with quintile 1 being least deprived and 5 most deprived.

Figure 2.1

MSAOs for London Borough of Newham



Ref. www.Neighbourhoodstatistics.gov.uk

2.6 OVERVIEW OF DEMOGRAPHIC AND CLINICAL DATA

2.6.1 Demographic Data presentation

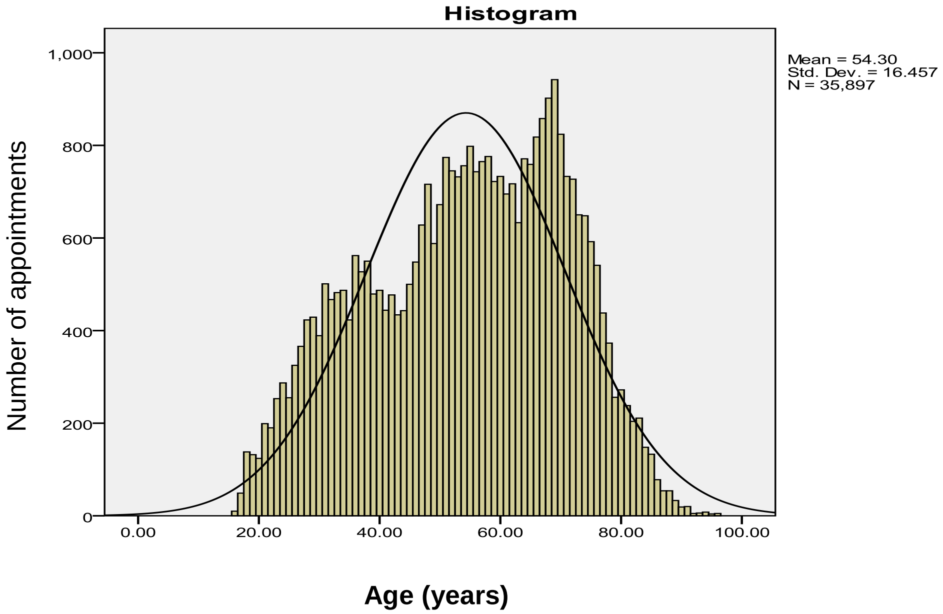
Descriptive statistics were used to examine the characteristics of the individual demographic variables (age, gender and ethnicity). The total number of validated appointments during the period Nov 2004 to March 2009 was N = 35997

Age

The age range for this patient population was 16 to 96 years old. Age was shown to be normally distributed with a mean age of 54.3 years ± 16 years (see Figure 2.2). The distribution of age was validated by undertaking a one-sample Kolmogorov-Smirnov test. This non-parametric test indicated that age was normally distributed with a mean of 54.3 and standard deviation of 16.46.

Figure 2.2

Age distribution



Gender

The distribution of appointments recorded indicated a gender difference. There were a greater number of appointments for females (56.2 %) as opposed to males (43.8 %).

Ethnicity

The original data was coded in accordance with the National Ethnicity codes; N=17 (see Figure 2.3). Due to the shift in focus of the analysis which explored local geography and deprivation, the 17 categories were aggregated into the six combined ONS categories (ONS 2001). The aggregation of ethnicity is standard practice particularly when handling large data sets and is evident in existing literature which reflects similar analyses (CEG 2011). Fifty-two percent of all appointments were for patients categorised as Asian (see Figure 2.4)

Figure 2.3

Disaggregated ethnicity 2004-2009

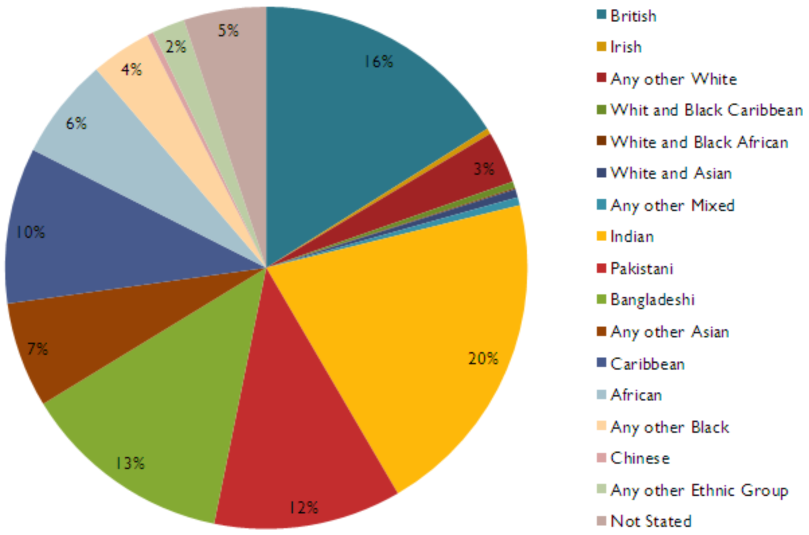
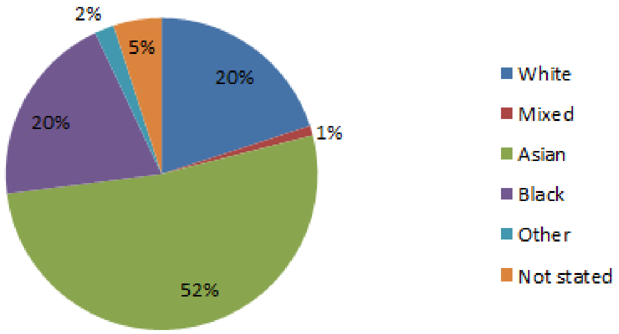


Figure 2.4

Aggregated ethnicity 2004-2009



2.6.2 Clinical Data presentation

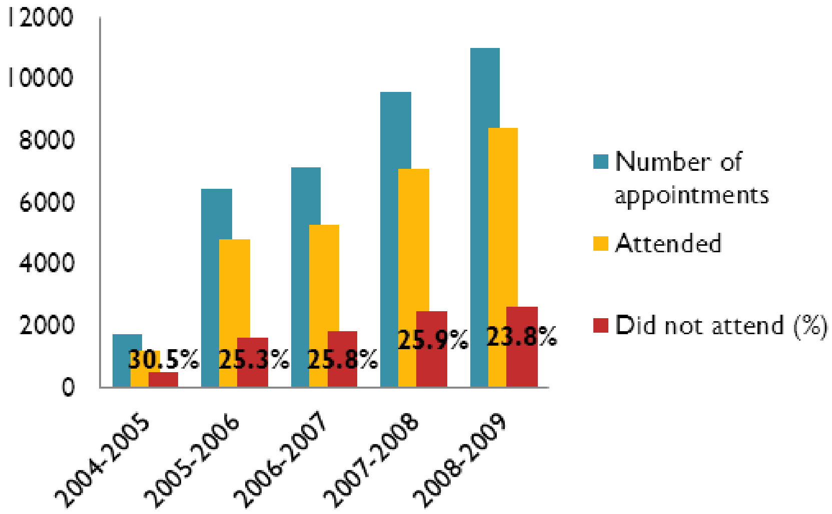
Descriptive statistics were used to illustrate the characteristics of the individual clinical variables (overall attendance, clinician/type of appointment and clinic location)

Attendance

Overall, there was a year on year increase in the number of diabetic appointments with an average non-attendance rate of twenty-five percent (see Figure 2.5) for three consecutive years (April 2005-March 2008). However, a reduction of two percent in the non-attendance rates was seen for the period April 2008 – March 2009. The year 2004-2005 illustrated the highest non-attendance rate but his was due to the data having been recorded for a shorter time (6 months). This shorter time was due to the transition in migrating from one data system to another. The reduced numbers for this time frame therefore created wider confidence intervals and does not provide an accurate reflection of the annual non-attendance rate.

Figure 2.5

Attendance profile 2004-2009



Clinician

The distribution of appointments per clinician and whether they were for a new or follow-up appointment was explored. Nurse appointments were only recorded as follow-up appointments and accounted for 55.5% of all appointments. Doctors overall appointments were 42.2% (35.9% follow-up / 6.3% new). Dieticians overall appointments were 2.4% (1.4% new / 1% follow-up).

Clinic locations

Clinics were conducted at four locations within the local borough with the primary locations being the diabetes centre, located at Shrewsbury Road Medical Centre and the local acute hospital. There were two satellite centres within a two-mile radius of either respective primary location. Non-attendance per clinic location ranged from 18% to 41% (see Figure 2.6). The clinic locations and volume (percentage) of appointments is illustrated (see Figure 2.7).

Figure 2.6

Location based attendance profile – number of recorded appointments (percentage) per location 2004-2009

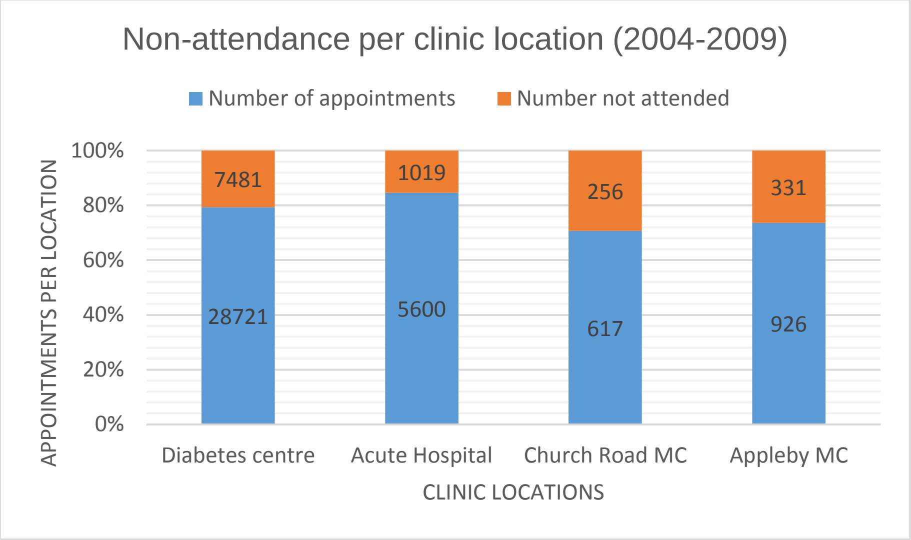
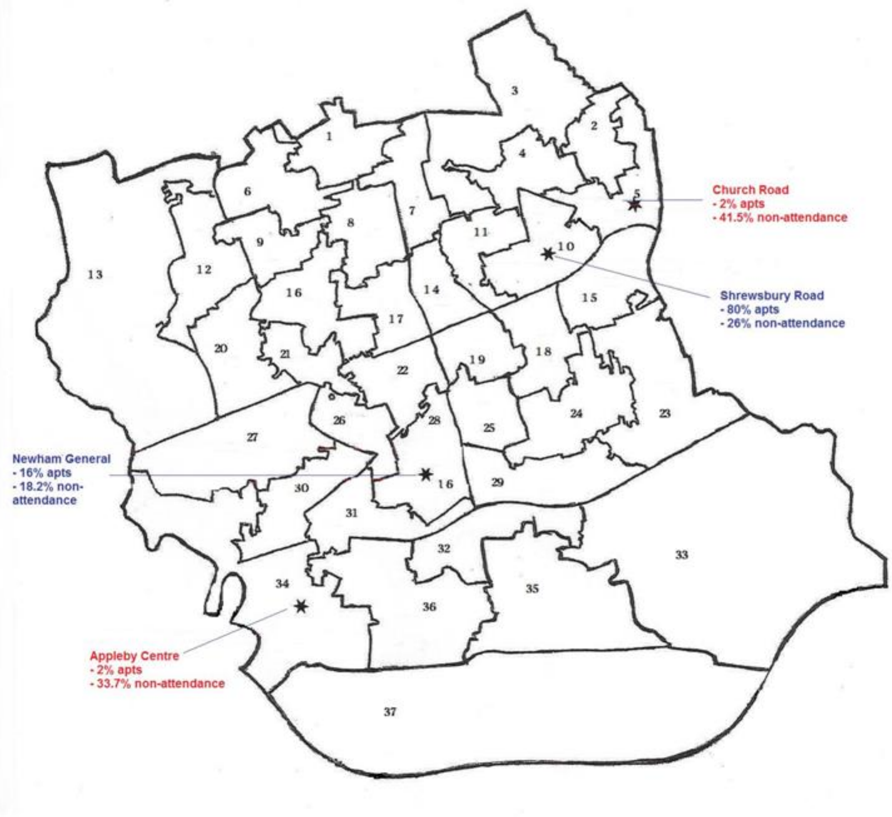


Figure 2.7

Clinic locations

Volume of appointments and rate of attendance (percentages)



Church Road
- 2% apts
- 41.5% non-attendance

Shrewsbury Road
- 80% apts
- 26% non-attendance

Newham General
- 16% apts
- 18.2% non-attendance

Appleby Centre
- 2% apts
- 33.7% non-attendance

2.7 DEMOGRAPHIC AND CLINICAL DATA ANALYSIS

The demographic and clinical data were analysed for **all** diabetic appointments which were booked during the period November 2004 to March 2009. The patients included in this analysis therefore resided locally or were from out of the borough. This analysis was conducted by utilising SPSS (Version 18) under the guidance of the School of Health Science's statistician.

The first phase of analysis was performed using contingency analysis to establish the level of statistical differences in attendance for two or more independent groups. Crosstabs was utilised to analyse the relationship between the independent categorical variables (gender, ethnicity, clinic location and type of appointment) and the dependent variable (attendance). Due to the sample size, the chi-square test was chosen to determine the level of significance in relation to attendance/non-attendance and males/females.

Utilising the 'explore' command in SPSS, age was explored to establish its distribution. Age (continuous variable) was shown to be normally distributed (see Figure 2.1). An Independent T-test was then done to compare the mean age between the patients who attended and did not attend appointments.

2.8 RESULTS

2.8.1 Demographic Analysis (cross tabulation)

Gender

The analysis indicated a highly significant ($p<0.001$) difference in non-attendance between men and women. The results are presented as a percentage with the corresponding P value (see table 2.3). The total number of appointments included in this analysis was 35864. Missing values were excluded (N = 33)

Table 2.3

Cross tabulation of gender and non-attendance

Question	Men (N=15732)	Women (N=20132)	P value
Number of appointments not attended	27.5% (4325)	23.7% (4726)	<0.001

Ethnicity

The attendance per ethnic group was analysed and indicated a highly significant (p<0.005) difference in non-attendance between ethnic groups. The results are presented as a percentage of the total number of appointments per ethnic group and the corresponding P value (see table 2.4).

The total number of appointments included in this analysis was 35860. Missing values were excluded (N = 37)

Table 2.4

Cross tabulation of ethnicity and non-attendance

No of appointments attended	Total number of appointments (N)	% of appointments not attended	P value
British	5756	23.1	<0.001
Irish	128	24.2	<0.001
Any other white	1159	28.7	<0.001
White and Black Caribbean	146	23.3	<0.001
White and Black African	30	33.3	<0.001
White and Asian	184	16.3	<0.001
Any other mixed	179	30.7	<0.001
Indian	7336	23.3	<0.001
Pakistani	4163	27.2	<0.001
Bangladeshi	4691	24.9	<0.001
Any other Asian	2343	25.7	<0.001

Caribbean	3458	23.0	<0.001
African	2254	25.6	<0.001
Any other Black	1334	29.0	<0.001
Chinese	143	14.0	<0.001
Any other ethnic group	727	33.7	<0.001
Refused	1829	33.7	<0.001

Age

A statistically significant difference (P < 0.005) was shown between patients who did not attend (53 years) as opposed to patients who attended (55 years). There was 95% certainty of the accuracy of the mean difference (C.I 1.85 – 2.63) (see table 2.5).

The total number of appointments included in this analysis was 35864. Missing values were excluded (N = 33)

Table 2.5

Cross tabulation of attendance outcomes and age

	Attended N=26777	Did not attend N=9087	Mean Difference	95% CI of Difference	P value (Equal variance assumed)
Age (mean)	54.87	52.63	2.24	1.85 to 2.63	<.001

2.8.2 Clinical Analysis (cross tabulation)

Location of appointments

The attendance per clinic location was analysed. The local acute hospital had significantly lower non-attendance in comparison to other sites; particularly the satellite sites (Church Road and Appleby). The analysis indicates a highly significant (p<0.005) difference in non-attendance based on the location of clinics. The results are presented as a percentage of the total appointments per site and the corresponding P value (see table 2.6).

The total number of appointments included in this analysis was 35864. Missing values were excluded (N = 33)

Table 2.6

Cross tabulation of non-attendance and clinic location

Question	*Shrewsbury Road Medical Centre N=28721*	*Newham University Hospital N=5600*	*Church Road Medical Centre N=617*	*Appleby Medical Centre N=926*	*P value*
Number of appointments not attended	*26%* *(7481)*	*18.2%* *(1019)*	*41.5%* *(256)*	*35.7%* *(331)*	*<.001*

Type of Clinician appointments

The attendance per clinician and type of appointment (new or follow-up) was analysed. The analysis indicates a highly significant ($p<0.005$) difference in non-attendance based on clinician and appointment type. Non-attendance was lowest for new doctor appointments (21.8%) but almost two and a half times higher for new dietician appointments (51.6%). The results are presented as a percentage of total number of appointments per clinician and the corresponding P value (see table 2.7 and Figure 2.8).

The total number of appointments included in this analysis was 35864. Missing values were excluded (N = 33)

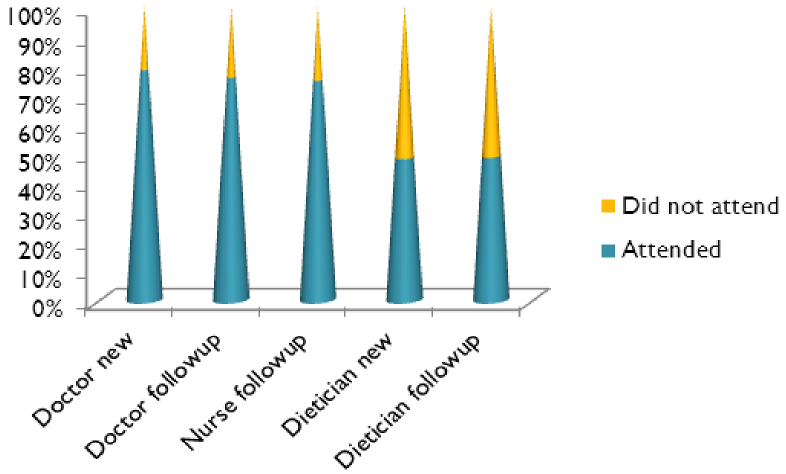
Table 2.7

Cross tabulation of non-attendance and clinician

Question	*Doctor New N=2252*	*Doctor Follow-up N=12864*	*Nurse Follow-up N=19902*	*Dietician New N=494*	*Dietician Follow-up N=352*	*P value*
Number of appointments not attended	*21.8%* *(490)*	*24.2%* *(3115)*	*25.4%* *(5047)*	*51.6%* *(255)*	*51.1%* *(180)*	*<.001*

Figure 2.8

Attendance rate (percentage) per clinician



2.8.3 Multivariable Analysis

Based on the findings of the initial contingency analyses, the combined effects of four variables (age, ethnicity and clinic location) which were shown to be significantly related to attendance were further investigated using multiple logistic regression. This form of analysis was used to determine the likelihood of non-attendance occurring based on the independent (predictor) variables. The results are presented as odds ratios (OR) and 95% confidence intervals (see table 2.14).

The total number of appointments included in this analysis was 35860. Missing values were excluded (N = 37)

Table 2.8

Multivariable analysis of non-attendance (age, ethnicity and clinic location)

Variable	Sig.	Odds ratio	95% C.I.for EXP(B)	
			Lower	Upper
AGE	0.000	0.985	0.984	0.990
Appleby	0.000			
Shrewsbury	0.000	0.613	0.533	0.705
NUHT	0.000	0.268	0.229	0.314
Church Road	0.275	0.887	0.715	1.100
British	0.000			
Irish	0.795	0.946	0.625	1.432
Any other white	0.003	1.243	1.077	1.436
White and Black Caribbean	0.903	1.024	0.693	1.515
White and Black African	0.524	1.283	0.595	2.770
White and Asian	0.008	0.585	0.393	0.871
Any other Mixed	0.022	1.466	1.055	2.036
Indian	0.579	1.023	0.942	1.112
Pakistani	0.000	1.288	1.173	1.414
Bangladeshi	0.002	1.154	1.052	1.265
Any other Asian	0.006	1.171	1.046	1.310
Caribbean	0.221	1.065	0.924	1.179
African	0.015	1.154	1.028	1.295
Any other Black	0.000	1.410	1.230	1.615
Chinese	0.022	0.571	0.354	0.923
Any other Ethnic Group	0.000	1.564	1.321	1.855
Not stated	0.000	1.636	1.457	.1.841
Constant	0.104	1.157		

When all three significant factors were analysed together, all remained significant with regards to non-attendance.

Age

For each year older a person is they are significantly less likely to not attend an appointment (OR 0.98).

Ethnicity

Patients categorised as Mixed (White and Asian) were significantly less likely to not attend appointments compared to White British. However, those categorised as Mixed other were significantly more likely to not attend appointments. Pakistani, Bengali and African patients were significantly more likely to not attend appointments than White British patients (OR 1.288, 1.154 and 1.154 respectively). Chinese patients were significantly less likely to not attend appointments compared to White British patient. However, patients categorised as Other and Not stated had a highly significant likelihood of not attending appointments (OR 1.564 and 1.636 respectively) than all other groups.

Clinic locations

There were two highly significant differences in attendance based on clinic location. Firstly, patients were three times more likely to attend appointments at NUH in comparison to Appleby Medical Centre. Secondly, the odds of patients attending appointments at Shrewsbury Medical Centre were 60% greater than Appleby Medical Centre.

There was a 10% increase in the odds of patients attending appointments at Church Road Medical Centre in comparison to Appleby Medical Centre. However, this finding was not statistically significant.

2.9 DISCUSSION

This study illustrated that over a five-year period there was a yearly non-attendance rate of between 23 and 25 percent which is significantly higher than the national average of 11 percent (HSJ 2009). This figure however only accounts for specific clinician appointments (doctors, DSNs and dieticians) within a service hence the overall non-attendance rate may alter if all diabetes services are considered for example podiatry and clinical psychology. The factors examined showed variations in attendance based on clinic locations, type of appointments delivered and by which clinician by group type. Demographic characteristics of patients were also significant predictors for likelihood of attendance.

The findings suggest that the type of appointment offered at each location may be a factor in the attendance trend seen. Routine diabetes appointments delivered at the diabetes centre were conducted by specialist doctors and nurses and had a lower non-attendance rate (26 percent) when compared to routine appointments delivered at another community location by diabetes specialist nurses only (36 percent).

These results highlighted that attendance may be influenced by factors such as the nature of appointments, clinic location as well as the type of clinician. This location based attendance profile is shown to be related to the service provided at each location (maternity, inpatient, young adult and routine appointments). NUH was shown to have the lowest non-attendance rate with patients being three times more likely to attend. However, the majority of patients seen at this location accounted for ante/postnatal women and a minority of inpatients who are followed up as out-patients post discharge. In accordance with the Health Belief Model (Hochbaum1958), women in either the ante or postnatal phase may perceive themselves to be more vulnerable therefore are more motivated to attend appointments. Gestational diabetes represents an acute and time-limited period hence appointments are for a relatively short period and are not long term as seen in patients with established diabetes. This may account for the lower non-attendance rate at NUH.

A like by like comparison of routine appointments demonstrated variability in non-attendance. Eighty percent of all routine diabetes appointments were conducted at Shrewsbury Centre. Despite the high non-attendance rate of twenty-six percent during the time under investigation, patients were more likely to attend for appointments in comparison to Appleby Centre where routine appointments were also conducted. This variability may be because of accessibility to service location as well as confidence in services provided and requires further investigation.

Despite the results of the multivariate analysis demonstrating a 10% increase in the odds of patients attending Church Road as opposed to Appleby; overall the highest non-attendance rate was demonstrated for Church Road. The patient group seen at Church Road are categorised as young adults (aged 16-25 years), and were predominantly patients with Type 1 diabetes who historically have presented a challenge in terms of non-compliance. The issue of non-attendance is complex and multi-factorial however understanding this group and providing services which meet their needs have been and continue to be a priority of the organisation. An audit conducted by Masding et al (2010) also highlighted the vulnerability of this patient group due to high non-attendance and the complex nature of transitional management. Several approaches have recently been piloted locally to redress issues of non-attendance and compliance amongst this patient group. One such approach was a pilot research project funded by the Health Foundation to implement the use of web-cam technology amongst the 16 to 25 age group. The project demonstrated a high level of engagement from participants. Focus groups were also conducted with this clientele to establish how best to modify service provision to improve attendance. The outcome of these groups was the establishment of an evening clinic which provisionally has shown a reduction in `non-attendance, from 41% to 16% (personal communication with clinician).

Attendance may also be attributed to patients' perceptions of services offered as the non-attendance rate was higher for DSNs (25.4%) and dieticians (51.4%) as opposed to doctors (22.8%). Many of the patients seen within this service possess co-morbidities and qualitative data gathered during a locally conducted diabetes research study (Greenhalgh et al 2011) highlighted a 'rationing' system which is utilised by patients who are managing multiple illnesses. An example of this rationing is the selective prioritisation and management of illnesses which is compounded by competing social factors. Appointments were reportedly ranked in order of priority and their impact on the patient's ability to function for example, attending a dietician appointment was deemed to be far less important than a doctor's appointment particularly if a patient is reliant on others to attend, has limited English proficiency or had scarce financial resources. Another plausible explanation of the higher non-attendance at DSN led clinic settings is the 'public lack of confidence in settings outside of the hospital' (NHS North East London 2009 p.12). This alludes to the impact of perceptions of services on one's willingness to engage with or utilise services.

The demographic characteristics of non-attenders were examined and highlighted significant differences in attendance based on gender, age and ethnicity ($p<0.05$).
Firstly, men were shown to be significantly less likely to attend appointments than women. However, it has been reported that women with diabetes have a higher risk of dying than men with diabetes (NSF 2001). Gender differences in diabetes outcomes have been linked to women experiencing a greater impact of socioeconomic deprivation (DUK 2006).

The mean recorded age for the sample was 54 years (SD ±16yrs). The results showed that for every year older you are, the more likely you are to attend appointments. This finding was reflected by a report on non-attendance which demonstrated a reduction in non-attendance from age 20 years and a slight increase after the age of 74 years (HSJ 2009). The trend in the individuals over 75 years may be attributed to factors such as multiple illnesses, psychological and social difficulties, lack of confidence, poor mobility and social isolation (DUK 2006).

Overall patients categorised as Pakistani, Bengali and African were significantly more likely to not attend appointments compared to White British. Within the Other group, patients categorised as Chinese were significantly less likely to not attend appointments. These findings are consistent with existing research. The Improvement and Development agency (2010) reported that Pakistani, Bengali and African patients report worse health outcomes whereas Chinese people report better health than the white British population. Overall, these findings have demonstrated that not only are there between group differences but more importantly, within group variations. Within group variations highlight the heterogeneity within aggregated ethnic categories. For example, within the group categorised as Black, which comprises of African, Caribbean and Black other, Africans were significantly more likely to not attend.

This analysis is limited by its quantitative nature therefore lacks the ability to address the variations shown in attendance both within and across ethnic groups. These findings support the need for a qualitative analysis conducted as part of this thesis to gain a better understanding of factors which influence attendance particularly amongst groups identified as least likely to attend appointments (see chapter 5).

2.10 OVERVIEW OF DEMOGRAPHIC AND GEOGRAPHIC DATA FOR LOCAL RESIDENTS ONLY

A comprehensive literature search yielded little information in the context of geo-demographic profiling utilising outpatient non-attendance data. Geo-demographic profiling is commonly used in epidemiology for health intelligence purposes.

The York and Humberside Public Health Observatory (YHPHO) which monitors the incidence, prevalence and outcomes of diabetes have endorsed the usefulness of geo-demographic profiling. In the context of health, five key uses were identified as:

- Population health profiling:
- Understanding the characteristics of small geographical areas
- Targeting health interventions by identifying areas with excess expected prevalence/incidence
- Measurement of health inequalities by: Explaining variation in health determinants, outcomes or services.
- Providing a more granular measure of health inequality.

Descriptive statistics (frequency) were used to illustrate the attendance characteristics for **only** patients who reside within the local borough. Exclusions from the original data set were based on the following:

- Out of borough postcodes
- Incomplete postcodes

- Postcodes which could not be identified as belonging to Newham from the MSOA file.

A total of 4033 records were excluded based on these criteria. The final number of appointments for only patients with a Newham residential postcode during the period Nov 2004 to March 2009 was 31864.

The data was examined firstly to determine the demographic and geographic distribution of appointment across the 37 MSOAs in LBN and secondly to determine the deprivation profile of the sample population in comparison to England based on the IMD (2007) LSOA deprivation scores. Approximately eight geographic areas had the highest number of appointments during the time period (see Figure 2.9). Patients categorised as Asian, accounted for most of appointments (see Figure 2.10).

The sample population when compared to England, were in the 4th and 5th most deprived quintiles (see Figure 2.11). Locally, the sample population deprivation profile was obtained and recoded into quintiles i.e. least deprived (1) to most deprived (5) (see Figure 2.12). An illustration of the nationally produced IMD profiles for LBN is illustrated in Figure 2.13 (Health Profiles 2008).

Figure 2.9

MSOA distribution of appointments for residents of LBN

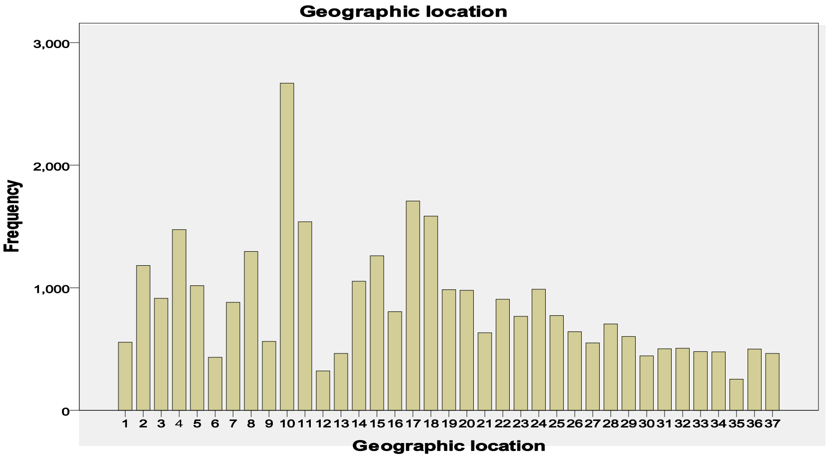


Figure 2.10

Number of appointments based on ethnicity for residents of LBN

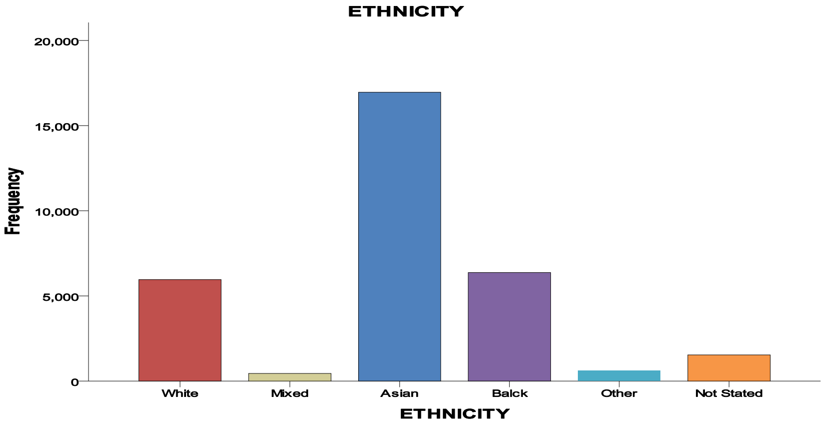


Figure 2.11

Sample population deprivation profile based on the UK IMD deprivation scores

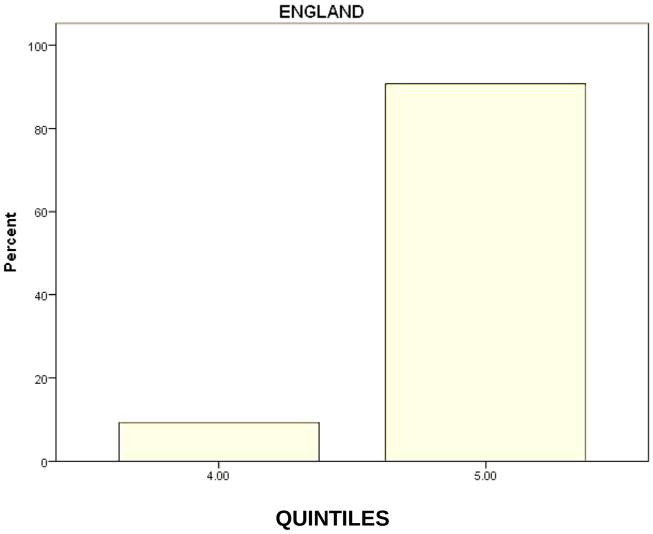


Figure 2.12

Sample population deprivation profile based on local IMD scores

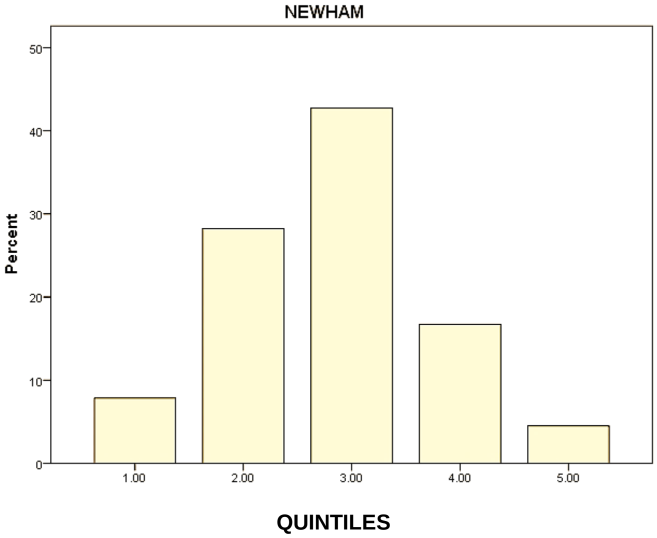
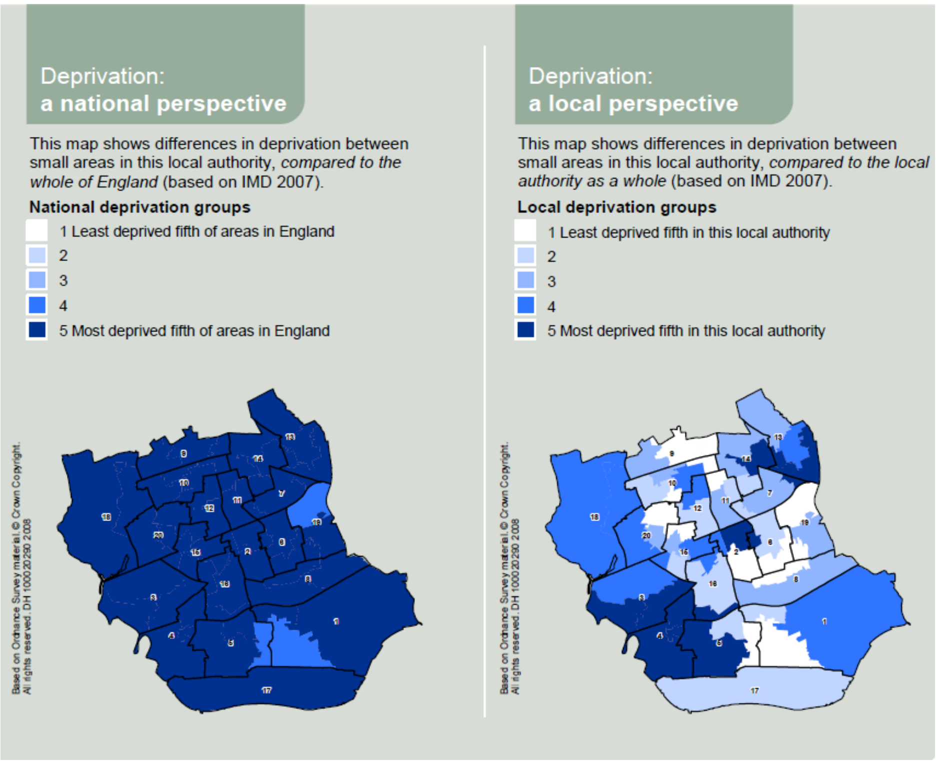


Figure 2.13

Deprivation profile of LBN (Health Profile 2008)



Deprivation:
a national perspective

This map shows differences in deprivation between small areas in this local authority, *compared to the whole of England* (based on IMD 2007).

National deprivation groups

- ⬜ 1 Least deprived fifth of areas in England
- 🟦 2
- 🟦 3
- 🟦 4
- 🟦 5 Most deprived fifth of areas in England

Deprivation:
a local perspective

This map shows differences in deprivation between small areas in this local authority, *compared to the local authority as a whole* (based on IMD 2007).

Local deprivation groups

- ⬜ 1 Least deprived fifth in this local authority
- 🟦 2
- 🟦 3
- 🟦 4
- 🟦 5 Most deprived fifth in this local authority

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2.11 Analysis of Geo-Demographic Data

The geo-demographic analysis was also performed using SPSS (Version 18) in collaboration with the School of Health Science's statistician. A geography specific programme was not utilised primarily due to the inability to obtain specialist input within an appropriate time frame.

The geographic data was analysed **only** for patients with a local residential postcode for diabetic appointments which were booked during the period November 2004 to March 2009. A contingency analysis was performed to establish the level of statistical differences in attendance based on geographical locations. Crosstabs was utilised to analyse this relationship. This analysis established a significant difference between locations therefore further analysis was undertaken using binary logistic regression in order to determine the likelihood of attendance based on geographic locations. Finally, a multivariate analysis was done to establish the likelihood of attendance based on both demographic and geographic characteristics.

The results of this analysis have been used to produce the dissemination artefact for this thesis (chapter seven).

2.12 RESULTS

2.12.1 Single variable analysis

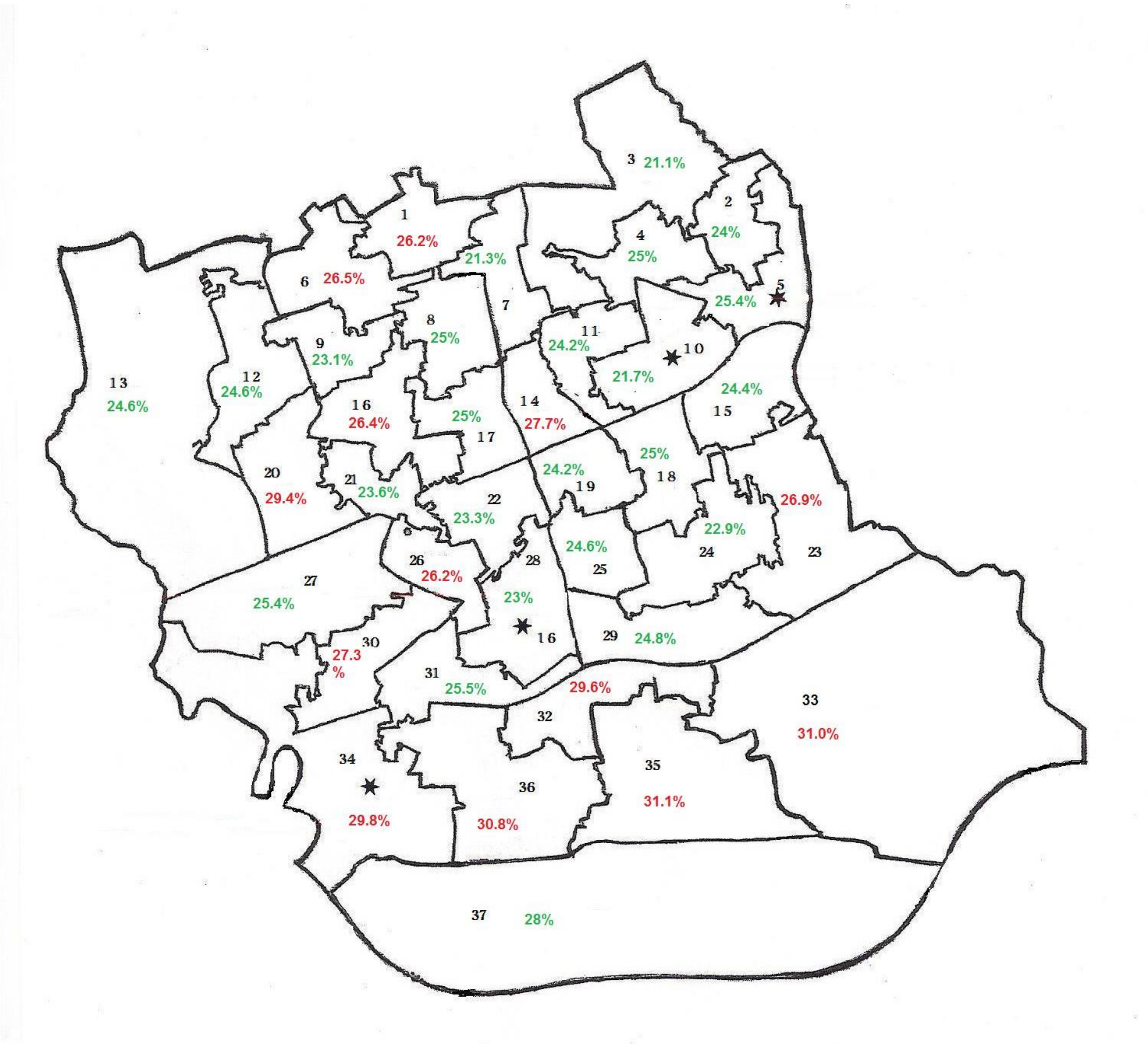
Cross tabulation (geographic location and attendance)

The analysis indicated a highly significant ($p<0.005$) difference in non-attendance between geographic locations. The results are presented as a percentage of the total number of appointments per geographic location and the corresponding p value (Appendix 2). The results are graphically represented (see Figure 2.14). Geographic locations 3, 7 and 10 had the lowest percentage of non-attendance (21.1, 21.3 and 21.7 respectively) whereas locations 20 and 32 to 36 had the highest percentage of non-attendance (29.4, 29.6, 31, 29.8, 31.1 and 30.8 respectively)

The total number of appointments included in this analysis was 31837. Missing values were excluded (N = 27)

Figure 2.14

MSOA non-attendance rate (percentage)



2.12.2 Logistic regression (geographic location and attendance)

Because of the overall level of significance of differences in attendance between locations, a single variable logistic regression was conducted. The purpose of this analysis was to determine the likelihood of attendance occurring based on the independent variable (geographic location). Location

37 was chosen as the comparator. The tabulated results are presented as odds ratios (OR) and 95% confidence intervals (see Appendix 3).

The analysis demonstrated with 95% certainty that compared to patients residing in the geographic location 37, patients residing in geographic locations 3, 7, 10 and 24 were significantly less likely to not attend appointments.

2.12.3 Multivariable logistic regression

The combined effects of four variables (age, gender, ethnicity and geographic location) which were previously shown to be significantly related to attendance were investigated using logistic regression. This form of analysis was used to determine the likelihood of attendance occurring based on the independent (predictor) variables. The results are presented as odds ratios (OR) and 95% confidence intervals (see table 2.9).

Aggregated ethnic categories were used for this analysis and the total number of appointments included in this analysis was 31837. Missing values were excluded (N = 27)

Table 2.9

Multivariable analysis of likelihood of non-attendance (age, gender ethnicity and patient location)

Variable	Sig.	Odds ratio	95% C.I.for EXP(B)	
			Lower	Upper
Location(37)	0.000			
Location(1)	0.551	0.918	0.694	1.215
Location(2)	0.132	0.828	0.648	1.059
Location(3)	0.009	0.707	0.545	0.918
Location(4)	0.204	0.857	0.675	1.088
Location(5)	0.431	0.905	0.705	1.161
Location(6)	0.571	0.918	0.682	1.235
Location(7)	0.015	0.721	0.555	0.937
Location(8)	0.309	0.882	0.692	1.124
Location(9)	0.099	0.787	0.592	1.046
Location(10)	0.005	0.721	0.574	0.904

Location(11)	0.099	0.818	0.645	1.038
Location(12)	0.474	0.887	0.640	1.231
Location(13)	0.558	0.915	0.681	1.230
Location(14)	0.701	0.953	0.743	1.220
Location(15)	0.110	0.819	0.641	1.046
Location(16)	0.580	0.929	0.717	1.205
Location(17)	0.205	0.859	0.679	1.087
Location(18)	0.181	0.851	0.671	1.078
Location(19)	0.115	0.816	0.634	1.051
Location(20)	0.495	1.090	0.851	1.395
Location(21)	0.110	0.799	0.606	1.052
Location(22)	0.115	0.813	0.628	1.052
Location(23)	0.363	0.886	0.683	1.150
Location(24)	0.037	0.763	0.593	0.983
Location(25)	0.142	0.821	0.631	1.068
Location(26)	0.709	0.950	0.724	1.245
Location(27)	0.438	0.895	0.675	1.185
Location(28)	0.112	0.803	0.613	1.053
Location(29)	0.229	0.844	0.640	1.113
Location(30)	0.877	0.977	0.729	1.310
Location(31)	0.632	0.932	0.700	1.242
Location(32)	0.710	1.055	0.797	1.396
Location(33)	0.301	1.161	0.875	1.540
Location(34)	0.383	1.134	0.854	1.506
Location(35)	0.411	1.152	0.823	1.612
Location(36)	0.329	1.149	0.869	1.519
White	0.000			
Mixed	0.358	0.896	0.709	1.132
Asian	0.005	1.114	1.033	1.200
Black	0.066	1.083	0.995	1.178
Other	0.000	1.482	1.235	1.778
Not stated	0.000	1.622	1.430	1.839
SEX (Male)	0.000	1.301	1.234	1.372
AGE	0.000	0.992	0.990	0.994
Constant	0.000	0.475		

When all four significant factors were analysed together, all the factors being examined remained significant as predictors of attendance. However, within each variable, the likelihood of the outcome occurring, and level of significance varied.

Age

For each year older a person is they are significantly less likely to not attend an appointment (OR <1)

Ethnic groups

Patients belonging to the groups Mixed were less likely to not attend appointments in comparison to whites. However, this finding was not statistically significant. Patients categorised as Black were eight percent more likely to not attend than whites. This finding was also not of statistical significance. However, patients categorised as Asian, Other or Not stated, were significantly more likely to not attend than Whites (11%, 32% and 38%) respectively.

Gender

Men were significantly more likely to not attend appointments than women (OR 1.3).

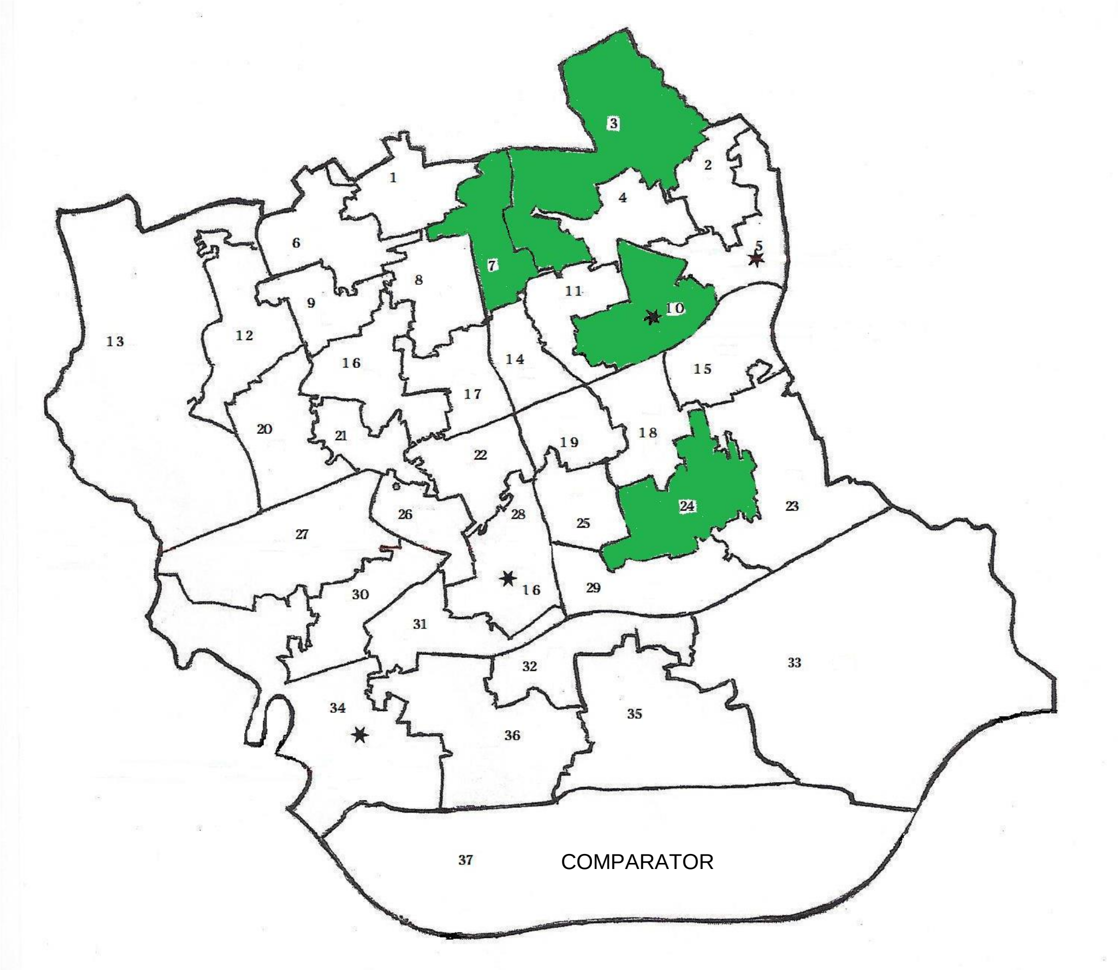
Geographic location

Patients residing in all other locations were more likely to attend appointments in comparison to geographic location 37. A level of statistical significance was only achieved for patients residing in geographic locations 3, 7, 10 and 24. Patients residing is these four locations were significantly less likely to not attend appointments compared to all locations (see Figure 2.15).

Figure 2.15

MSOA – Likelihood of attendance

Significantly less likely to not attend (p<0.05)



2.12.4 *Geographic location, deprivation and likelihood of attendance*

To establish the relationship between an individual's geographic location, deprivation and likelihood of attendance, further analysis was conducted utilising data on LSOAs. This was deemed to be necessary as indices of multiple deprivation rank and scores are recorded based on LSOAs. MSOAs are larger geographical areas which comprise of several LSOAs therefore each MSOA is subject to variability in deprivation profiles on a LSOA level.

2.12.4.1 Logistic regression (LSOA location and likelihood of attendance)

Firstly, a logistic regression of attendance and LSOA was performed to identify specific locations of a greater or lesser likelihood of non-attendance (Appendix 4). The output of this analysis is summarised in table 2.10 and illustrated in Figure 2.16.

Table 2.10

Logistic regression summary of likelihood of non-attendance based on LSOA

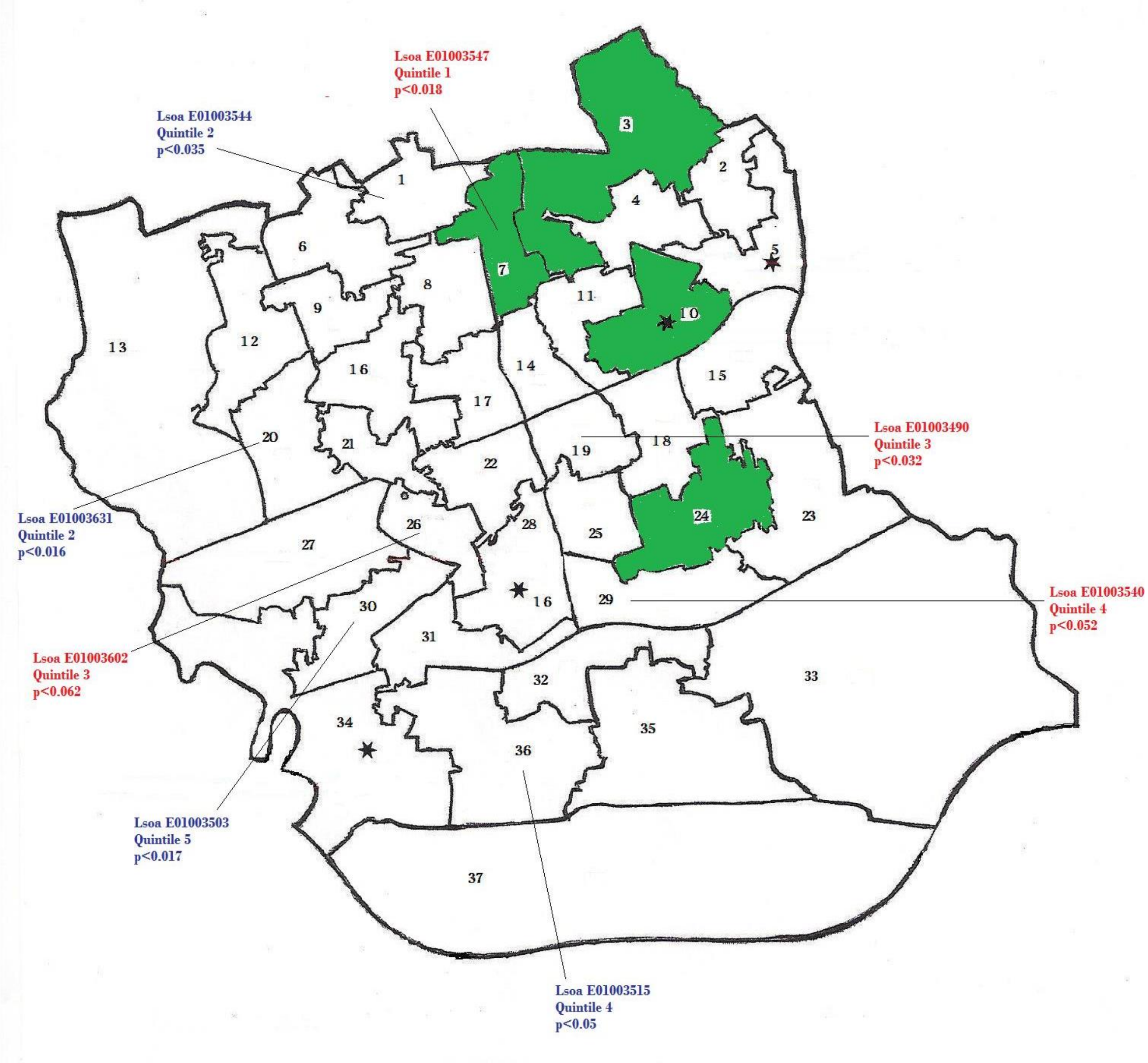
Non-attendance	Sig.	Odds ratio	95% C.I for EXP (B)			
			Lower	Upper	MSOA location	Quintile
Intercept	0					
LSOA=E01003490	0.032	1.833	1.054	3.188	19	3
LSOA=E01003503	0.017	0.451	0.235	0.867	30	5
LSOA=E01003515	0.050	0.590	0.348	1.001	36	4
LSOA=E01003540	0.052	1.733	0.996	3.018	29	4
LSOA=E01003544	0.035	0.522	0.286	0.955	1	2
LSOA=01003547	0.018	2.222	1.144	4.318	7	1
LSOA=E01003602	0.062	1.659	0.975	2.823	26	3
LSOA=E01003631	0.016	0.547	0.334	0.894	20	2

Figure 2.16

Likelihood of non-attendance and local deprivation status

Lsoas more likely to attend

Lsoas less likely to attend



2.12.4.2 MVA (age, gender, ethnicity and deprivation)

Secondly, to establish the relationship between deprivation and attendance, a multi-variable logistic regression which adjusted for age, gender and ethnicity was conducted based on quintiles of deprivation (Table 2.11). In order to determine the deprivation quintiles, the IMD (2007) scores for Newham were recoded in accordance with guidance provided by Communities and Local

Government (indices.deprivation@communities.gsi.gov.uk). The values have been illustrated earlier on page 31.

Table 2.11

MVA of likelihood of non-attendance (deprivation, age, gender and ethnicity)

Variable	Sig.	Odds ratio	95% C.I.for EXP(B)	
			Lower	Upper
White	0.000			
Mixed	0.378	0.901	0.714	1.136
Asian	0.087	1.064	0.991	1.142
Black	0.115	1.070	0.984	1.163
Other	0.000	1.440	1.201	1.726
Not stated	0.000	1.550	1.370	1.754
SEX(Male)	0.000	1.302	1.236	1.373
AGE	0.000	0.991	0.990	0.993
LBN_QUINTILE(5)	0.000			
LBN_QUINTILE(1)	0.003	0.798	0.688	0.926
LBN_QUINTILE(2)	0.068	0.889	0.783	1.009
LBN_QUINTILE(3)	0.001	0.810	0.716	0.917
LBN_QUINTILE(4)	0.153	0.908	0.796	1.036
Constant	0.000	0.516		

The multi-variable analysis showed that where ethnicity is known, Asians are significantly more likely to not attend appointments. In the context of gender, men are also significantly more likely to not attend appointments. However, for every year older an individual is, the less likely they are to not attend appointments.

Individuals residing in the least deprived (quintile 1) and in areas of average deprivation (quintile 3) were significantly less likely to not attend appointments.

2.13 MAIN FINDINGS

The results of this study indicated that demographic factors such as ethnicity, age and gender were significant indicators of non-attendance. In addition, a relationship was demonstrated between deprivation and clinic attendance (see Figure 2.16). People who resided in the least deprived and in areas of average deprivation (3rd quintile) within the borough were significantly less likely to not attend appointments when all factors were considered (age, gender and ethnicity).

Within the clinical context, the type of appointment (new/follow-up) and clinician were also significant indicators of attendance. However, the location of the appointment was a highly significant indicator of attendance when all factors were considered (age, gender and ethnicity).

A summary of the main findings is presented in table 2.12.

Table 2.12

Summary of main findings

Main findings

1. The yearly average out-patient non-attendance rate is significantly higher than the national target of 11%
2. Patients residing in the least deprived (quintile 1) and areas of average deprivation (quintile 3) are significantly less likely to not attend appointments than those in the most deprived areas
3. Men are significantly more likely to not attend appointments than women ($P<0.01$)
4. There are significant differences in attendance both across and within groups based on ethnicity
5. For every 1 year older a patient is, they are less likely to not attend appointments
6. The location of clinics and type of appointment are highly significant factors in attendance

2.14 DISCUSSION

These findings are consistent with existing literature which highlights gender, ethnic and socio-economic variations in access and utilisation of healthcare services (Goddard 2001, Peek 2007, Harriss 2008). The cost to the NHS of non-attendance and the subsequent treatment of preventable complications is significant hence each NHS Trust in the UK is tasked with utilising strategies to provide safe, cost-effective services which meet the needs of local populations. To reduce non-attendance, organisations have utilised telephone and text messaging. Telephone reminders were shown to be very effective in reducing non-attendance rates at care of the elderly clinics (Dockery et al 2001). The use of social media and technology has been proposed as more effective ways of engaging with younger patients to improve attendance (Masding et al 2010). However, the success of any chosen method is limited by factors such as language and literacy. Some alternative methods such as telephone and text reminders may be less effective in boroughs such as LBN due to the demographic composition whereby language and literacy are potential rate limiting factors. Overall, a better understanding of the acceptability of interventions to reduce non-attendance is required for the methods to be both effective and cost-effective.

Statistics have shown that more diabetic patients in Newham attend hospital appointments as opposed to their GP (Healthcare for London, 2008). Within Newham there are a small number of GPs with specialist interest in diabetes (GPSIs) therefore this may in part account for the increased out-patient attendance rate. Despite this higher incidence of outpatient appointments, NHS Diabetes reported that Newham fell within the lowest quartile for diabetes outcomes. Based on Quality Outcome Framework (QOF) data; there is a higher than national average spend on pharmaceuticals but poorer outcomes within Newham (YHPHO).

Within the local context, two of the appointment sites are in the North-East sector of the borough and the other two are in the South West sector of the borough. The ease of access to these clinic locations is variable.

Shrewsbury Medical Centre which facilitates 80% of the diabetes appointments is located in the North-East sector of the local borough. There are reasonable and convenient public transportation links to this location (underground and bus). However, the further away you move from the centre; the more difficult the journey. There is both limited and restricted parking at this site with a maximum parking limit (paid) of two hours. For patients who do not reside within this locality, transportation as well as the cost associated with parking may have an impact on their ability or willingness to attend appointments.

Clinicians within the diabetes service at NUH have highlighted that a significant number of patients who are referred to the diabetic out-patient service present with diabetic complications and co-morbidities. A recent study conducted at NUH highlighted that non-attendance is in part influenced by the difficulties associated with managing multiple illnesses as well as diabetic complications (Greenhalgh et al 2011). With multiple illnesses, attendance may be further influenced by the individual's ability to access services due to difficulties accessing transportation or their reliance on the availability a carer (Salway 2007).

Accessibility of transportation has been identified as a rate limiting factor in the public's ability to access services (Goddard 2001, Paterson 2010, Winkley 2014). The institute of public health in Ireland (2005) highlighted the relationship between "transport poverty" and health. Transport poverty was viewed in the context of "affordability, availability and accessibility". It concluded that poor access to transportation increased social exclusion, reduced access to services and altered perceptions of services. Geographic analyses conducted have also demonstrated the impact of spatial decay whereby the further away someone moves from a service, the more likely they are not to attend. This effect is enhanced by poor access to transportation. The Reconfiguration Programme Guide (NHS London & TFL 2008) highlighted the need for a detailed travel time analysis to determine the potential effect of new or reconfigured sites on accessibility, both for existing populations and for future forecasts. It specified that the impact on patients, visitors and staff should be considered. The analysis is essential because it could be used to highlight the extent to which people do or do not use their nearest available health service facility by evaluating the location of existing services and patient home postcode information.

Based on the demographic and socio-economic profile of the local borough, the attendance data was explored based on the local geography and in the context of deprivation. The local deprivation profile was obtained from the IMD 2007 (DH 2008). Most of Newham is ranked within the most deprived fifth of areas in England. However, the deprivation profile of Newham shows significant variations both within and across the twenty local wards. Within most wards, there is mixed levels of deprivation with only three wards displaying uniformed deprivation (Stratford and New Town, Canning Town South and Royal Docks).

The geo-demographic analysis highlighted only three locations within LBN where patients were less likely to not attend appointments when the data was analysed on a MSOA level. Due to the lack of uniformity of deprivation within MSOAs, a logistic regression of LSOAs was performed to identify specific locations where people were more or less likely to not attend appointments. This approach was necessary for geographic specificity because a number of LSOAs are located in each MSOA. The overall findings indicated that in areas of the least and average deprivation (quintiles 1 and 3), the likelihood of non-attendance was significantly lower in comparison to the most deprived area (quintile 5). However, interpretation of these finding should be done cautiously as factors such as proximity to the nearest clinic location as well as transportation access are potential influencing factors. Also, when the data were analysed in the context of individual LSOAs, variability was shown in attendance whereby individuals residing in above average (quintile 4) and the most deprived (quintile 5) areas were significantly less likely to not attend appointments. Conversely, individuals residing in one of the least deprived LSOA were significantly more likely to not attend appointments.

There is a wealth of evidence about the impact of ethnicity and deprivation on health inequalities and it is widely agreed that people living in the poorest and most deprived areas have the worst health and poorest outcomes (Postnote 2007, NSF 2001). Deprivation and its associated factors such as unemployment, poor housing, and education have been shown to be significant determinants of health seeking behaviours. It is believed that in areas of deprivation, health becomes less of a priority due to competing socio-economic factors (McCloskey et al., 2013)

The London Health Observatory (2009) published a graphic representation of the impact of deprivation on life expectancy utilising the Jubilee Line of the London Underground map . It demonstrated a seven-year reduction in life expectancy for men and four-year reduction for women as you travel from Westminster towards Canning Town. Canning Town is in the most deprived fifth of LBN and patients within this location were found to be less likely to attend appointments. A geo-demographic study which explored the impact of deprivation on the uptake of retinal screening demonstrated a significant relationship between social deprivation and uptake. It highlighted that people who lived in more deprived areas were significantly less likely to attend for retinal screening (Leese 2008). Another plausible argument of non-attendance may be the compound effect of deprivation, the psychosocial impact of living with a long-term illness and accessibility of services. A report published by Diabetes UK (2010) highlighted that the most deprived people in the UK are two-and-a-half times more likely than the average to have diabetes at any given age. Also, there is a higher incidence of depression amongst patients diagnosed with diabetes in comparison to the general population (Katon et al, 2004).

One conclusion which could be drawn from this analysis is that when all demographic and geographic factors are considered; age, gender, ethnicity and deprivation appear to be the most significant determinants of a patient's willingness or ability to attend local diabetes outpatient services.

It is therefore imperative that the issue of non-attendance is examined within its broadest context if diabetes health inequalities are to be effectively addressed by health care organisations. Dahlgren and Whitehead's social determinants of health (1991) identified that an individual's response is constrained by social, cultural, economic and environmental factors and highlighted the importance of structural interventions to impact on the causes of health and ill health.

A more recent review conducted by Scheppers et al., (2006); highlighted the multidimensional factors which impact on access and utilisation of healthcare services in the context of ethnicity. This review identified barriers to utilisation of services by ethnic minority groups because of patient, provider and organisational factors.

The vulnerability of groups has been attributed to factors such as gender, age, ethnicity, language etc. Dixon-Woods (2005) contextualised the permeability of services and access to health care by vulnerable groups. She highlighted that high levels of non-attendance at services are indicative of low permeability therefore difficult to use and recommended qualitative exploration of the reasons.

The importance of robust, accurate and up to date health intelligence information as a means of identifying and tackling health inequalities has been demonstrated by Roos et al (2010). They highlighted that significant investment and organisational collaboration is required to enable such a strategy as it links an individual’s area of residence to census and health data. A criticism of the UK with regards to data which is utilised to inform policy is that it is reliant on Census data which is only updated every ten years.

Policy change and legislation are key drivers for initiating and sustaining change. In the health context, the focus should be to change the socio-economic environment as a means of enabling change at both an individual and community level (Marmot 2010).

Therefore, to initiate and sustain changes which could potentially reduce health inequalities, there must be a synergistic relationship between all stakeholders (patients, providers and policy makers).

2.15 CONCLUSION

The purpose of this case study was to investigate and identify trends in non-attendance at diabetes outpatient clinics. The findings highlighted that the variations observed in attendance are multi-factorial and can be attributed to gender, age, ethnicity, deprivation and geographic location of services.

The limited scope of this case study is acknowledged as there may be several confounding and intangible variables which may only be ascertained by undertaking further research. Geo-demographic profiling is a useful and explorative tool which provides a foundation for identifying trends and potential issues of concern in a geographical context. This is therefore a worthwhile approach as it provides quite robust information which can be used as part of an approach for strategic healthcare planning and service delivery. Geo-demographic profiling however is limited in the context of health intelligence as it does not answer questions such as why and how.

These findings have highlighted potential areas for exploration. Firstly, there is a potential for services to be re-configured whereby a multi-professional service is provided at more strategic locations.

Secondly, a qualitative evaluation of the trends observed from the findings is required to explore the factors (drivers and barriers) which influence both access and utilisation of services locally. This should provide valuable information with regards to current service provision and recommendations for change. Geo-demographic variations in attendance trends were identified which can be useful to inform strategic approaches locally.

Thirdly; to determine the level of accessibility, a robust geographic interrogation of the data is required which may provide a foundation for informing service re-design and the delivery of targeted public health interventions. The analysis demonstrated the relationship between geographical factors such as patient and clinic location and attendance. However, an in-depth analysis is required to examine factors such as spatial decay and its relationship with attendance.

Overall, this study has provided a better understanding of both the clinical and geo-demographic profile of local service users of diabetes out-patient services. As such these findings can be utilised to inform health strategies which are aimed at optimising access and utilisation of services by groups defined as disengaged, hard to reach or marginalised.

2.16 Chapter summary

This case study was conducted six years ago solely for this thesis therefore the findings reported have not been revisited because they are relative to the time the analysis was conducted. However, recent discussions with clinicians as well as a review by the Care Quality Commission (CQC 2015) highlight the on-going pervasiveness of out-patient non-attendance within the host organisation. A CQC recommendation is that a strategic solution is required to address this issue.

The next chapter will discuss a critical review of literature of two educational interventions used in diabetes care to improve self-management and engagement with services.

The findings of this evaluation were presented as a poster at the Society for Academic Primary Care (SAPC) conference in October 2012 (see appendix viii) and the Canadian Public Health Association conference (Toronto), 2014. The findings of this evaluation will form the dissemination artefact.

CHAPTER 3

Literature review

3.1 Introduction

This literature review is motivated by practical concerns which link directly to the findings of the case study. The case study identified specific groups of patients who had high non-attendance rates and sub-optimal engagement with their diabetes healthcare provider. Additionally, public health data demonstrated poorer diabetes related health outcomes for the local borough (LBN) (YHPHO 2010). Existing literature indicates that patients who are empowered are more likely to engage with healthcare services and better self-manage. This is achieved by improving a patient's knowledge, skills and confidence about the disease and services through education. The NHS framework for Diabetes (2001) and NICE (2003) identify education as a key enabler of empowerment and self-management. However, it must be accessible, acceptable and responsive to the needs of the target population.

Health educationalists utilise diverse theories and models such as the Health Belief Model (HBM), the Social Theory of Learning, the Stages of Change model and Precede-Proceed model in diabetes educational programmes (Jones et al. 2003, Sharifirad et al 2009, Phillips et al 2012). The fundamental principles of these models and theories are to improve education and medical outcome, produce behavioural and social change and provide empowerment through experiential learning. Despite the various educational learning theories and methods which are utilised, what has been consistently documented is that the traditional didactic and transactional approaches of learning are less effective than had been anticipated in achieving these outcomes. Some researchers have reported that the didactic approach to learning has limited effectiveness particularly with some ethnic minority groups and those with low health literacy (Lorig et al., 2001, Perez 2008, Sorensen et al., 2012).

Diabetes education aims to develop the self-management capabilities of the person with diabetes and develop their understanding of the relevance of engaging with their health care providers. Historically, diabetes education has been delivered either on an individual basis or in a group setting with the primary outcome being improved clinical and bio-chemical outcomes. A systematic review of individual versus group education for T2 patients, reported no significant differences between both the two forms of educational delivery (Duke et al., 2009).

Diabetes education methods and programmes have been designed and adapted over time due to factors such as poor attendance and lack of cultural appropriateness. It has been widely reported that educational methods, restrictive access to programmes, deprivation and cultural influences are contributing factors to the poor uptake of education by high risk groups (DH 2001, Jack 2003, Greenhalgh et al. 2005, DUK 2010, APPG, 2015). In response to reported findings of disengagement based on the design and delivery of educational programmes, as well as cultural influences, alternative models such as storytelling have been evaluated (Feathers et al., 2007, Utz et al., 2008, Greenhalgh et al., 2010) and have reported better engagement. Due to the local demographic, socio-economic profile and poor engagement of the diabetes population examined in the case study, it is pertinent to examine alternative educational interventions. In this instance, Community Health Worker (CHW) and Peer Support interventions has been evaluated as they are designed to minimise barriers to engagement such as inflexible methods, poor access and culturally incompetent programmes.

This review focuses on educational strategies that align with the National Service Framework for Diabetes (DH 2001) which highlighted the importance of empowerment, support and joint decision making with patients with diabetes to enable better engagement with services, more effective lifestyle choices and improve self-management. This review will critically review literature that evaluates the effectiveness of alternative educational interventions aimed at improving engagement and reducing health disparities in patients with T2 diabetes.

3.2 The review question

The question posed is: "How effective, cost-effective and sustainable are Community Health Worker (CHW) and Peer support educational interventions in improving engagement and diabetes related outcomes amongst disadvantaged groups?"

3.3 Aim of the literature review

To critically review and synthesize the literature which examines CHW and Peer support diabetes educational interventions in disadvantaged groups and identify any central issues (enablers and barriers) and how they relate to clinical care.

3.4 Methods

A literature review has been defined as:

“The selection of available documents (both published and unpublished) on the topic, which contain information, ideas, data and evidence written from a particular standpoint to fulfill certain aims or express certain views on the nature of the topic and how it is to be investigated, and the effective evaluation of these documents in relation to the research being proposed” (Hart, 1998, p. 13).

One component of the Structured Doctorate is the undertaking of a critical review of the literature. The literature review guidance is not explicit that the review must be a systematic review. However, a critical review requires that evidence is assessed by systematically reviewing its relevance, validity and results. The present review can be defined as a 'traditional narrative review' undertaken in a systematic manner. Traditional reviews have been reported to lack the rigor and methodological transparency of a systematic review, are subjective and not easily reproducible due to an “open and flexible” approach (Jesson et al., 2011 pg. 24). However, it has been stated that a traditional review may provide valuable insights which may be overlooked during the rigorous quality control process of a systematic review (Jesson et al, 2011).

The Centre for Reviews and Dissemination (CRD) has published guidance for undertaking systematic reviews in health care. The guidance states that healthcare decision making should be guided by credible research evidence and the process of systematic reviews provides a sound basis for enabling the process of informed decision making (CRD 2009). There are defined methods which govern the conduct of systematic reviews which underpin the robustness, objectivity and reproducibility of conducted reviews. The first guiding principles are whether there is a valid requirement for the review and its purpose. Conducting the review should be a transparent process and requires a clearly defined question and well documented methods (search, selection, data extraction and synthesis).

This review was conducted by following the methods indicated below:

3.4.1 Type of studies

Studies which evaluate the effects of diabetes self-management educational interventions were evaluated. Interventions delivered both in primary and secondary care settings were examined and consisted of a range of studies i.e. Randomised controlled trials (RCTs), controlled trials (before and after) and qualitative studies.

3.4.2 Sample characteristics

Adult patients (>18 years) with Type 2 (T2) diabetes

Disadvantaged populations (high disease burden), low-income

3.4.3 Outcome measures

Disease specific measures will primarily include:

- Clinical outcomes (biomedical)
- Psychological evaluations (self-efficacy, empowerment, knowledge, coping, well-being, social functioning etc.)
- Behavioural modifications (improved self-care, diet and lifestyle changes and medication adherence)

3.4.4 Cost effectiveness measures will include:

- Incremental cost effectiveness ratio (ICER)
- Cost per quality adjusted life years (QALY)
- Direct cost

3.4.5 Search criteria

Search terms were developed using PICO (Richardson et al 1995)

Population = Adult patient with Type 2 diabetes

Intervention = Peer group or CHW

Comparison = Structured education and standard care

Outcome = Improved self-management, health-outcomes, adherence to treatment, reduction in hospital episodes

Table 3.1

Keyword search

Keywords	Diabetes mellitus, diabetes, education, patient education, education strategies, Peer support, health literacy, self-management, cost, effectiveness, evaluation, outcomes, lay person, community health worker, type 2, disadvantaged
Date of publication	2001 – December 2016
Language	English
Geographic locations	Unrestricted

The time point of 2001 was chosen as it aligns with the inception of the National Framework for Diabetes (DH 2001) and increasing academic interest in psycho-social approaches to diabetes education.

Guidance on key literature sources is available and illustrated (see table 3.2)

Table 3.2

Key literature sources (adapted from Hickson2008; p 26)

Primary databases Provide references to original research published. Each database covers specific specialities.	Embase, Medline, Cinahl PsycInfo
Secondary databases The Cochrane Library is considered the gold standard for evidence which provides high-quality independent evidence to inform health care decision making.	Cochrane Database of Systematic Reviews (CDSR) Database of Abstracts of Reviews of Effects (DARE) Health Technology Assessment Database (HTA) NHS Economic Evaluation Database (NHSEED)
Bandolier Presents evidence on effectiveness or lack of in a simple format. Sources of information include systematic reviews, meta-analyses, RCTs and high-quality observational studies	www.ebandolier.com
Internet sites	TRIP – http://tripdatabase.com SCOPUS – http://scopus.com NICE – http://nice.org.uk Google scholar – http://scholar.google.co.uk
Research in progress	National Institute for Health Research – https://nihr.ac.uk
Researchers	Personal contact with experts with related interest

Except for SCOPUS, all the databases detailed above were accessed to provide a broad overview of the literature available (systematic reviews, meta-analyses, protocols and literature reviews). Grey literature was included in this review and comprised of articles found through hand searching of printed journals, conference proceedings, seminar presentations and commissioned reports. The approach of including grey literature is thought to be a means of avoiding selection bias or publication bias (Hart, 1998).

Critical appraisal of selected literature was assessed in accordance with the Critical Appraisal Skills Programme (CASP). This method of appraisal aims to examine the article's results and conclusions based on the methods and findings and establish the validity, applicability and generalisability of the findings (Hickson 2008; p 38). Appropriate CASP evaluation guides were used depending on the study evaluated e.g. qualitative, quantitative or economic evaluation.

3.5 Background to the literature review

3.5.1 Context: factors influencing engagement

Hard to reach groups are defined as groups of individuals who have never engaged or disengage with services and are usually from disadvantaged groups. The terms hard to reach and disadvantaged are interchangeable and women, children, elderly, mental health, disabled, ethnic minorities and socio-economically deprived individuals have been identified as commonly found in these groups (Dixon Woods 2005). From an epidemiological perspective, there is a significantly higher prevalence of T2 diabetes in South Asian, Afro-Caribbean groups and an increasing prevalence amongst deprived groups (DUK, 2010). These groups have been consistently categorised in literature as 'high risk' and 'hard to engage/reach' and empirical evidence has demonstrated greater disengagement, worse self-reported health and worse diabetes related health outcomes amongst these groups (Goddard 2001, Dixon Woods 2005, DH 2010). Many factors have been reported to influence disengagement with services and the greater health disparities seen amongst disadvantaged groups. However, Scheepers (2005) identified three key elements namely: individual, organisational and structural barriers as determinants of access to and utilisation of healthcare. Individual factors include personal perceptions, gender, culture, ethnicity and social capital. Organisational factors include service location, quality of the service as well as culturally competent staff. Structural factors include the organisation of health care policies and systems.

Psycho-social theories have been used to explain and evaluate individual health-seeking behaviours. The Health Belief Model (Hochbaum 1958) was adapted by Rosenstock et al (1988) and used to evaluate the interplay between psycho-social elements and their influence on health-related decision making. On an individual level, it examines issues such as motivation understanding and the level of importance an individual attach to their health and engaging with health services.

Candidacy has also been proposed as an important factor in health seeking behaviors amongst vulnerable groups (Dixon-woods, 2005). Candidacy has been described as the process of negotiation which occurs between individuals who have a need for medical intervention and their access to health services. This process is subject to levels of permeability or porosity which can be measured by levels of engagement and rates of attendance. Services which require minimal effort and negotiation to use are deemed to have high permeability whereas services which require greater effort and negotiation to enter and maintain engagement with are deemed to be less permeable. High non-attendance rates are viewed as a direct reflection of services which are less permeable.

Poor health literacy has also been attributed to the poor engagement and health disparities seen amongst vulnerable groups and is considered one of the greatest barriers to educating individuals living with long term conditions (Sorensen et al, 2012). Health literacy is quite complex and has variable definitions. One definition describes health literacy as "the personal, cognitive and social skills which determine the ability of individuals to gain access to, understand and use information to promote and maintain good health" (Nutbeam 2000; p 264). Health literacy involves more than information transfer therefore can be described as a transformational as opposed to a transactional process and has been reported to be a valid and measurable outcome of educational interventions (Osborne et al, 2007).

The National Framework for Diabetes (DH, 2001) has specified empowerment as a key component to diabetes care at it enables people to gain control over their lives, is ethically sound and can be individually or community focused. Empowerment refers to an individual having the knowledge, skills and confidence to self-manage.

3.5.2 Structured T2 diabetes education (what is known)

In the UK, disparities in diabetes care and outcomes have been consistently reported and the need for high quality education was highlighted in response to the disparities (access and availability) observed in structured education for patients with T2 diabetes (Diabetes UK, 2006, APPG 2015). The need for access to structured diabetes education programmes for all newly diagnosed or existing patients with diabetes (T1 and T2) was initially identified in the Diabetes National Service Framework (NSF) (Department of Health 2001) and by the National Institute for Health and Clinical Excellence (NICE 2003). The NSF and NICE educational guidance are not prescriptive and recommend either individual or group based education. Over time, it has been reported that diabetes education tends to be ‘ad hoc’ at best and subject to geographic variations (APPG 2015). The use of educational programmes with diverse educational methodologies have been recommended by NICE in its guidance for T2 diabetes self-management. However, these programmes must be compliant with the educational content guidance, quality assurance and control processes as determined by the NICE criteria or should have Quality Institute for Self-Management and Training (QISMET) certification.

The primary aim of health education is to enable individuals to make informed choices about their health through information, understanding, attitudes, feelings and skills. There are two NICE recommended structured educational programmes for patients with T2 diabetes, namely Diabetes Education and

Self-Management for Ongoing and Newly Diagnosed (DESMOND) and Expert Patient Education (X-PERT) and these have been concisely summarised below.

In 2004, the DESMOND programme for people with T2 diabetes was piloted in 15 Primary Care Trusts in England. The programme was revised in response to feedback from pilot sites and a second version was produced. Organisations delivering DESMOND are required to submit a quality assurance programme following the first year of DESMOND delivery and every three years thereafter. To maintain competency as a DESMOND educator, five courses should be delivered annually.

DESMOND

This educational programme has been subject to effectiveness and cost-effectiveness reviews with favourable conclusions. A one year cluster randomised trial of DESMOND (Davies et al, 2008) conducted across 13 primary care sites to evaluate its clinical effectiveness demonstrated significant changes in the primary endpoints (weight loss and smoking cessation). However, there was no significant change in HbA1c which is a biological marker of diabetes management. A systematic review of the clinical effectiveness of education for T2 patients with diabetes highlighted that longer term interventions and follow-up are required to demonstrate any potential effect (Loveman et al 2008). A cost-utility analysis of DESMOND (Gillett et al 2010) reported that it was likely to be cost-effective with a significant reduction in weight and smoking. This conclusion was based on the predicted cost savings when compared to a hypothetical primary care trust (PCT).

Expert Patient Education (X-PERT)

The X-PERT educational programme is a ‘lay-lead’ six-week programme which was co-designed with patients and Diabetes UK and was set up in April 2002. The aim of the programme is to provide patients living with long term conditions with the knowledge, skills and confidence to self-manage. The underpinning framework for this programme is patient empowerment. Delivery of the programme requires 15 hours of learning and comprise of six, weekly sessions, which last 2.5 hours each.

The clinical effectiveness (Deakin et al 2006) and subsequently cost-effectiveness (Deakin 2011) of the X-PERT programme was evaluated. The randomised control trial which compared X-PERT to routine treatment demonstrated improvement in all measurable outcomes including attendance, patient satisfaction and empowerment. Significant improvements in biochemical and anthropometric measures were also reported. It was noted that the reporting of X-PERT audit data was low by participating organisations which could have an influence on the validity of the reported results. The cost-effectiveness analysis also compared X-PERT to routine treatment and concluded that X-PERT was cost-effective therefore should be offered as a key component of diabetes management.

Despite the reported clinical and cost-effectiveness of both NICE recommended structured education programmes, low attendance rates continue to be a pervasive issue (APPG 2015). Commonly reported factors which influence non-attendance at structured education have included venue location, course timing, time commitment, stigma, course content and delivery methods. A criticism of structured diabetes education is that it continues to be delivered in a relatively inaccessible manner particularly for populations where language, literacy, transportation access, carer responsibilities, educational, employment and financial issues are present. It requires a specific level of effort and commitment which has been reported as barriers to attendance (Winkley et al., 2014). These rate-limiting factors highlight the need for educational interventions which are more flexible in delivery and responsive to the needs of the local population.

3.6 Introduction to the review

3.6.1 Diabetes Self-Management Education (DSME)

DSME is an 'umbrella' term for diverse methodological approaches which aim to address the limitations of structured education particularly for diverse ethnic and low-income groups and thereby improve engagement, empowerment and health outcomes (Jack 2003). DSME approaches therefore aim to minimise the influence of poor social capital, low health literacy and impermeability of services. Reviews of structured T2 diabetes education have consistently shown low attendance rates as demonstrated by the UK National Diabetes Audit (2012-2013) which highlighted that of 15.9 percent of newly diagnosed individuals with diabetes who were offered education, only 3.4 per cent attended (Health and Social Care Information Centre, 2014). A long-standing recommendation is the need for diverse educational methodologies which consider both social and cultural factors (Jack 2003, Scheppers et al., 2006). A recent report, highlighted that there is an on-going deadlock in the provision and uptake of diabetes education which needs to be broken (All Party Parliamentary Group, 2015). The Diabetes UK education commissioning guide (DUK 2016) highlighted that commissioned diabetes education should be responsive to local needs, based on demographics, should have a wide reach locally, allow for different learning preferences, have diverse methods of delivery and provide on-going learning.

Health educationalists utilise diverse theories and models such as the Health Belief Model (HBM), the Social Theory of Learning, the Stages of Change model and Precede-Proceed model. The fundamental principles of these models and theories are to improve education and medical outcome, produce behavioural and social change and provide empowerment through experiential learning. Despite the various educational learning theories and methods which are utilised, what has been consistently documented is that the traditional didactic and transactional approaches of learning are less effective. Some researchers have reported that the didactic approach to learning has limited effectiveness particularly with some ethnic minority groups and those with low health literacy (Lorig et al., 2001, Perez 2008, Sorensen et al., 2012).

For this review, two specific DSME methods which have been subject to extensive evaluations in diverse therapeutic areas have been evaluated:

- Community Health Workers (CHWs)
- Peer support

These two interventions have been selected due to the global recognition of their importance in addressing health care disparities. CHWs and Peer educators are routinely used in public health programmes (prevention, screening and health promotion) and routine disease specific healthcare intervention programmes (Bamrah et al., 2010). Due to persistent barriers in access to and uptake of structured education in the UK, Peer support has been recently recommended as a means of re-engaging people who are deemed hard to reach (All Party Parliamentary Group, 2015).

3.6.2 Community Health Workers and Peer supporters

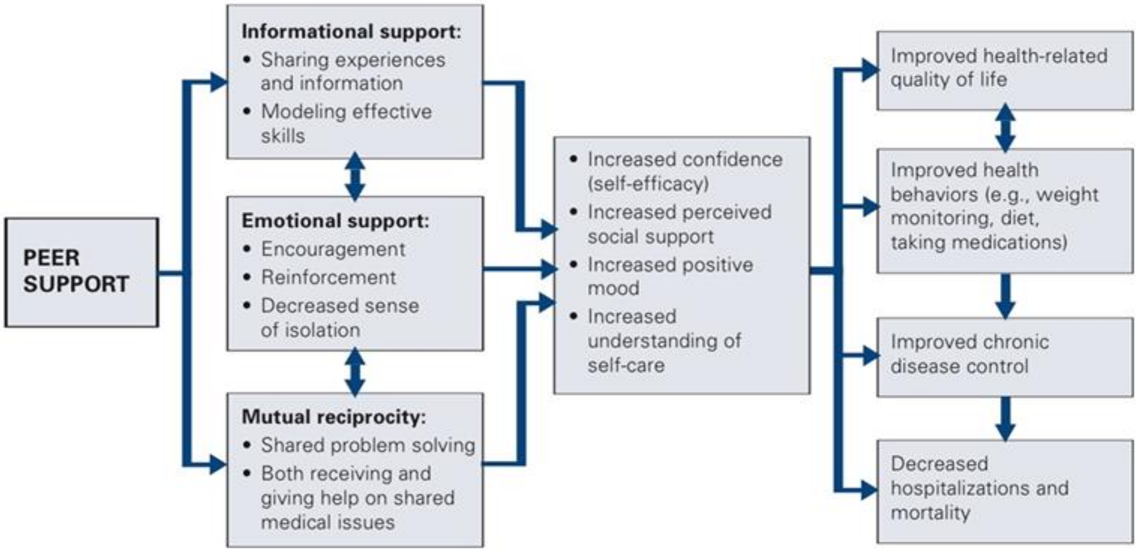
The history of CHWs has been reported to date back to the 17th century with the Russian *feldshers*("barber-surgeons"), Chinese "barefoot doctors" and Latin American *promotores* in the 1950's. There was an emergence of CHWs in the United States in the 1960's which was borne out of the Great Society domestic programme (Perez and Martinez 2008). Throughout the CHW trajectory, their primary function has been to bridge the gap in health inequalities for disadvantaged communities. CHW are viewed not just as community advocates due to their understanding of the issues of importance for the communities to which they belong but are also thought to be policy influencers and have been described as "natural researchers" (Perez and Martinez 2008 p 11). Peer support and CHW interventions have been reported as low-cost and effective interventions for extending capacity within primary care practices, minimising the shame and stigma associated with diabetes for some black, Asian and minority ethnic communities, mitigating against diabetes 'burn out', addressing organisational inflexibility and providing a more holistic approach on both an individual and population specific level.

With increasing recognition of the importance of CHWs in addressing health disparities, their roles and responsibilities have evolved with a progressive move by countries such as Brazil, India, Pakistan and Ethiopia making CHWs an integral part of community health delivery (Singh and Sachs 2013).

Peer support has been defined as social support on an individual or group level. This support is deemed to be beneficial to health and therefore has a role in health-related interventions at both an individual and community level. The philosophy of Peer support that it is a relationship based on reciprocity as opposed to a hierarchical one. It is of importance in increasing social capital for disadvantaged or vulnerable groups. The hypothesized effects of Peer support are illustrated (Figure 3.1) based on an adaptation of Heisler's (2007) congestive heart failure model.

Figure 3.1

Hypothesized effects of Peer support on self-care attitudes, behaviours and outcomes (Heisler 2007)



The importance of Peer support in healthcare has been highlighted by the World Health Organisation and in 2007, a summit was convened to examine the functions of Peer support in diabetes care globally (including definition, role, training, evaluation, interventions and cost-effectiveness). Because of the WHO summit, Peers for Progress was formed and funded by the Lilly Foundation ($15million USD) to demonstrate the value of Peer support in terms of diabetes daily management, social and emotional support and linkage to clinical care and to promote its integration in diabetes management globally (Caro and Fisher 2008).

The role of CHWs and Peer support is underpinned by psychosocial theories and frameworks. However, there are differences in their role definitions, scope and functions as summarised in the table 3.3.

Table 3.3

Role comparisons between Peer supporters and CHWs

Community Health Workers (lay community workers)	Peer supporters (coaches, lay peer educators)
Are from the community of the individuals they assist and provide an understanding of cultural norms and community dynamics	May or may not reside within the local community
Do not have the same disease as the patient	Always have the same disease as the individuals they assist
May be volunteers but are usually employed by a health facility or community agency. Provide self-management support but also acts as a bridge between patients and healthcare organisations	Are usually volunteers whose primary focus is providing self-management support based on lived experience. They are not usually employed by a healthcare organisation.
High utilisation in areas of scarce healthcare resources (human, specialist and financial) and developing countries.	Emerging use as an adjunct to educational programmes in developed countries
Use has been integrated in healthcare policy in some countries	Use is recommended however integration in healthcare policy is yet to be embedded.

3.7 Review of CHW literature

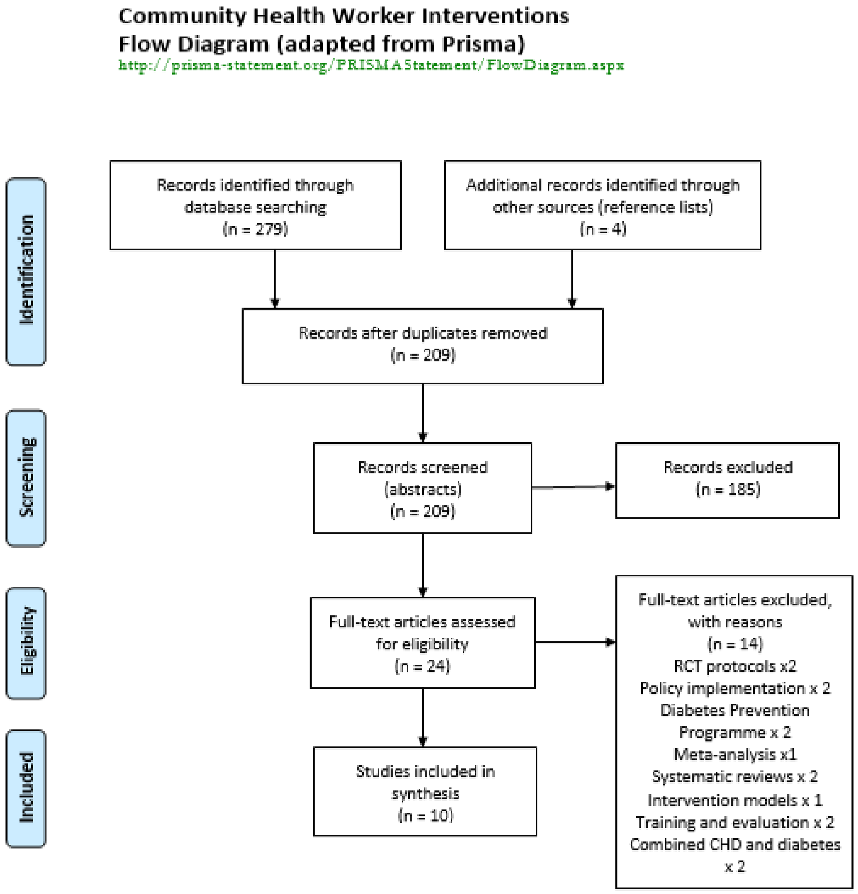
3.7.1 Search strategy

The literature search was conducted using electronic databases (EBSCO Host, Ovid, Embase, TRIP, Google Scholar, NICE, DARE, COCHRANE) in addition to hand searches derived from reference lists and conference proceedings and as specified in section 3.3.5. Key search terms included were: diabetes mellitus, diabetes, type 2, education, patient education, education strategies, self-management, cost, effectiveness, evaluation, outcomes, lay person, community health worker, long term effects.

Boolean operators were used to narrow the search and improve specificity and a combined total of 283 articles were found. Due to the volume of results generated by Google Scholar using the search terms diabetes CHW (157,000) and diabetes CHW cost (92,000) and the inability to use Boolean operators, the decision was made to use this source primarily for finding specific full text articles either by searching the title or author. The screening process for relevant articles involved reviewing abstracts which matched some of the criteria to determine appropriateness. Exclusions included out of scope articles based on a review of the abstracts, systematic reviews, literature reviews and duplicates. Study search and selection is illustrated base on an adaptation of the Prisma flow diagram (2009) (Figure 3.2).

Figure 3.2

CHW literature selection flow chart



3.7.2 Study selection

Studies were eligible if they were published in English from the period 2001 to the present involved adult patients (≥ 18 years of age) with T2 diabetes from ethnic minority or low-income or low-literacy populations and where the intervention was CHW lead or where CHWs were part of the intervention team. Methods included quantitative, qualitative and mixed methods. There was neither a restriction on the duration of the intervention nor duration of follow-up. The setting was unrestricted and therefore included hospital, homes and community settings. The duration of intervention ranged from three to twelve months and follow-up ranged from six to twenty-four months post intervention. Most of the studies selected were conducted in the USA (n= 8). Other countries included, South Africa (n=1) and UK (n=1).

Outcome measures in the selected studies included, clinical, bio-chemical, medication adherence, knowledge, self-reported improvement, attendance, empowerment and costs.

3.7.3 Assessment of study quality

Studies were assessed by using the Critical Appraisal Skills Programme (CASP) checklists for randomised controlled trials (RCTs), qualitative research and economic evaluations. These checklists enable assessment of the study's validity, robustness of the methods, analyses and results as well as applicability and generalisability of the findings.

3.7.4 Results

A summary of literature reviewed is summarised in table 3.4

Table 3.4: Summary of CHW literature reviewed

Reference	Aims	Setting	Design	Sample	Methods	Duration of intervention and Follow-up	Outcome measures	Results
Fedder et al., 2003	To evaluate the impact of CHWs on healthcare utilization for T2 diabetes	USA - Maryland	Retrospective comparison study with direct utilisation cost analysis	**N = 117** (intervention)	Weekly home visits and telephone contact	Intervention -12 months Follow-up -- 12 months post intervention	-Utilisation of emergency room (ER)and hospitalization -Utilisation costs (Medicaid)	- 40% reduction in ER visits - 33% reduction in ER admissions to hospital - 27% reduction in Medicaid reimbursements - $2,245 cost saving per patient per year - Overall cost saving of $262,080 for 117 patients - Improved quality of life
Gary et al., 2003	To evaluate the effectiveness of nurse case manager and CHW interventions on risk factors and diabetes complications	USA – East Baltimore	RCT (Mixed methods) 4 Parallel arms -Usual care -Usual care + nurse -Usual care + CHW -Usual care + Nurse + CHW	Urban African-Americans **N = 186**	Intervention delivered in primary care and the community	Follow up - 24 months	-Clinical (HbA1c, lipids and BP) -Behavioural (physical activity, diet	- Clinically significant reduction in HbA1c, diastolic BP and lipids from the CHW and Nurse arm as opposed to usual care
O'Hare et al., 2004	To evaluate the delivery of enhanced diabetes care using link workers	UK (Birmingham and Coventry)	RCT -Cluster design with General Practices - CHW + specialist nurse	6 west Midlands General Practices South Asians **N = 401**	Intensive management clinics in GP practices	Follow-up at 12 months	-Clinical (HbA1C, BP, cholesterol	- Significant reduction in systolic and diastolic BP and total cholesterol in

			- Standard care	Birmingham practices (183), Coventry practices (178)				the intervention group -No significant differences in HbA1C in either group
Brown et al., 2012	To evaluate the cost-effectiveness of a CHW intervention in T2 diabetes	USA - Texas	Interventional Cohort study – Purposive sampling	Low-income Hispanics **N = 30**	-Lifestyle modification intervention (home and community based) -Usual care -Archimedes simulation Model (20 year projection)	Intervention 18 months Follow up (mean HbA1c follow-up recording 75 days). Range 37 to 565 days	ICER Cost per QALY gained and lifetime costs associated with HbA1c	- Intervention group ICER range of $10,995 - $33,319 per QALY gained when compared to control group -Intervention highly cost effective for patients with high HbA1c of >9%
Collinsworth et al., 2013	To evaluate the effectiveness of a CHW led diabetes self-management programme	USA - Dallas	Interventional -Mixed methods	Hispanic **N = 497**	Community clinics	12 months	-Clinical (HbA1c, blood pressure and body mass index)	- Statistically significant decrease in mean HbA1c and systolic BP 1 year post baseline in the intervention group
Cummings et al., 2013	To evaluate the effectiveness of a CHW lifestyle intervention program	USA - Rural South America	RCT	Low-income African-American women **N = 200** Intervention (100) Control(100)	Community venues using the EMPOWER approach	Intervention 16 contacts Follow up – 6 and 12 months	-Clinical (HbA1c, BP, weight and BMI) -Behavioural and psychological (diet, activity, diabetes distress, empowerment, distress, life satisfaction)	- No clinically or statistically significant improvements in any of the parameters measured in the intervention group

Isalm et al., 2013	Pilot study to evaluate the effectiveness and feasibility of a CHW intervention in T2 diabetes among Bangladeshi-Americans	USA – New York	Community-based participatory research -Mixed methods	Bangladeshi-American **N = 47**	- Intervention delivered in clinics and community venues	Intervention 6 months Follow-up 12 month	-Clinical -Behavioural -Satisfaction	-Decrease in clinical measures (HbA1c, weight and body mass index) in the intervention group -Improvements in diabetes knowledge, life-style behaviours, self-efficacy in the intervention group -High CHW acceptability
Prezio et al., 2014	To evaluate the cost-effectiveness and health outcomes of T2 diabetes education using CHWs	USA - Texas	RCT -CHW culturally tailored education and management program -Standard care	Un-insured Mexican-Americans **N = 180**	- One-to-one CHW intervention in community clinic -Archimedes simulation Model (20 year projection)	Intervention 12 months	- Clinical (HbA1c over 12 months) - ICER Cost per QALY gained and lifetime costs associated with HbA1c	-Lower HbA1c estimated for intervention group at 5, 10 and 20 years - 20 year estimated ICER ratio of $355 per QALY gained for the intervention group
Mash et al., 2015	To evaluate cost-effectiveness of a diabetes group education delivered by Health Promoters	South Africa – Cape Town	RCT -Pragmatic cluster design (34 community centres)	Underserved communities Number included in economic evaluation **N = 866** Intervention 391 Control 475	-Lifestyle modification intervention (community based group intervention) -Usual care -Markov simulation Model (30 year projection and till death)	Intervention 4 sessions Follow-up 12 months	ICER Cost per QALY gained and lifetime costs associated with HbA1c, self-care activities, psychological factors and clinical measurements	-Significant reduction in HbA1c at 12 months -ICER $1862 per QALY gained when compared with the control group

Perez-Escamilla et al., 2015	To evaluate CHW-led structured intervention on blood glucose in T2 diabetes	USA	RCT -Parallel community based	Latinos **N = 211** Intervention (105) Control (106)	Home visits utilising principles of behavioural change theory and motivational interviewing	Intervention 12 months Follow-up - Baseline to 6 months post end of intervention	-Clinical (HbA1c, fasting glucose, lipids, BP, weight) -Behavioural (diet, medication adherence	-Statistically significant reduction in HbA1c at 3, 6, 12 and 18 months in the intervention group -Clinically significant reduction in fasting glucose at 12 and 18 month in the intervention group - No significant effect seen in lipid levels, BP and weight

Ten studies were identified as being relevant to the review and consisted of 6 RCTs, and 4 intervention studies. The interventional studies used methodologies such as before and after, retrospective comparison, community based participatory research and mixed methods. Sample size populations ranged from 34 to 866

All RCTs reported their method of randomisation and attrition rates.

3.7.4.1 Physiological and health outcomes

All studies reported their findings using the United Kingdom Diabetes Prospective Study (UKPDS) study as the benchmark for clinical assessment parameters. All studies used HbA1C as a primary outcome measure with seven studies also including blood pressure and lipids. Clinically significant improvement in HbA1C, blood pressure and lipids were found in the intervention groups in 2 studies, whereas only 2 studies reported statistical significance.

3.7.4.2 Knowledge

Diabetes knowledge was measured in two studies and was evaluated both pre and post intervention using a diabetes knowledge scale. Other measures were used to assess knowledge and were either self- reported, clinician assessed (nurse, doctor) based on adaptations of validated measures.

3.7.4.3 Psychological and behavioural outcomes

The prevalence of depression in people with diabetes is approximately twice as high as in the general population (Katon et al., 2004, Mommersteeg et al., 2013). However, only three studies evaluated psychological outcomes using either validated questionnaires such as the personal health questionnaire depression scale (PHQ-2) or adaptations of validated questionnaires. Psychological evaluations included depression, motivation, diabetes distress, life satisfaction and empowerment. Behavioural frameworks were used in some studies and included Bandura’s self-efficacy framework and the Precede-Proceed behavioural model. In addition to self-reported changes, behavioural outcomes were evaluated in three studies using validated measures. Two studies reported improved self-efficacy and behavioural changes such as medication adherence, diet and physical activity. However, one study reported no changes in the parameters stated above. This was thought to be directly related to the influence of deprivation within the study's population (Cummings et al., 2013)

3.7.4.4 Utilisation outcomes

Healthcare utilisation was evaluated predominantly by documentation of hospital episodes (attendance, emergency attendance and length of stay following admission from the Emergency Room (ER) and formed the basis of economic evaluations. Two studies recorded attendance and reduction in hospital attendance as outcome measures. One study reported a reduction in the rates of visits to the emergency room, admission from the ER (40% and 33% respectively) as well as overall hospital admissions reduced in addition to health insurance reimbursements (27%). Length of stay (LOS) following admission was reported by two studies.

3.7.4.5 Economic outcomes

Three studies conducted cost utility analyses (CEA) with incremental cost effectiveness ratios (ICER) and quality adjusted life years (QALY) whilst one study performed a direct cost analysis which comprised of costs such as reduction in ER visits, reduction in ER admissions to hospital and reduction in Medicaid reimbursements. Sensitivity analyses were conducted in two studies to evaluate future cost-effectiveness.

3.7.4.6 Long-term effects (sustainability)

Only two studies examined whether any improved outcomes were evident at least 18-24 months post end of the intervention.

3.8 Review of Peer support literature

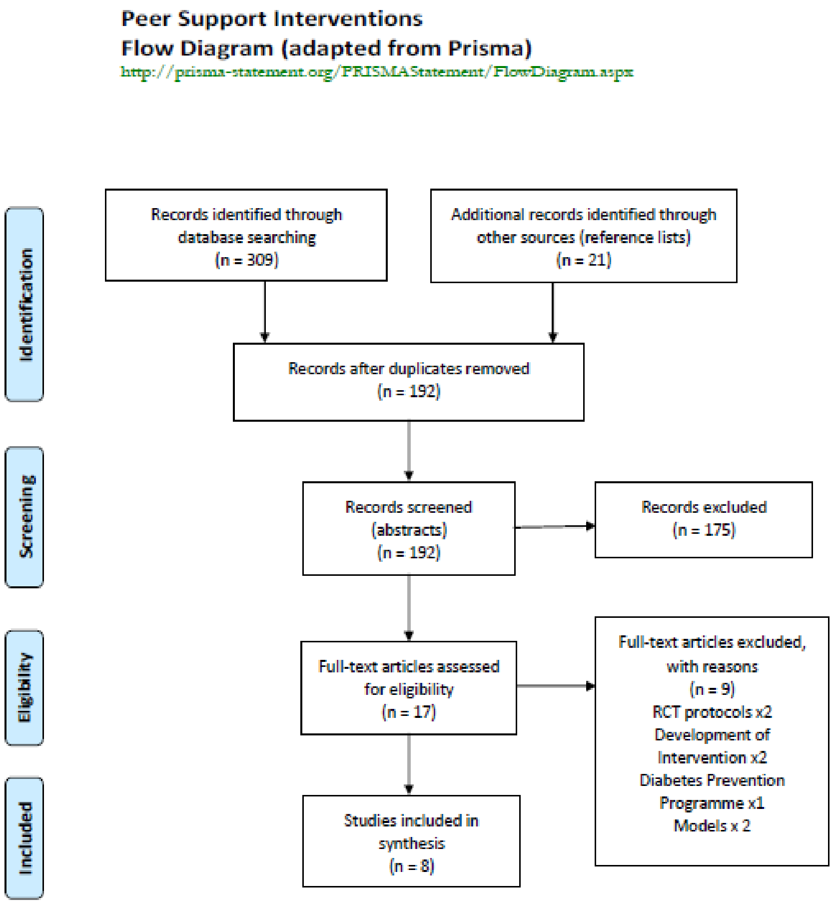
3.8.1 Search strategy

The literature search was conducted using electronic databases Ovid, Embase, TRIP, Google Scholar, NICE and COHRANE) in addition to hand and website searches derived from reference lists. Key search terms included were: diabetes mellitus, diabetes, type 2, education, patient education, education strategies, Peer support, peer educator, health literacy, self-management, cost, effectiveness, evaluation, outcomes, long term effects, deprivation and disadvantaged.

Boolean operators and were used to narrow the search and improve specificity. A combined total of 330 articles were found. As documented earlier, Google Scholar was used primarily for finding specific full text articles due to the issues identified i.e. volume and lack of selectivity. The screening process for relevant articles involved reviewing abstracts which matched some of the criteria to determine appropriateness. Exclusions included out of scope articles based on a review of the abstracts, systematic reviews, literature reviews and duplicates (see Figure 3.3).

Figure: 3.3

Peer support literature selection flow chart



3.8.2 Study selection

Studies were eligible if they were published in English from the period 2001 to December 2016 involved adult patients (≥ 18 years of age) with T2 diabetes from ethnic minority, disadvantaged or low-income or low-literacy populations and where the intervention was peer lead or where Peer supporters were part of the intervention team. Methods included quantitative, qualitative and mixed methods. There was neither a restriction on the duration or type of intervention nor duration of follow-up. The setting was unrestricted and therefore included hospital, homes and community settings. The duration of intervention ranged from six to 24 months and follow-up ranged from six to 24 months post intervention.

Eight studies were identified as being relevant to the review and consisted of six RCTs, and two secondary studies based on RCTs. Sample size populations ranged from 299 to 1299.

All RCTs reported their method of randomisation and attrition rates.

There was greater diversity in the countries where these studies were conducted (USA 1, UK 1, Austria 2, China 1, Hong Kong 1 and Ireland 2. Two cost-effectiveness studies (Gillespie et al., 2012, Johansson et al., 2016) were conducted as secondary studies based on the data of specific RCTs.

Outcome measures in the selected studies included, clinical, bio-chemical, diabetes distress, medication adherence, knowledge, self-reported improvement, attendance, empowerment and costs (utilisation and direct patient costs).

3.8.3 Assessment of study quality

Studies were also assessed using the Critical Appraisal Skills Programme (CASP) checklists for randomised controlled trials (RCTs), qualitative research and economic evaluations.

3.8.4 Results

The peer support literature reviewed is summarised in Table 3.5

Table 3.5: Summary of Peer support literature reviewed

Reference	Aims	Setting	Design	Sample	Methods	Duration of intervention and Follow-up	Outcome measures	Results
Smith et al., 2011	To evaluate the clinical, effectiveness and acceptability of peer support in primary care	Ireland	Cluster RCT -Intention to treat analysis -Based in General Practice	20 GP practices **N = 395** -Intervention 192 -Control 203	Mixed methodology	24 months	-Primary outcome measures- Systolic BP, HbA1c, total cholesterol, well-being score -Secondary outcomes – BMI, service utilisation, behaviour and life-style changes, medication use, process of care	-No statistically significant differences between intervention and control groups in any of the outcome measures.
Gillespie et al., 2012	A secondary cost-effectiveness analysis to evaluate for T2 diabetes in general practice	Ireland	Cost Utility analysis based on Smith et al., 2011	**N = 395**	N/A	N/A	Cost per QALY	-Peer support was cheaper and more beneficial than the control - No statistically significant differences in costs and QALYs at the 5% level
Thom et al 2013	To evaluate the impact of peer health coaching on glycaemic control in low-income patients with poorly controlled T2 diabetes	San Francisco (USA) -Public health clinics	RCT - clinic-based peer coaching versus usual care	**N = 299** -Intervention 148 -Control 151	1:1 peer coaching - via telephone or face to face	6 month intervention. Assessments at baseline and 6 months	Primary outcome – HbA1c at 6 months	-Clinically and statistically significant reduction in HbA1c in peer support group at 6 months (p=0.01)
Juliana et al 2014	To evaluate the effectiveness of telephone peer support in T2 diabetes patients receiving integrated care	Hong Kong	RCT -Intention to treat analysis	**N = 628** Intervention 312 Control 316	-Integrated care + peer support -Integrated care	12 month intervention and Follow up at 12 months	Primary outcomes Changes in HbA1c, systolic BP and LDL cholesterol Secondary outcomes	-No statistically significant differences in outcome measures (cardio-metabolic risks and psychological well-being)

Johansson et al 2015	Evaluate the effectiveness of a Peer Support Programme versus usual care in patients with T2 diabetes	Austria	-Unblinded cluster design RCT -Intention to treat analysis - Based in General Practice	49 GP practices. **N = 337** -Intervention 148 -Control 189	-Weekly peer group exercise meeting -Monthly peer group meeting with HCP	24 months	Primary outcome – HbA1c Secondary outcome – QoL (EQ5D) and cardiovascular risk	-No statistically significant reduction in HbA1c -Statistically significant improvement in QoL for control group (p= 0.046) -Low attrition rate of 6.8%
Johansson et al 2015	A secondary cost-effectiveness analysis to evaluate a peer support programmed for T2 diabetes	Austria	Cost-effectiveness analysis	**N = 337**	N/A	N/A	ICER	-Significant reduction in length of hospital stay with intervention group and estimated cost saving of Euro 1660.60 per patient -No differences in the number of prescribed drugs and hospital admissions
Simmons et al 2015	To evaluate the impact of community based peer support in T2 diabetes	Cambridge UK -Primary Care	RCT 2x2 factorial cluster design - Intention to treat analysis	**N = 1299**	-Individual intervention -Group intervention	8-12 months intervention	Primary outcome - HbA1c Secondary outcomes - QoL, diabetes distress, BP, Waist, total cholesterol and weight	-1035 (79.7%) completed mid-point questionnaire -1064 (81.9%) had final HbA1c -92.6% telephone contact between PSF and peers 61.4% of intervention participants attended face to face sessions - No significant change in HbA1c detected - Statistically significant reduction in systolic BP by group peer support attendees (p=0.008)

								-6% reduction in diabetes distress
Zhong et al., 2015	To evaluate the effectiveness, feasibility and acceptability of a peer leader-support program for diabetes	Anhui Province – China	Cluster RCT 3 cities in Anhui Province -2 sub communities within each city randomly assigned to intervention	**N = 726** Intervention (365) Control (361)	Mixed methodology	Bi-weekly meetings in community venue and life-style modification activities in addition to individual support through informal contact	-Clinical (fasting glucose, post-prandial glucose, systolic and diastolic BP) -Behavioural (self-efficacy, knowledge, life-style modification)	-Statistically significant improvement in diabetes knowledge, self-efficacy, BMI, BP ,fasting and 2 hour post-prandial blood glucose in the intervention groups in 2 out of the 3 cities randomised

3.8.4.1 Physiological and health outcomes

All studies used HbA1C as a primary outcome measure with seven studies also including blood pressure and lipids. Clinically significant improvement in HbA1C, blood pressure and lipids were found in the intervention groups with shorter durations of intervention and follow-up. Studies which had larger sample sizes, longer periods of intervention and follow-up found no statistically significant differences between the intervention and control groups.

3.8.4.2 Knowledge

Four studies reported on diabetes knowledge (pre/post intervention) following the use of variable assessment measures. Knowledge was assessed in some studies through clinician or Peer supporter interface as well as using validated measures such as the Diabetes knowledge scale. Adaptations of validated assessment measures were used sometime in addition to validated measures

3.8.4.3 Psychological and behavioural outcomes

Studies used validated quality of life tools such as the EQ-5D visual analogue scale, the diabetes distress scale and the diabetes empowerment scale for self-efficacy (DES-20) to assess these outcomes. Psychological evaluations included depression, motivation, diabetes distress, life satisfaction and empowerment. Where Self-reported behavioural outcomes such as smoking cessation, medication adherence was evaluated, all studies reported improved self-efficacy and behavioural changes such as medication adherence, diet and physical activity.

*3.8.4.4 Utilisation outcome*s

Utilisation outcomes were recorded in one study and contributed to secondary cost-effectiveness analyses. Measures of utilisation included but were not limited to out-patient attendance, clinician encounters, hospital admission and length of stay and medication costs. A significant reduction in length of hospital stay with intervention group and an estimated cost saving of (Euro) €1660.60 per patient was reported. There were no differences observed in the number of prescribed drugs and hospital admissions.

3.8.4.5 Economic outcomes

Economic evaluations were conducted either as primary or secondary evaluations. Primary evaluations were integrated into the study design and analyses were done contemporaneously (Paul et al., 2007). Secondary evaluations were done based on the findings of studies which had be conducted separately. Cost utility analysis (1), cost-effectiveness analysis (1) and direct cost analysis (1) were conducted by individual studies. Utilisation factors which were evaluated included length of hospital stay, clinical consultations (doctor, nurses, dietician, podiatrist), accident and emergency visits and diabetes treatment costs. Incremental cost effectiveness ratios (ICER) based on quality adjusted life years (QALY) were determined.

3.8.4.6 Long-term effects (sustainability)

Two studies delivered interventions of 24 month durations. These studies however, reported that there was no statistically significant difference (clinical and behavioural) between the intervention and control groups. Therefore, there was no evidence to support extension of the intervention beyond the study period. Despite this finding, a greater improvement in quality of life was reported in the intervention groups. In the smaller studies with a shorter duration of intervention more clinically favourable results were obtained. Improvement outcome measures were reported up to 12 months post intervention. One study reported on sustainability and adoption post intervention (Zhong et al., 2015). They reported that based on the improvements seen with their peer leader-support programme, the Provincial Health Bureau expanded the initiative to another speciality (cardiovascular disease) and other communities in the province. This was achieved by national health reform.

3.9 DISCUSSION

This review focused on study populations which were categorised as underserved or low-income groups, groups with low levels of education, those with a significant diabetes disease burden and as such, comprised of diverse ethnic groups (African-American, South Asian, Chinese, European, Hispanic, Micronesian and South African). The studies selected represented a cross-section of countries therefore the use of CHW and Peer support interventions was evaluated in both developing and developed countries with different healthcare systems such as universal health which is free at the point of access or private insurance based healthcare. Various study methods were used to evaluate the effects of CHW and Peer support in diabetes care as a means of reducing disparities to at risk or marginalised groups. Effectiveness of CHW and Peer support interventions were measured by evaluating clinical effectiveness (short, medium and long term) and cost-effectiveness. A general observation based on searching existing literature has been that Peer support intervention have been more widely and robustly studied particularly in resource rich and developed countries as opposed to CHW interventions.

3.9.1 Clinical effectiveness

Clinical effectiveness was universally determined by evaluating physiological and behavioural outcomes with a focus on reduction in biochemical markers such as HbA1C (A1C), lipid, blood pressure and body mass index (BMI). An interesting finding was highlighted (Islam et al 2013) in relation to the discordance between clinical and statistical significance of biochemical markers (HbA1c and lipids). Their study demonstrated a clinically significant reduction from baseline in HbA1C, weight and BMI at twelve months however these reductions did not achieve statistical significance. Collinsworth et al (2013) also demonstrated significant clinical reductions in HbA1C (1.3%) and systolic blood pressure one year post baseline but no statistical significance. Despite the lack of statistical significance, it is widely accepted that a reduction in biochemical parameters has a significant influence on reducing the risk of complications. For example, a 1% reduction in HbA1c can reduce the risk of developing eye, kidney, and nerve disease by 40% and the risk of heart attack by 14% (UKPDS 1998). However, the use of HbA1c as an outcome measure of effectiveness of an intervention has been questioned. The ACCORD study demonstrated that low HbA1c is not necessarily related to better outcomes (Gerstein et al., 2007). It was reported that the level of significance of clinical outcomes could be affected by factors such as randomisation. It was noted that where there is open randomisation, selection bias may occur, whereby well-controlled patients are selected, therefore leaving little room for statistically significant improvement in clinical outcomes (Johansson et al 2015).

Behavioural interventions were delivered by CHWs and were shown to provide significant improvement in medication compliance, physical activity, motivation and depression scores. The Precede-Procede behavioural model was used in one study and demonstrated sustained effect on follow up at up to 24 months (Gary et al 2003). These improvements were reportedly due to the cultural competence of the CHWs, their ability to build relationships based on shared experiences and gain participants' trust. The importance of relationship building and trust as a behavioural enabler between CHWs and participants was again highlighted by Collinsworth et al (2013). Cultural competence is a valuable benefit of CHW and Peer support interventions as they are individuals with an understanding of culture, local challenges and lived experiences. The use of CHWs and Peer supporters helps to minimise social isolation and exclusion reported by some 'disadvantaged' groups thereby increasing their social functioning and support.

Conversely, there were studies (Johansson et al., 2015, Simmons et al., 2015) which reported negative findings with Peer support interventions whereby there was no significant improvement (statistically, self-reported or observed) in clinical or behavioural outcome measures. These studies had larger sample sizes with a longer follow-up period of up to 24 months' post intervention. Cummings et al (2013) also reported no significant improvement in outcome measures following a CHW intervention. However, they highlighted the influence of socio-economic factors on one's ability to effectively manage diabetes and reported that despite their results, the role of CHWs is invaluable in assisting patients to reduce barriers to care and improve their ability to navigate healthcare systems to optimise their care.

Overall, significant improvement in healthcare utilisation outcomes were observed and thought to be a direct effect of the empowerment and health-navigational role of CHWs or Peer supporters. This improvement was reported in terms of more appropriate use of healthcare facilities and reduction in either ER admissions or hospital LOS. Despite the general reporting of improved healthcare utilisation, it should be noted that the impact of co-morbidities in the population groups may be confounding factors in ER attendance and hospital admission therefore it cannot be conclusively determined that any improvement is solely attributed to CHW or Peer support interventions.

Despite mainly positive findings, there have been reported challenges to using CHWs or Peer supporters. Interventions were either CHW/Peer support led or had either as part of a healthcare team. Being part of a team did not negate the importance a CHW particularly in relation to their cultural competence. One reported challenge of using CHWs was the perception of credibility as deliverers of healthcare interventions (Islam et al 2013). Respectability was another issue identified in a South African study in that despite CHWs being viewed as an invaluable and cost-effective resource in South African healthcare delivery, it was reported that CHWs were not as respected in the community as health care professionals and they “struggle to fully adopt the guiding style” (Mash et al 2015 p.625). The issues of credibility and respect may have a cultural basis based on possible paternalistic views held by some groups and how healthcare is structured in some countries. Both CHWs and Peer supporters were valuable resources due to their ability to engage with and empower the target populations.

Qualitative evaluations of the acceptance of CHWs and Peer supporters by participants found high levels of acceptability despite initial concerns by participants about CHWs credibility. This issue of credibility was mitigated by participants being informed of the CHWs affiliation with a medical institution (Mash et al 2015). The quality and variability of training offered has been identified as an area for improvement. As the role of CHWs and Peer supporters has evolved so has the need for role clarification and robust training standards. Training reported in the studies was diverse and included formal educational programmes with set levels of proficiency (Ferguson et al 2011, Richards et al 2015) and informal training programmes by health care professionals (HCPs).

The potential for altered dynamics between the Peer supporter and individual receiving support was noted. The role of a Peer supporter has been described as that of a non-directive facilitator, however, it was reported that in some instances there had been a tendency by Peer supporters to adopt a 'quasi health professional' role which altered the fundamental dynamics of Peer support. The patient/clinician relationship and dynamics have been shown to be a rate limiting factor in clinical consultations and engagement due to factors such as paternalism and power imbalance with dis-empowerment reported as a result. It is therefore essential that the philosophical principle of an equitable relationship is maintained with Peer support initiatives.

3.9.2 Cost-effectiveness

The purpose of cost-effectiveness analyses is to establish whether something (programmed, intervention and treatment option) is value for money. In the context of healthcare, value is determined by factors such as improved efficacy, outcomes, and reduction in healthcare and societal costs. Therefore, cost-effectiveness is a key driver in the funding and implementation of healthcare interventions.

The literature reviewed concluded that in the short to medium term, CHW and Peer support interventions are cost effective as they reduce out of pocket expense, medication costs, insurance costs, hospital emergency admissions, hospital in-patient admissions and length of stay (Fedderer et al. 2003, Thom et al., 2013). A recurrent finding in both primary research and systematic reviews of CHW and Peer support interventions in diabetes care has been the lack of long-term cost effectiveness outcomes (Norris et al 2006, Loveman et al 2008, Viswanathan et al 2010).

However, recently, there has been growing evidence of its long-term cost-effectiveness in the management of long-term conditions both in developed and less developed countries (Brown et al., 2012, Prezio et al., 2014, Mash et al., 2015). In the studies reviewed, long term economic modelling was used to demonstrate the cost-effectiveness of these interventions with predictions done for 5, 10 and 20 years (Shelton et al., 2012, Prezio et al., 2014) and 30 years (Mash et al., 2015). These studies concluded that in the long term, CHW and Peer support interventions were very cost effective based on the incremental cost effectiveness ratio (ICER: see table of tables) per quality adjusted life years (QALYs: see table of tables).

Two economic simulation models were used to demonstrate long-term cost-effectiveness namely; the Archimedes Model and the Markov Model. These models are designed to factor human physiology, disease progression and healthcare utilization as they address risk factors, interventions and cardio-metabolic outcomes using biological, clinical and healthcare utilization information and determine cost-effectiveness over time. These models factor in changes over time and track service utilization, health outcomes, quality of life and costs (Brown et al., 2012, Prezio et al., 2014, Mash et al., 2015). Larger sample sizes and longer follow-up periods have been recommended to improve the validity and generalisability of cost-effectiveness analyses. In the absence of long-term data, modelling provides decision makers with informed estimates of the impact of these interventions. It has been recognised that this approach may be very expensive and infeasible due to the nature of diabetes whereby the costs associated with complications may occur many years after an intervention has ended. Based on these limitations, there is clearly a need for long-term prospective randomised controlled trials of these types of interventions.

Variability in cost-effectiveness evaluation measures (cost-effectiveness analysis (CEA), cost-utility analysis (CUA) and direct cost analysis) was observed in the literature examined. Despite the heterogeneity observed in study design and evaluation measures, all the studies reviewed reported that CHW interventions either stand alone or in combination with health care professionals (HCPs) were cost-effective.

The cost evaluation methods used in the literature reviewed were CEA, CUA and direct cost which were fit for purpose despite not being full economic evaluations. A direct cost analysis as used by Fedder et al. 2003, lacks the rigour and generalisability of a CEA or CUA but is deemed to be a valuable method which can inform future cost-effectiveness analyses. Within healthcare, a cost-benefit analysis (CBA) is deemed to be a full economic evaluation but is problematic to undertake because all outputs must be measured and valued. If a CBA is used in its truest form, a monetary value would have to be assigned to social value judgements such as empowerment or perceived improvement in well-being in addition to the cost of sustaining a programme or intervention.

Despite emerging cost-effectiveness data, it has been highlighted that the observed benefits of successful Peer support interventions such as reductions in HbA1c, hospital length of stay and hospital admissions may increase short term medication and out-patient costs due to increased compliance with medication and appointments (Thom et al 2013). An observation made based on studies which reported improvements in healthcare navigation and perceived improvements in self-management in the absence of statistical evidence (Islam et al., 2013, Johansson et al., 2015) raises the question of how does one cost for intangible but meaningful benefits?

Recommendations for diabetes education in the UK are that it must be accessible, acceptable and culturally competent. It is recognised that alternative methods of education delivery and support are required that are more responsive to the needs of varying patient populations. However, a challenge for commissioners of diabetes education such as CHW and Peer support interventions which aim to enhance engagement and improve health outcomes in the UK may be the paucity of cost-effectiveness evidence and long-term impact.

3.9.3 Sustainability

There was little evidence to support sustainability of improved health outcome post CHW and Peer support interventions. Lack of clarity with follow-up schedules was evident with most studies because follow up durations did not always state whether the follow-up time-point was from baseline or end of intervention. The longest reported follow up was at 24 months and was seen in the Peer support interventions as opposed to the CHW ones. Research is constrained by both time and funding therefore the ability to assess long term sustainability would depend on the level of funding which can be obtained.

Sustainability of clinical improvements post educational interventions has been identified as an area for further examination. Bamrah et al (2010 reported two significant gaps in educational reviews: firstly, the relationship between better standards of education in the population and better long-term health outcomes in adults and secondly, analyses which explore the effects of educational policies and health outcomes over time. The concern regarding lack of on-going support is reflected in the lack of sustainability of clinical improvement which has consistently been identified as a short-fall of diabetes educational programmes. Most recently, the need for on-going support beyond the end of an educational intervention and throughout the ‘diabetes journey’ was been reported via direct patient feedback (APPG, 2015).

The NHS Modernisation Agency (2002) highlighted the “improvement evaporation effect” i.e. lack of sustainability of improvement in healthcare interventions. It described sustainability as the normalisation of new ways of working which achieve improved outcomes. This is achieved by a system-wide change in processes, attitudes and thinking thereby embedding the intervention into the organisation. It defined sustainability as “holding the gains and evolving as required, definitely not going back.” To address sustainability of CHW and Peer support interventions, two key questions need to be addressed i.e.

1. How can their use be supported outside research studies?
2. How can they be successfully embedded into the health care organisations?

Hiesler (2009) recognised that Peer support programmes lack the mechanism for sustained support but viewed these programmes as a key component of achieving and maintaining long term outcomes.

Despite the well documented benefits of these initiatives, areas for improvement have been identified. This review has demonstrated the difficulty in making study comparisons due to the heterogeneity of study methods (RCT, qualitative, intervention with or without control groups), interventions, settings, outcome measures and duration of follow-up. Regarding Peer support, more robust evaluations were conducted but there were significant variations in follow-up attendance and completion of clinical measurements between control and intervention groups (Simmons et al 2015). Methods of statistical analyses were variable whereby some studies adjusted for differences in baseline variables and others did not (Norris et al 2006, Loveman et al 2008, Thom et al, 2013). A meta-analysis of RCTs on Peer support interventions in T2 diabetes recommend programmes with mid to high frequency contact for patients with poor glycaemic control. Low frequency contact programmes were deemed to be less effective (Qi et al., 2015).

The training of CHWs and Peer supporters has been identified as an area which requires standardisation due to the variability demonstrated throughout the literature. Training programmes ranged from days to weeks with variations in both content and delivery as opposed to standard education which has an accredited framework for training, delivery and evaluation of the educators. In response to this criticism, some researchers and organisations have compiled Peer support curriculums which aim to provide quality assurance and reproducibility (Tang and Funnell, 2011, Johansson et al, 2013). The potential for Peer supporters to develop a quasi-health professional role was identified therefore training providers must be mindful of this phenomenon when delivering training. In addition, there should be quality reviews by the host organisations within which either CHWs or Peer supporters are based to ensure that the philosophical principles of this form of healthcare education delivery are maintained.

Globally, there is a growing body of evidence which report the successful integration of CHWs Peer support in public health policy and healthcare delivery in some countries and therapeutic specialities for example: USA, New Zealand, South Africa, Brazil and India and specialities such as diabetes and cardio vascular disease. This integration of CHWs on both an organisational and policy level is an effective sustainability strategy. On a more practical level, CHWs have been an invaluable resource for countries which experience significant shortages of health care professionals. Following a review by the South African Nursing Association (SAN) which highlighted that the patient-nurse ratio for all of South Africa was 417:1, the South African government was prompted to transform the roles and responsibilities of CHWs making them an integral part of healthcare delivery.

Locally, within recent years, there has been a reduction in the bilingual health advocacy (BHA) staff numbers due to the re-structuring of language services or de-commissioning of services by some organisations therefore, the use of CHWs and Peer supporters may be a means to minimise the impact of the reduction in or removal of this service. This would require collaborative working with charitable, community or voluntary organisations. CHW and Peer support interventions have consistently demonstrated to be minimal dropout rate and an average reported retention rate of 78.6 percent (Fisher et al., 2015). In contrast, there continues to be consistently high non-attendance rates at structured education programmes by underserved populations (Thom et al 2013). Diabetes UK (DUK) is a charitable organisation which has piloted time-funded Peer support programmes with the most recent being the Type 2 Together programme in six localities (Cambridgeshire and Peterborough, Coventry and Rugby, Dudley, East and North Hertfordshire, Mid Essex and North East Essex) during the period 2014 - 2016. This initiative was reported as being a success and as such, DUK Peer support initiatives will extend to Type 1 individuals also (https://www.diabetes.org.uk/Type-2-Together).

3.10 Social Models of Health

This review identified the degree of heterogeneity in the design, conduct and evaluation of CHW and Peer support interventions which impacts on generalisability of findings.

Despite this limitation, important observations were made from the overall findings which can be framed in an individual, organisational and structural context in accordance with the Social Models of Health (Dahlgren and Whitehead, 1991, Barton and Grant, 2006) (see Chapter 1; Figure 1.3).

3.10.1 Individual perspective

Both forms of intervention have been shown to improve patient's confidence, satisfaction and perceived ability to self-manage and in some instances in, bio-chemical outcomes and knowledge. The use of CHWs and Peer supporters can enable sustainability of educational support which is an essential component of self-management and allows for maintenance and improvement of gains.

3.10.2 Organisational perspective

There are potential cost-savings to be made from improved and appropriate access to services, reduction in hospital admissions and length of stay in addition to treating avoidable complications which should be minimised with improved self-management. CHW and Peer support initiatives bridge the gap between providers and service users and provide the information necessary for services to be provided which are fit for purpose and receptive to the needs of the population served. Funding of these interventions and having the infrastructure to deliver innovative models of care was identified as an ongoing challenge. However, this challenge makes a case for collaborative associations with organisations which are equipped both strategically and operationally to deliver such initiatives.

3.10.3 Structural perspective

Health disparities have significant impact at local, national and global levels. In developing countries which have both specialist and financial resource constraints CHW and Peer support interventions have been readily integrated into health policies. However, in resource rich countries, embedding such initiatives into healthcare policies and organisations remains an outstanding challenge. This issue of embedding such interventions into policy may be due to how health care is structured (universal or privatised) and its political drivers.

This review demonstrated that CHW and Peer support interventions are valuable additions to the educational repertoire for healthcare organisations particularly considering the significant global burden of illness of diabetes and the finite resources of countries and healthcare organisations. These interventions may be a simple, effective and sustainable solution to a mammoth problem.

3.11 CONCLUSION

This literature review is supportive of the use of Peer support and CHWs as a means of improving engagement with healthcare services and improving health outcomes. It has demonstrated these interventions to be both clinically effective and cost-effective in the short to medium term with emerging evidence of longer term benefits. Dahlgren and Whitehead's social model of health illustrates the importance of social and community networks of which CHW and Peer Support interventions would have an integral function.

It was consistently reported that their value (CHWs and Peer supporters) is most evident in improving access to healthcare for underserved groups. Additional gains included: increasing patient satisfaction, building community trust in healthcare organisations, providing comprehensive care for communities as well as obtaining funding through the development of strategic partnerships (Spiro et al. 2012). A high level of acceptability has been demonstrated with CHW and Peer support interventions based on retention rates. Peer support is thought to be more beneficial as peers share similar characteristics such as age, gender, ethnicity and similar disease status (Heisler, 2009). Further benefit is derived through role modelling, flexibility in time and location thereby increasing access and acceptability of peer led interventions. Feedback from CHWs indicated that relationship building and trust are two key factors which make people more receptive to educational interventions and help to improve compliance with treatment (Collinsworth et al., 2013).

Caution should also be exercised particularly in relation to the findings of the cost-effectiveness studies based on factors such as sample size, lack of long-term follow-up data and heterogenous comparators and measures. CHW interventions had smaller sample sizes which ranged from 47 to 401 in contrast to Peer support studies which ranged from 299 – 1299. Only two studies had sample sizes more than 800 (Mash et al 2015, Collinsworth et al 2013). To evaluate cost-effectiveness based on the time-limited data, economic modelling was performed in all studies to predict long-term cost-effectiveness. Economic simulation has been reported to be an effective means of predicting long-term health and cost outcomes of interventions where short-term data are available (Carol et al., 2009).

What is undisputable is the increasing global burden of illness of diabetes and the catastrophic resource implications associated with its direct and indirect costs. In the UK alone, the direct yearly cost to the NHS of treating diabetes is £9.8 billion which is 10 per cent of the health system expenditure. Eighty per cent of the cost is due to treating avoidable complications (APPG, 2015). The use of CHWs and Peer support workers can be a means of minimising cost whilst improving health outcomes particularly in countries, organisations and patient populations where there are limited resources, high diabetes prevalence and poorer health outcomes. In the UK, commissioning of these initiatives may be one of the greatest challenges for organisations as the gold-standard for evaluation and subsequent commissioning of interventions relies on unequivocal results based on empirical data. What may be missed because of an inflexible commissioning framework are the benefits of qualitative evaluations which provide richness in relation to reach, delivery and acceptability of educational programmes. It was recently highlighted that pragmatism is required for Peer support translation into the “real world” as this method does not fit into the standard clinical research designs (Fisher et al., 2015). It has also been stated that many healthcare professionals and organisations are ill-equipped to provide the type of education and support needed to facilitate effective long-term self-management while with robust training, Peer supporters and CHWs could provide effective and economical long-term self-management support (Funnell, 2009).

The use of CHWs and Peer supporters is an additional tool in the educational ‘tool-kit’, and despite the heterogeneity of interventional programmes and evaluation methods, this review has demonstrated these approaches to be effective in engaging with underserved individuals and those with poorer health outcomes. Their use is valued as a means of reducing the gaps in healthcare systems. Caro and Fisher (2008) reported that a metamorphosis in the mind set of healthcare organisations and individual care providers towards the role and value of persons with diabetes and communities where they live is required. Peer support has been proposed as the key to enabling this metamorphosis. It has also been highlighted that where gaps in healthcare systems occur, care is compromised and disparities increase. The value of Peer supporters was aptly described in a video excerpt from Peers for Progress:

“Community Health Workers provide humanizing, person-centred care that improves healthcare quality, health outcomes and healthcare costs.” (http://www.peersforprogress.org/).

Recommendation

Based on existing literature, if Peer support and CHW interventions are to be successfully integrated into policy and embedded in healthcare organisations in developed countries further research is needed in addressing questions such as:

- What is the optimum design for a common intervention programme?
- Can evaluation approaches be standardised to assess common end points?
- What is the most effective method for delivering and evaluating peer training?
- How best can CHW and Peer support intervention be effectively embedded in healthcare policy?

3.12 Linkage

The following chapter will introduce the research component of this thesis which was conducted in two separate stages. The research component explores the factors which influence diabetes out-patient non-attendance. Each research phase will be reported in subsequent chapters (5 and 6) therefore the following chapter provides an overview of shared elements such as ethical processes, methods and theoretical frameworks.

CHAPTER 4

INTRODUCTION TO RESEARCH REPORT:
An evaluation of factors influencing diabetes out-patient attendance

4.1 Introduction

This chapter provides an overview of the research component of this thesis which was undertaken in two stages. The first stage was a predominantly qualitative exploration of attendance utilising focus groups, semi-structured interviews and an adapted health literacy questionnaire. The second stage was developed following critical analysis of the initial research approach and resulted in a quantitative enquiry utilising the Patient Activated Measures (PAM) questionnaire and three supplementary open-ended questions. The background, rationale to the studies, research processes, methodological approach and underpinning frameworks are discussed in this chapter. The individual research stages and findings are reported in chapters 5 and 6.

4.2 Background

4.2.1 Idea for research proposal

Upon completion of the case study, I attended a PhD educational retreat organised by the School of Health Sciences in February 2011 where the findings were presented. This retreat provided an opportunity for all doctoral candidates in attendance to benefit from shared learning through knowledge exchange and academic guidance from attending lecturers. Appraisal by peers and the attending senior lecturers was invaluable as it prompted critical and reflective thinking.

Based on the findings presented, a recommendation was made by the attending lecturers that the research component for this thesis should provide a meaningful understanding of non-attendance hence a qualitative evaluation of the factors which influence non-attendance in the diabetes out-patient service was proposed.

Qualitative research is focused on answering the why and how questions as opposed to how much which is a common characteristic of quantitative research. Qualitative research aims to describe and understand people by asking what is happening, how does it happen and why does it happen. It generates data which is usually from observation and interviews and is described as a means of researching the socially constructed world (Fox et al., 2007). It has also been described as a means of understanding and evaluating social phenomena from the inside and can be achieved through analysis of individual or group experience, interactions and emerging forms of communication and documents (texts, images, film or music) (Gibbs, 2007). Therefore, in discussion with PhD supervisors, it was agreed that this form of enquiry would be complementary to the quantitative undertaking of the case study and provide a better understanding of the non-attendance phenomena. With guidance from the School's librarian, a literature review was conducted to determine the feasibility of the approach recommended and to inform the development of the research component.

4.2.2 Process of conducting research

The DH (2002) defined research as a "structured activity which is intended to provide new knowledge which is generalisable and intended for wider dissemination. All research studies must be conducted in accordance with the Research Governance Framework (DH 2001) and subject to formal approval processes.

The Research governance framework therefore underpins health and social care research with its core principles being the safety of participants, appropriately trained and skilled staff, suitable organisational resources and compliance with all regulatory guidelines. in the UK, the National Institute for Health Research (NIHR) provides comprehensive guidance on the categorisation of proposed studies in addition to advice on ethical submission processes

4.2.2.1 Ethical review processes

The Integrated Research Application System (IRAS) algorithm was used to determine which type of ethical submission would be appropriate for the proposed research study. The study was assessed to have no material ethical issues therefore was categorised as low risk with minimal burden or intrusion for research participants. As such, the study met the criteria for Proportionate review submission. However, following submission for ethical review, the study was subjected to Full ethical review. Concerns raised included:

- Lack of clarity around disclosure by participants and confidentiality
- Primary outcome measure had not been made explicit
- The extent of experience to undertake qualitative research
- Insufficient information about the conduct of and use of focus group information

Full ethical review requires the researcher to be present at the committee meeting with a decision-making period of 60 calendar days from the submission date of a valid application.

Despite the initial application being rejected for proportionate review and subsequently requiring full ethical review, a request was not made for my attendance at the committee meeting and correspondence was successfully conducted via email and ethics approval granted in January 2013 (see Appendix 5.)

The second research study also required ethics approval and was assessed as suitable for Proportionate ethical review due to no material ethical issues. This study did receive proportionate ethical review and ethics approval was granted in November 2015 (see Appendix 6).

Full ethical review is required for any study which does not meet the “No Material Ethical Issue” criteria. These criteria include but are not limited to clinical trials, research involving vulnerable individuals, research databases and prison research.

Proportionate ethical review is recommended for any study which meets the "No Material Ethical Issue" criteria. Proportionate review is an expedited process whereby applications are reviewed by a sub-committee instead of at a full research ethics committee meeting. The turnaround for a decision following receipt of a valid application is within 14 days calendar days. Researchers are not required to attend the meeting and any queries raised are conducted either via telephone or email. Email correspondence was made between the ethics committee co-ordinator and myself on two occasions with regards to an omitted source document and an incorrect document version. Upon addressing the queries, a favourable opinion was granted.

Upon reflection and scrutiny of the proportionate review guidance, the use of a non-validated questionnaire may have been the rate limiting factors for gaining proportionate ethical review with the first study's application. The published findings of the first study (Campbell-Richards, 2016) were used as the rationale for development of the second study and a validated measure was included. These factors may have contributed to the study achieving proportionate review.

4.2.2.2 Reflections on the research approval processes

The process of gaining ethical approval has in the past been described as a bureaucratic minefield which requires a great amount of patience, resources and time (Fox et al., 2007) and which one is fortunate to navigate in a timely manner. However, within the past decade, significant strides have been made to streamline ethical processes to expedite the conduct of research. This expedited process remains very robust and ensures the scientific integrity, safety and ethical conduct of research.

The first application submitted for ethical approval provided valuable learning about the step-wise processes involved in addition to the potential pit-falls. This learning made the process of submission for the second stage of the research element less daunting and more efficient. None-the-less, the process of gaining Trust's R&D approval remained a protracted and bureaucratic processes on both occasions primarily due to factors such as Trust specific requirements (peer review) and issues around study related costs, in particular, Bilingual Health Advocacy costs. The Trust's processes highlighted a gap in how nurse-led research is approved and managed. It was evident that the Trust's R&D infrastructure was geared towards clinical trials and grant funded projects as opposed to academic research. This resulted in a confusing and protracted process on both occasions. At a time when the role of nurse-researcher is being advocated nationally, the requirements of such a role needs to be accommodated in NHS R&D structures to enable a seamless and timely study conduct. On the 31st of March of 2016, a new research approval (Health Research Authority (HRA) approval) was implemented in the England following a phased roll out which commenced in May 2015. This new approval process aims to streamline ethics and regulatory processes which in theory should simplify the setup of research studies and expedite approvals by removing duplication (HRA 2015).

4.3 Methodological approach

The research component of this thesis comprised of two distinct stages of enquiry. However, is reported as a whole as the research questions posed in stage two emerged from the findings of the initial enquiry (stage 1). As a nurse researcher, I was aware of the complex nature of disengagement of which non-attendance is a manifestation. Due to the complexity of disengagement, an approach which would provide context as well as objectivity was deemed to be most appropriate to enable a comprehensive evaluation and understanding of the problem.

A multi methods approach using mixed data sources was chosen as this facilitated a more comprehensive assessment of the problem. It is suggested that multi method designs are a means to improving the reliability and validity of conclusions (Knight 2002). However, it is stressed that the researcher must have a clear rationale and understanding of what each methodological paradigm (quantitative and qualitative) will contribute. In this instance, a multi methods designs enabled the findings of the initial qualitative enquiry to be checked against a larger sample in the second stage of enquiry by using a validated self-evaluation questionnaire.

Multi method designs are have the potential to produce greater uncertainty due to incongruous methods chosen from different theoretical paradigms.

4.3.1 Research design

A complementary and sequential research design was used to conduct this study. Both qualitative (focus groups, semi-structured interviews) and quantitative (questionnaire) methods were used in the study design. Miles and Huberman (1994, p.41) outlined four integrated research designs and their associated quantitative and qualitative sequencing. It is highlighted that no one approach is superior to the other in the integrated models. The four integrated strategies are:

1 Both quantitative and qualitative strategies are pursued in parallel
2 Continuous qualitative field observation provides a basis for a quantitative evaluation which is conducted in stages
3 A qualitative method of evaluation is followed by a questionnaire. The results from both steps are then used to conduct a second in depth qualitative phase
4 A quantitative evaluation is followed by a qualitative exploration to provide in depth understanding of the quantitative results. A further quantitative evaluation is conducted to test the results of the first two steps.

A complementary design uses both qualitative and quantitative methods within the same project based on priority and sequencing decisions. The priority decision is based on determining which method will be the main method for data gathering. This decision must be based on the method which is most important to the proposed research. The contrasting complementary method's purpose is to add data to enhance the main method.

A sequence decision relates to the order in which the complementary methods are used and is based on the best way to optimise the effectiveness of the main method. For example, a primarily qualitative study may use a small quantitative component such as survey to aid in the evaluation and interpretation of the study results and vice-versa. It has been stated that the use of complementary designs are useful for practitioner researchers as it help them address real life multi-dimensional problems which they encounter daily.

The method of combining research methods is defined as triangulation (Fox et al., 2007, Flick, 2009). Triangulation is described as strategy used in research for either producing better knowledge in research or improving the quality of qualitative research. Triangulation utilises four types of strategies (methods, data, theories and investigators).

In this research component, triangulation occurred by using data generated from the focus groups to modify the interview topic guides where appropriate and inform non-scripted prompts during the interviews.

4.3.2 Sampling

Qualitative sampling has been subject to great debate over time. A criticism of qualitative sampling is that the decision making appears to be driven by quantitative presumptions that the more interviews, the more scientific the study (Kvale, 2007). It is suggested that a sampling frame should be drawn up which provides scope for modification as the study progresses, insights evolve or opportunities arise (Barbour, 2007).

In qualitative interviews, the answer to the question of how many participants is appropriate have included 30-50 participants (Morse,1995) and 20-30 (Creswell, 2007). It is recognised that a common problem in qualitative research is that the sample size tends to be either too small or too big. Both of these issues identified influence findings by either limiting generalisability due to small sample sizes or minimising the depth of analysis due to large sample sizes. It has been suggested that the sample size should be determined by the purpose of the study and as such, the researcher should ‘interview as many subjects as necessary to find out what you need to know’ (Kvale, 2007, p.43). This approach appears to be quite pragmatic because factors such as time and resources are considered. However; if ethical approval is required for the conduct of the study, a sample size must be included with an accompanying rationale thus limiting this pragmatic approach. Kvale went to elaborate that the sample size of most qualitative interviews is 15 ± 10.

4.3.2.1 Focus groups

The purpose of a focus group is to create consensus via interaction and has been described as

any group discussion with a skilled researcher who actively encourages and is attentive to the group interaction (Barbour, 2007). A fundamental characteristic of a focus group is that it is an in-depth facilitated discussion with a small number of people who have shared social and cultural experiences or shared area of concern (Liamputtong and Ezzy, 2005). These authors suggest that focus groups can be used as a self-contained method, a supplementary method or as a component of a multi-method study. It is recommended that focus groups should be conducted in an informal manner and should last no more than two hours. There should be an element of flexibility in relation to time based on the topic being discussed and level of interaction by participants.

4.3.2.2 Interviews

Prior to undertaking interviews, good practice dictates that there must be topic specific and methodological knowledge, in addition to an awareness of the ethical implications associated with the process (Flick, 2007). It is recommended that interviews must be open with a reflective component to improve data exploration and quality.

Interviews can be either explorative or hypothesis-testing whereby they seek to either gain empirical knowledge of a topic or a social situation or life history.

Semi-structured interviews were used in this study due to the probative and flexible nature of this type of interview. Structured interviews on the other hand can be restrictive both in the choice of response and ability to express one's self freely. A potential drawback of semi-structured interviews is the interviewer/interviewee dynamics and the effect this may have on the data integrity (reliability and validity). This may be more evident in practitioner research as the boundaries and expectations between the practitioner researcher and patient may become blurred whereby a patient may expect a clinical focused interaction as opposed to a research specific interaction.

4.3.2.3 Questionnaires

Questionnaires are an objective assessment of any topic being reviewed as they produce quantifiable data. It is recommended that questionnaires used in research studies should be appropriate for the client group and topic but more importantly, be validated. Appropriate chosen and validated questionnaires improve the validity and replicability of research. The process of validation of questionnaires is rigorous and requires design, extensive testing and evaluation.

4.4 Patient and public involvement and Incentive to participate

Service user involvement is a core component of research design and delivery. Guidance on the use of service users in NHS, public health and social care research is provided by INVOLVE. INVOLVE was established in 1996 and is funded by the National Institute for Health Research (NIHR). A primary function of this organisation is to promote social inclusivity and equality in research.

Prior to designing the research proposal, advice was sought from a local DUK patient representative to gain insight into whether the proposed study and design was appropriate and how best it should be conducted. The expertise of the patient representative who was also an individual living with diabetes and a service user was invaluable. He expressed concern about the difficulties he had encountered in trying to engage with the wider diabetes community and felt an incentive may have to be added. Having personally worked on two locally delivered research projects whose target population were BAME participants and gaining hands-on experience of the challenges of recruitment, I also sought advice from the Head of Chaplaincy at Barts Health NHS Trust who incidentally is an Imam about recruitment strategies. A recommendation from the Imam was that like most individuals in society, the “what’s in it for me” question would have to be addressed. Based on the recommendation of both the head of chaplaincy and DUK patient representative, the decision to provide an incentive of a voucher for a nominal amount (£10 GBP) was made. These views were also highlighted in a service evaluation conducted at the NHS Trust reviewed in this thesis which explored barriers to research participation in 2010. Factors such as such as incentives to participate, research which benefits the participant’s community and ethnicity of the researcher were identified as determinants to participation. The use of an incentive was detailed in the ethical submission and described as a token of appreciation for the time given to be interviewed. The use of this financial incentive was approved by the reviewing ethical committee.

The use of incentives in health and social care research raises ethical concerns due to the potential of perceived coerciveness hence their use requires adequate justification and ethical approval. Despite the apprehension and justifiable concerns about the use of incentives, it has been acknowledged that its use has a purpose in the conduct of some research studies particularly in hard to reach groups. Within Phase I and Phase II clinical trials whose participants are usually healthy volunteers, compensation for time and inconvenience is standard practice with the level of compensation determined by the sponsor company. However, within Phase III and academic research whose participants are predominantly patients, rates of compensation or incentives are subject to greater scrutiny due to the potential influence of incentives on decision making (coercion). In all instances, the level of compensation or incentives require robust justification and are subject to ethical approval.

4.5 Accessing participants

4.5.1 Defining a non-attendee

The organisation's definition of a non-attender during the period covered by this thesis was anyone who failed to attend two consecutive appointments. Should this occur, the result was referral back to the individual's GP. However, During the process of screening potential participants, it was noted that there were many patients who had been discharged from the diabetes specialist nurse (DSN) due to non-attendance but maintained their appointments with the diabetes specialist consultant. Therefore, a stringent definition of what constituted a non-attender was used i.e. patients who were completely discharged from the diabetes service (DSN and Doctor). The impact of this definition was a reduction in the potential sample population. Despite the reduction in sampling, this observation of disparities in non-attendance trends for DSNs and doctors raises an important question: What are patients' perceptions of the function and value of a diabetes specialist nurse?

4.5.2 Process of making contact

Once identified, the process for contacting potential participants was performed via letter, follow-up telephone contact or in person. Follow-up phone calls were conducted at least one week following posting of letters with a maximum of three attempts made to contact all potential participants. Phone calls were made at various times throughout the day (mid-morning, noon, mid-afternoon and early evening (before 6 pm). This approach was very time consuming and in many instances required scheduling around the BHAs daily work schedule. Phone calls were the most successful in terms of gaining acceptance for participation however many calls went unanswered. Initiating phone calls from the hospital proved to be a barrier to recruitment because the number displays as anonymous on the recipient's end. It is recognised that many individuals do not respond to anonymous phone callers. To have calls made whereby the telephone number does not register as anonymous must be done on an individual basis via the Trust's switchboard. This approach was neither feasible or sustainable. Use of a mobile telephone may have yielded a better response rate however, there were no funds available for either the purchase of a mobile phone or the cost of purchasing top-up cards.

When calls which were made from the fixed office telephone were answered and a discussion initiated, many callers stated that they had not received a letter informing them about the study. Lack of prior information was a common reason used to decline participation. Despite me having a copy of the letters posted, it was difficult to disprove what was said because the letters were posted via the Trust's postal service and neither required a record of postage nor a signature of receipt by recipients. A record of postage and signed receipt by potential participants serves an auditing purpose however, has a cost implication which was not deemed to be necessary or feasible. In addition, this administrative practice is not standard practice in the conduct of research. One of the core principles of research is the individual's right to freely choose to either accept or decline participation. Introducing checks such as signature of receipt for letters posted infringes on the element of freedom.

4.5.3 Challenges

Other factors which also influenced the rate of acceptance or refusal to participate were religious periods and input from other family members. Recruitment efforts for both phases of the research studies fell within the period of Ramadan and this was a reason given for either non-participation or delayed decision-making. Very few individuals who delayed decision-making to after Ramadan actually agreed to participate once contacted after Ramadan. Ramadan is a holy period which is observed by Muslims which requires an extended period of fasting and prayer. During this time, many individuals who observe Ramadan, limit their activities including health-related activities such attendance at out-patient appointments and blood testing. It was very apparent that participation in research was categorised as a non-essential undertaking during the period of Ramadan. Cultural insensitivity has been shown to be a recurrent theme in empirical evidence which evaluates factors which influence some ethnic minority groups relationship with healthcare.

Some female, elderly and non-English proficient individuals indicated that a discussion about participation would have to be made with appropriate family members (husband and or children). This highlighted the influence of culture and language on decision making. In some cultures, decision making is a collective process which involves the family as opposed to an individualistic process.

The ability to readily access non-English speakers was determined by the availability of BHAs to assist in the recruitment process and the patient's willingness to attend. Patients were less willing to attend for interviews therefore most of the interviews were conducted as home visits. Despite the time-consuming nature of home visits, they provided an insight into the lived experiences of individuals with diabetes and brought light to the challenges of accessing services where there is difficult transportation access and scarce financial resources.

4.6 The use of others

Bilingual health advocates were used for facilitating informed consent and interviews. Having used the expertise of the BHAs on previous projects I was confident that they had the knowledge and skills required for obtaining informed consent in accordance with research governance guidance. This assurance was based on my involvement in the provision of annual research training for the BHA service during the period 2010 to 2013. Their initial training was delivered by an independent research consultancy company with subsequent training undertaken by the Education and Training department of the Trust. This training was favourably evaluated in relation to knowledge, skills and confidence gained. The research expertise of the BHAs, proved very valuable during the recruitment process when concerns were raised about anonymity and the impact of either participation or refusal to participate on future care.

The use of BHAs to facilitate semi-structured interviews was less straight forward because none of the BHAs used had received training on conducting interviews. Providing training for the advocates was not feasible due to the timescale for undertaking the research, their work schedules and the cost for accessing suitable training. Having completed a one-day course at the University of Surrey (conducting qualitative interviews), I felt equipped to provide guidance to the BHAs prior to commencing the interviews. However, once interviews commenced, it became apparent that some BHAs were more comfortable and skilful in facilitating interviews than others.

The use of BHAs is advocated in healthcare consultations to provide quality assurance between the clinician and individual. The use of friends and family members for translating information is not encouraged mainly due to issues of confidentiality and confidence in the accuracy of the information relayed.

Two independent researchers were used to co-facilitate the focus groups with me. Both researchers were qualified to undertake the role of co-facilitators with one being a social anthropologist and the other a research associate. The use of an independent researcher is advocated where practicable as this reduces researcher bias as well as participant responsiveness. In addition, both researchers used were accessed through other projects within the department on a basis of ‘good will’ thereby did not have any direct involvement or influence on the study’s conduct.

Recording of the focus group session was included in the consent form however, prior to conducting the first focus group, it was discovered that the available tape recorder was defective and needed to be replaced. Purchasing of a new recorder had to be done in accordance with the Trust’s procurement process therefore the recorder was not received until both focus groups had been conducted.

At the first focus group session, field notes were taken solely by the independent researcher, however, for the second group session supplementary notes were also taken by myself. Field notes are contemporaneous documentation of specific research interactions and by nature are selective. Field notes are descriptive and give an account of both speech and actions. Field notes are commonly used in ethnography and participant observation but can also be used in focus groups and interviews

(Flick, 2007). The decision to take supplementary notes was based on both reflection and a review of the field notes which were produced by the researcher from the first group. These notes highlighted points of missed information on my part. This missed information was primarily due to selective listening as I was more focused on observing the carer/patient dynamic between one participant and his spouse.

4.7 Funding

The initial research study was funded however the funders had no influence on the research processes (conduct and interpretation of findings). It has been reported that research integrity can be compromised by influencing factors such as the funding body with the result being a skewed interpretation of some findings whereby some may be ignored whilst others are emphasized to the detriment of the phenomena investigated (Kvale, 2007).

4.8 Theoretical frameworks

The primary purpose of the research undertaken was to examine the factors which influence patient engagement (attendance) with diabetes out-patient services in an ethnically diverse and socio-economically deprived borough in London in the UK. Two frameworks which provide a context for the research enquiries were chosen as they provide the theoretical underpinning of psycho-social determinants and the wider determinants of health and their influence on engagement and decision making.

Health inequalities frameworks provides an understanding of micro, meso and macro influences on healthcare relationships and health-seeking behaviours whereas psychosocial frameworks provide an understanding of factors which influence an individuals' cues to action (knowledge, skills and confidence).

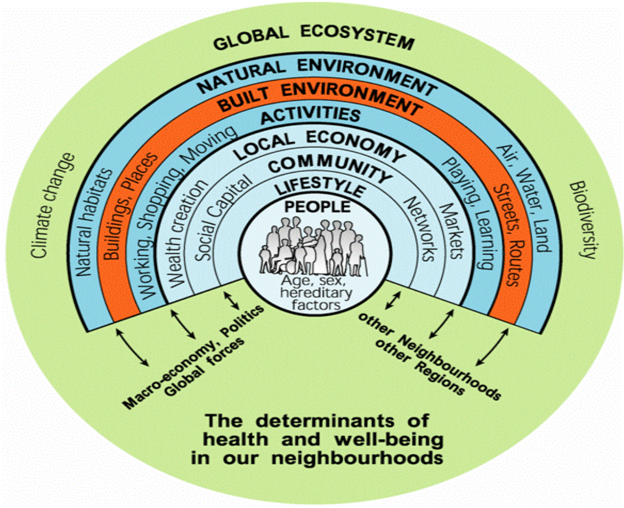
4.8.1 Health inequalities

Dahlgren and Whitehead's Social Model of Health (1991) which has been illustrated in the introductory chapter one (Figure 1.2) was chosen as the underpinning framework for this thesis as it an all-encompassing framework. It recognises the influences of both intrinsic (individual characteristics) and extrinsic factors (social, organisational, governmental and global policy) on an individual's relationship with health. Over the past two decades, national reports and policy documents such as: The independent inquiry into health inequalities (Acheson, 1998), Tackling health inequalities: A programme for action (DH, 2003), Fair society healthy lives and Fair society healthy lives: 2 years on (Marmot 2010, 2012), have reinforced the relevance of this framework. The framework was more recently adapted by Barton and Grant (2006) with a resulting locally designed Health Map (Figure 4.1). This adaptation has remained consistent with its predecessor whereby the fundamental principles of the micro, meso and macro influences on health have been maintained. Validation of these frameworks is evident by the WHO's (2006) recognition of the correlation between factors such as individual characteristics (age, gender and ethnicity) and socio-economic factors on lifestyle behaviours, access to and utilisation of health care as well as outcomes.

Figure 4.1

Barton and Grant (2006)

The Health Map for the Local Habitat



(Adapted from Dahlgren & Whitehead's – Social Determinants of Health 1991)

4.8.2 Health Belief Model (HBM)

The HMB was chosen as the framework for both the literature review and research study and is illustrated in the introductory chapter (Figure 1.4). It was first developed in the 1950's by the US Public Health Service (Hochbaum 1958) in response to the poor uptake of medical screening programmes. It is a psychosocial model which examines the relationship between psycho-social factors and their influence on an individual's health behaviours. The core concepts of the HBM include: perceived susceptibility to, severity and threat of illness, perceived benefits of action weighed against perceived costs or barriers to action and health motive i.e. the value to the individual of reducing the perceived threat(s).

4.8.3 Social Change Theory (SCT)

With the growing body of literature over the past two decades which examine diabetes self-efficacy and outcomes (educational, psychological and clinical), there has been an evolution of psycho-social models being used. Another commonly used model is the SCT formerly called the Social Learning Theory (SLT) (Bandura 1969). This theory is an adaptation of the HBM with the main difference being the incorporation of self-efficacy as an independent variable into the model.

The SCT is integration of both cognitive and stimulus theories which gives a greater account and understanding of health-related behaviour. A significant contribution of the SCT is the concept of self-efficacy which is an individual's conviction to perform the behaviour needed to produce desired outcomes (Rosenstock et al., 1988). Key concepts of the SCT include: expectancies about environmental cues, expectations about outcomes, expectations about self-efficacy and incentives (cues to action).

The theories referenced in this thesis are widely used in literature which evaluates health care disparities, empowerment and self-efficacy as they recognise the interplay between social determinants and individual behaviours. They identify that individuals have the power of self-determination but this is influenced by a synergistic relationship between cognition, behaviour and multiple external factors. Despite the emergence of new theories, the HBM provided a blue-print for the psycho-social understanding of health-related behaviours considered in this thesis.

4.9 Linkage

The following chapter will provide a detailed report of the conduct of the proposed study which aimed to explore the barriers and drivers to diabetes non-attendance amongst patients (African, Bengali and Pakistani) identified in the case study evaluation as being significantly less likely to attend diabetes out-patient appointments when compared to White British patients.

An opportunity to bid for research funding (Mary Seacole Development Award) was identified and an application was submitted in July of 2012 to undertake the initial research proposed. Funding was successfully granted for the award period of October 2012/13.

CHAPTER 5: Phase I research report

An exploration of factors influencing Diabetes outpatient attendance amongst African, Bengali and Pakistani patients in a London borough

5.1 Introduction

This report details the first study of the research component conducted between May 2013 to September 2013 in a diabetes out-patient setting in an inner London borough in the UK. The research study was developed based on the findings of the case study (Chapter 2).

This chapter is a report of the study undertaken.

5.2 Background

5.2.1 Non-Attendance

The projected incidence and associated management of diabetes will produce a significant financial burden for local healthcare organisations. Diabetes care in England is driven by the National Service Framework (NSF) for Diabetes (DH 2001) and the National Institute for Clinical Excellence diabetes guidance. The NSF consists of twelve standards for diabetes care. The third standard of the guidance focuses on empowering patients with diabetes and highlights that services should encourage partnership in decision making and support to enable more effective lifestyle choices and self-management. The decision-making process should also ensure that parents and carers are fully engaged.

This standard emphasised the multi-dimensional aspects of diabetes care and the need for collaborative working and decision making. However, for this to occur, services provided should be responsive to the needs of the population it serves, easy to access and utilise. Indicators of gaps in services commonly include non-attendance and poor or inappropriate utilisation of services (MORI, 2009).

Non-attendance continues to be a significant financial burden to the NHS hence each organisation is tasked with utilising strategies to cost-effectively reduce non-attendance. One outcome of missed appointments by patients with long term conditions is poorer health outcomes due to inadequate self-management and the subsequent development of avoidable complications. Diabetes constitutes a significant financial burden on the NHS, in addition to the human and societal costs. The direct and indirect cost implication of diabetes in England and Wales for the period 2010/2011 was calculated at £23.7 billion (Hex et al.,2012). They highlighted that direct costs were associated with the management of avoidable complications, however indirect costs included sickness, loss of productivity and informal care. Dixon-Wood (2005) highlighted that non-attendance at healthcare services is rooted in issues around access and utilisation of services. She emphasised that this phenomenon is not fully understood and the impact of factors such as ethnicity and deprivation on access to services and health seeking behaviours requires further qualitative examination.

The NHS was tasked with saving £20 billion by 2014/15 in accordance with the Quality Innovation Productivity Prevention (QIPP) agenda. Cost savings continue to be a priority by the NHS remains a priority due to finite resources and increasing demand. More recently, the Five Years Forward Plan was launched (DH, 2016) with the emergence of the Transformation and Sustainability Partnership (TSP) programme. The TSP involves the NHS and 44 local councils working together to ensure health and social care services in England are receptive to the needs of local populations (NHS England, 2016)This programmed is tasked with increasing efficiency in healthcare delivery and improving health outcomes by streamlining processes and pathways and multi-stakeholder collaborations. Due to the burden of disease associated with diabetes both nationally and internationally, prevention, education and innovation are two key elements for the transformation of diabetes care if improvements are to be made in outcome measures such as prevalence, morbidity, mortality and cost.

5.2.2 Factors influencing DNA rates

Existing literature on outpatient attendance has consistently highlighted the multi-factorial nature with relation to barriers and drivers of attendance. It has been shown that patients from ethnic minority groups and areas of high deprivation sometimes experience difficulties in navigating healthcare systems with high non-attendance being an indication of this problem (Goddard 2001, Greenhalgh 2011). Other factors which have repeatedly been shown to influence non-attendance include forgetfulness, apathy, family and work commitments, administrative errors, waiting times, transportation and deprivation (Gatrad (2000), Ogeah (2003), Patterson et al. (2010)). Overall, influencing factors have been shown to comprise of three main elements i.e. individual, organisational and structural.

The diabetes services in Newham serve one of the most culturally diverse and deprived areas in the UK (Health Profiles 2009). This creates multiple challenges for not only the clients but the multidisciplinary care team. Patients who require specialist management are referred to the diabetes outpatient service at the local acute hospital by their general practitioner (GP) in accordance with local protocol. Unfortunately, historically, there has been a high incidence of outpatient non-attendance within the diabetes service. An unpublished service audit demonstrated non-attendance rates of 25 to 41 percent depending on age. Local attempts to reduce the non-attendance rate have included telephone and text reminders but with little impact and were subsequently withdrawn. However, text reminders were re-introduced following the merger of three NHS Trusts (Barts Health NHS Trust 2012) and its effectiveness is subject to evaluation. Text reminders have been successfully used by some organisations and have been reported as being a cost-effective option in reducing non-attendance. Other approaches have included telephone, letter and email reminders. Ogeah (2003) reported that the effectiveness of these methods is quite variable with only moderate success. He also highlighted that such methods weren’t shown to be cost-neutral, removed ownership for one’s own health from patients and are resource intensive therefore unsustainable. Conversely, Gatrad (2000) demonstrated the effectiveness of telephone reminders in significantly reducing paediatric outpatient non-attendance. Non-the-less, the degree of success of these approaches is limited by population groups, particularly ones where there are issues of language and literacy.

The task of tackling non- attendance is therefore more challenging when issues of language, literacy, deprivation and health literacy are considered. Despite existing literature, two main questions remain relatively unanswered. Firstly, what other approaches are needed to effectively improve attendance in hard to reach groups and secondly, are there any unmet needs which are influencing attendance? To address these questions, a comprehensive understanding of this phenomenon is required locally to develop strategies aimed at tackling non-attendance.

5.2.3 Local perspective

Seventy percent of Newham's population are from an ethnic minority group (JSNA 2010) and in comparison to the national average; African-Caribbean and South Asian communities have a significantly higher prevalence of Type 2 Diabetes. In 2008, the Health Care Commission highlighted that diabetes mortality and emergency admissions rates in Newham were higher than England's average whilst the York and Humber Public Health Observatory (YHPHO) (2010) listed Newham as having the 3rd highest estimated total diabetes prevalence in England.

The Ordnance Survey (2007) indicated that when the borough of Newham was compared to the whole of England, it registered in the fifth most deprived areas in England. The GLA (2007) forecasted that by 2016 there would be a sustained and significant growth of BME residents within Newham. Within North East London (NEL), diabetes and hypertension have been identified as the main long term conditions which lead to reduced life expectancy (NHS North East London 2009). Mortality and emergency admission rates for diabetes within Newham are higher than the English average (Health Care Commission 2008). Healthcare for London (2009) attributed the high mortality rate, reduced quality of life and life expectancy as well as the increased use of emergency and inpatient services to poor diabetes service provision and management. The National Survey of People with Diabetes 2006-2007 reported that the percentage of respondents at Newham Primary Care Trust who attended the hospital clinic was 28.6%, compared to the average in England of 19%. This higher than average attendance at hospital clinics may be explained by the diabetes prevalence and poorer health outcomes seen in Newham. Patients with diabetes who are unable to be managed by General Practitioners are referred to the hospital diabetes services for appropriate specialist management in accordance with locally agreed guidelines.

Deprivation is strongly linked with higher levels of obesity, physical inactivity, unhealthy diet and smoking; all of which are risk factors of diabetes or are a precursor for serious complications amongst those already diagnosed.

Despite having the youngest age profile/structure in England and Wales, Newham has several key factors (deprivation, inactivity, high ethnic population) which influence health care outcomes (morbidity and mortality). Healthcare for London identified several factors which make delivering diabetes care challenging and as such contribute to significant inequalities in outcome. These factors include at-risk communities, mobile population, ethnic and cultural diversity and organisational barriers. Sub-optimal diabetes service provision and management was also attributed to a reduced quality of life and life expectancy. An evaluation of trends in the utilisation of planned and unplanned care also highlighted that black and minority ethnic (BME) people within Newham use accident and emergency services and out of hours care more than planned care.

Reduced quality of life, life expectancy and poor health outcomes are associated with deprivation. It has been documented that certain ethnic groups (African, Bengali and Pakistani) consistently report worse health than individuals categorised as whites (POST 2007). Locally, lack of engagement with healthcare services for example non-attendance at appointments, has been attributed to limited English proficiency, poor health literacy and the impact of deprivation on health seeking behaviours within the local community. The lack of engagement of certain groups reflects a recurrent dilemma for many healthcare organisations which is how best to engage with groups which are 'hard to reach'. Hard to reach groups have been described as those which are difficult to access or engage with as a result of factors such as gender and ethnicity (Dixon Wood 2005). BME groups have been frequently categorised as 'hard to reach' however it must be recognised that these groups are heterogeneous and therefore subject to variability in terms of vulnerability or perceptions of vulnerability. For instance, Bengali, Pakistani and African groups have consistently reported poorer health whereas Chinese groups reported better health (POST 2007). Generally, reasons for limited access to, or engagement with, hard to reach groups have included suspicion of organisations, perceptions of racism, institutional racism and cultural insensitivity (Harris & Salway 2008). Peek et al (2007) highlighted that the disparities in diabetes health outcomes for 'hard to reach' groups has been explained in the context of health inequalities.

Health inequalities have been defined as "population-specific differences in the presence of disease, health outcomes or access to health care" (Goldberg et al., 2004). Health inequalities in the UK are broadly categorised in the context of mortality, morbidity and health care access. It should be noted that there are inherent biological variations between individuals which influence health status however, the WHO (2009) highlighted that from an ethical or ideological perspective, it may be unacceptable to change those health determinants, therefore in this instance health inequalities are unavoidable. There is a wealth of evidence that demonstrates the correlation between determinants such as gender, ethnicity and socio-economics and their influence on health opportunities, health-seeking and lifestyle behaviours and outcomes (WHO 2006). There is concordance that disparities in the population's health and social well-being between social groups and nations are largely societal in origin and commonly referred to as the 'causes of the causes'. Health inequalities are therefore influenced by the way society is organised (socially, economically and politically) and are a direct reflection of the stratification observed between life opportunities and social need. Within the LBN, it has been recognised that the health inequalities persist along the lines of gender, deprivation, geography and ethnicity. A recent evaluation highlighted that men and women from the most deprived group have a four year shorter life expectancy than those in the least deprived group (Health Profile 2008).

The Social Model of Health (Dalgren and Whitehead, 1991) was chosen to underpin this study (see Figure 1.1, chapter 1) because it illustrates the relationship between determinants such as demographics, geography, socio-economics and health. This framework examines the micro and macro influences on health and focuses on the social, economic and ecological theory of health. It highlights their influences on health which are subject to modification either on a personal, community or structural level. This framework contextualises the inter-relationship between people, social determinants and the government and rationalises the need for a cohesive, seamless and efficient health and social care policy if health inequalities are to be redressed both locally and nationally.

5.3 Aims

A better understanding of non-attendance is required to contribute to local strategies aimed at reducing the financial burden of disease and improve health outcomes. The aims of this study were determined by the findings of the case study which quantified the trends in non-attendance but left the questions of why and how unanswered. The case study identified two significant factors with regards to non-attendance: firstly a non-attendance rate more than twenty-five percent per year and secondly, variations in attendance between ethnic groups. Patients categorised as African, Bengali and Pakistani were found to be significantly less likely to attend appointments in comparison to patients categorised as White British (Campbell-Richards and Warburton, 2012). Therefore, the aims of this study were to explore the individual meanings, perceptions and experiences attached by patients to diabetes outpatient attendance services in LBN.

The main aims of the study were:

- To establish the factors which influence diabetes outpatient attendance/non-attendance

- To determine what approaches needed to improve attendance
- To determine whether there are any unmet needs

Based on the aims of this study, the research question posed was:
"*What are the barriers and enablers to diabetes out-patient attendance experienced by specific ethnic minority groups?"*

A second research element was included in the research proposal which proposed to explore clinicians' (doctor, nurses, dietitian and podiatrist) perspective of non-attendance if feasible.

5.4 Methods

This was a mixed methods study which was sequentially structured using semi-structured interviews and a questionnaire with the interviews being the primary data source. It has been stated that a sequential research design is complementary and one method should not be considered as being superior to the other (Flick, 2009). In this study, the use of a questionnaire following interviews provided additional information to aid the overall interpretation of findings. An holistic approach was utilised for this research. Holistic exploration has been described as a method which allows the researcher to select the variables of interest but allows participants to put their responses in context (family, work etc) thereby providing a total account of their experience (Parahoo 2006; p65).

Full ethical approval was required for this study with a favourable ethical opinion granted by the Berkshire B Ethics Committee in March 2013 and the local Trust's research and development department in May 2013 (see Appendix 5)

5.4.1 Sampling

Participants were deliberately chosen from referral sources and allocated accordingly based on a stratification criterion. The stratification criteria included specific ethnic groups (African, Bengali, Pakistani and White) who had either attended regularly attended outpatient appointments or not attended appointments and subsequently discharged back to their general practitioner (GP). This form of sampling is defined as quota sampling because it involves both purposive and stratified sampling without random selection (Parahoo 2006: p271).

5.4.2 Eligibility criteria

Patients over the age of 25 years with diabetes who were booked to attend outpatient appointments, able to understand the information provided and give informed consent. Language support was provided by Bilingual Health Advocates where required.

5.4.3 Exclusion criteria

Patients who fulfilled the eligibility criteria but were either not willing or unable to give informed consent due to limited mental capacity.

5.4.4 Recruitment sources

A list of patients who were discharge from the diabetes outpatient service due to nonattendance as specified by the Trust nonattendance policy was collected prospectively over a three-month period from the diabetes team secretaries.
Patients who attend appointments were identified during clinic consultations by either the diabetes specialist nurses (DSN) and doctors or by examination of clinic lists over a three-month period. The recruitment target was a maximum of 60 patients (20 - focus group and 40 – interviews).

5.5 Recruitment methods

Focus group participants: (Patients)

A flier which specified the purpose of the focus group (see Appendix 7) was circulated in the diabetes clinic areas with contact details for the researcher. Patients who expressed an interest were contacted and invited to attend the focus group.

The proposed design was to conduct two focus groups with a maximum of 10 patients per group (diverse gender and ethnicities) which consisted of both regular attendees and non-attendees. A maximum number of eight participants is recommended by Barbour (2007) however, Barbour (2007) suggests that a larger group (10-12) is feasible depending on the moderator's abilities to ensure everyone can have an equal voice. A minimum number of three to four participants has been deemed to be acceptable but this is dependent on the sensitivity of the topic being discussed (Kizinger and Barbour, 1999, Bloor et al, 2001). Most importantly, the focus group sample should reflect diversity within the group and population being studied (Barbour, 2007).

The groups were scheduled to be held at either the local hospital or diabetes unit and conducted over approximately ninety minutes. To reduce investigator bias, the groups were facilitated by an independent researcher with Bilingual Health Advocate (BHA) support where appropriate. At the commencement of the group, consent was obtained and an introduction including the purpose of the group session was done by myself. I remained in attendance however, the independent researcher asked questions based on the topic guide (see Appendix 8) and recorded field notes. Brief notes were also written by myself during and following completion of the session. The recording of notes based on recall has its limitations however, Flick (2007) suggests that active listening and recall may serve as a selective filter for retaining topic specific information. The data produced from these groups were used to inform possible amendments to the topic guide for individual interviews.

5.5.1 Focus group participants

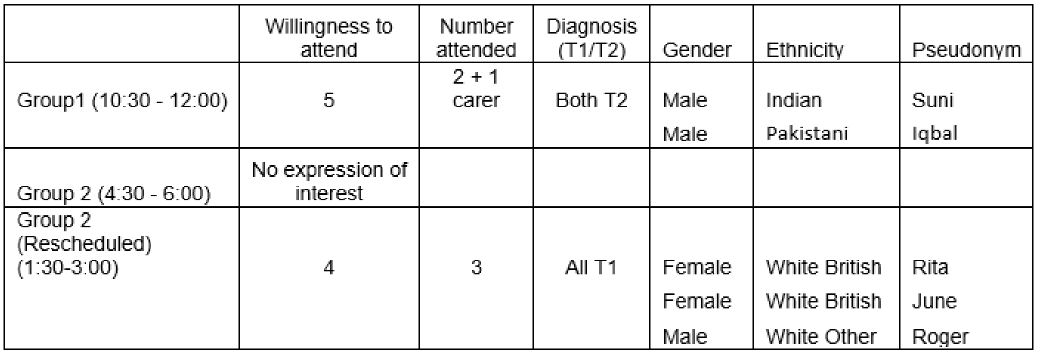
Two focus groups were planned with the primary focus being to generate themes to help refine the questions for the planned semi-structured interviews. The questions asked were designed in response to existing literature on outpatient non-attendance (Gatrad 2000, Ogeah 2003, North East Lincolnshire Council 2004, NHS Newham 2009).

Efforts were made to have participants who were representative of the diabetes population within LBN with regards to age, gender and ethnicity.

Focus group participants were identified by doctors and specialist nurses during the course of clinic consultations over a three week period. A list of patients who were willing to be contacted was compiled and these patients were contacted to confirm their willingness to participate. A total of 19 patients were identified, however, only nine patients expressed an interest in participating and only five of the nine attended the scheduled groups (Table 5.1). Both focus groups were facilitated by a researcher and field notes were documented. A researcher was selected to conduct the focus groups to minimise researcher bias.

Table 5.1

Focus group attendance



	Willingness to attend	Number attended	Diagnosis (T1/T2)	Gender	Ethnicity	Pseudonym
Group1 (10:30 - 12:00)	5	2 + 1 carer	Both T2	Male Male	Indian Pakistani	Suni Iqbal
Group 2 (4:30 - 6:00)	No expression of interest					
Group 2 (Rescheduled) (1:30-3:00)	4	3	All T1	Female Female Male	White British White British White Other	Rita June Roger

5.5.2 Interview participants

5.5.2.1 Regular attendees

Patients who attend outpatient appointments were identified by either the DSN or doctor. Patient information was sent to patients who expressed an interest in participating for further consideration. A telephone call was made one week later to confirm their willingness to participate. The intended recruitment target of regular attendees was twenty patients i.e. 5 patients per ethnic group (African, Bengali, Pakistani and White British).

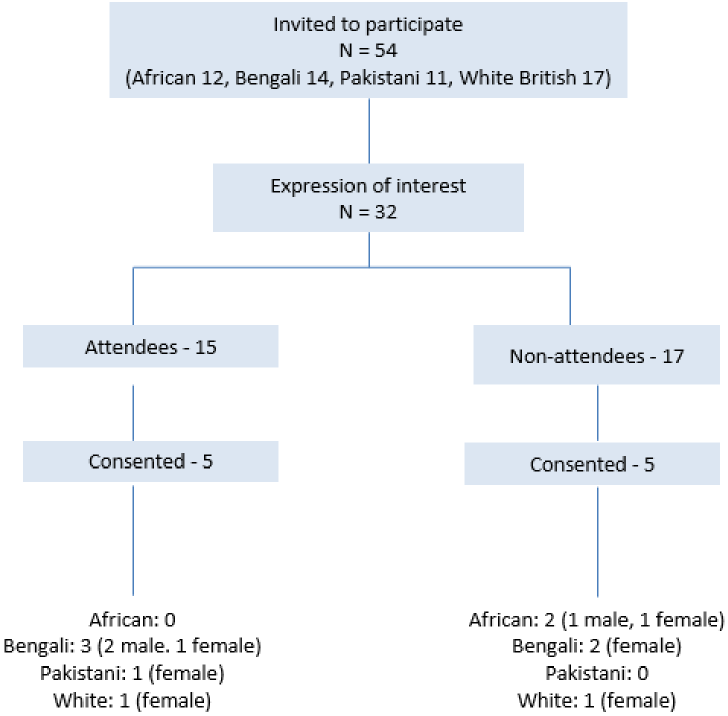
5.5.2.2 Non-attendees

An invitation letter was sent to patients who had been discharged due to nonattendance. The letter stated that a telephone call will be made one week following the postal date with the assistance of a BHA where appropriate to establish the patient's willingness to participate. The intended recruitment target of non-attendees who were discharged from the outpatient service due to nonattendance was twenty patients i.e. 5 patients per ethnic group (African, Bengali, Pakistani and White British).

The recruitment process for the patients interviewed is illustrated below (see Figure 5.1). Participants belonged to the four ethnic groups identified and consisted of patients who regularly attend appointments and those who were discharged due to non-attendance. The rationale for this design was to evaluate the similarities and differences between those who attended and those who did not attend.

Figure 5.1

Recruitment of Interview participants



5.6 Conducting Interviews

The aim of the study was to determine the barriers and enablers to attendance/non-attendance at diabetes out-patient appointments by specific groups of patients. This thesis hypothesised that a comprehensive evaluation of non-attendance could inform patient engagement and self-management strategies within the diabetes service.

Semi-structured interviews were selected as the most appropriate form of enquiry based on existing literature and the level of flexibility afforded. Based on clinical experience, I felt this type of interview would capture not only what was important to the research but also allow the interviewee to provide an account of what was important to them. The interview topic guide was refined following analysis of the focus group transcripts (for interview guide see Appendix 9). The focus group field notes provided information for non-scripted prompts during interviews. The key concepts of enquiry for the interviews were rooted in the individual, organisational and structural domains in accordance with the health inequalities framework.

Semi structured interviews were conducted by myself in a location which was accessible and acceptable to both parties. It was specified in the ethics application that only in exceptional circumstances (limited mobility or childcare commitments) would interview be conducted in the patient’s home. However, six of the ten interviews were conducted as home visits to minimise refusal and inconvenience by willing participants.

In preparation for conducting the interviews, a one-day course (Introduction to Qualitative Interviewing) course was completed at the University of Surrey’ School of Social Science as I had experience of group facilitation but none of conducting interviews. Ten interviews were carried out with four done at a location in the hospital and six in the participant’s home.
Interviews were facilitated by a trained, bilingual health advocate where necessary and scheduled to last no more than an hour. The duration of interviews ranged from 20 to 45 minutes with all interviews tape recorded following written consent by the participant. The interviews were recorded using a tape recorder with a noise reduction facility and placed centrally to both the interviewer and interviewee. In addition to the tape recording, notes were taken in the event of a technical fault which was experienced prior to the second focus group.

Immediately following the interview, participants were asked to complete an adapted health literacy questionnaire (see Appendix 10). The questionnaire used was an adapted version of what was at that point in time a non-validated health literacy questionnaire (Chew et al., 2004). This was done to aid an objective assessment of additional factors which may influence the interviewees' ability to access services.

5.6.1 Questioning techniques

All interviewees were asked the majority of questions on the topic guide. Prompts were not scripted as they emerged during interviews and were influenced by individual responses and prior knowledge from the focus groups. Therefore questions were sometimes omitted, rephrased or substituted based on the responses received. The sequence of questions were also sometimes modified in response to prior answers. One observation was that some interviews facilitated by BHAs were stilted despite prompts and the responses were not very detailed. In such instances, my ability to be flexible and probative was limited by language and the reliance on another person's ability.

Upon reflection, this could have been influenced by multiple factors. On a personal level, I was a novice interviewer and as such, either my interviewing style or the nature of questions may have contributed to the less open responses. From an interviewee's perspective, the presence of relatives in the room, apprehension about confidentiality and perceived impact of participation on future care may have contributed to their responses. In addition, it was noted that not all BHAs appeared confident in conducting interviews.

All interviews concluded with the interviewee being given an opportunity to asks questions or provide recommendations. Some interviewees expressed appreciation about the opportunity to provide recommendations.

5.7 Data handling (transcription)

There are discussions about who should transcribe and to what extent qualitative data should be transcribed. It has been suggested that it is not always necessary to transcribe all of the information collected to conduct an analysis (Flick, 2007). However, the value of transcription is recognised from a viewpoint of transparency and quality assurance particularly if team work is involved. Good practice dictates that transcripts should always be checked against the voice recordings for accuracy, fidelity and interpretation (Kvale, 1988).

Transcription by the researcher is an approach supported by Duffy et al. (2004) and Barbour (2007). Barbour suggests that novice researchers should do some of the transcribing themselves as it improves familiarisation with the data. All tape-recorded data were transcribed by myself as it allowed for immersion in the data and from a practical aspect, was feasible due to the reduced number of interviews (10) conducted. The decision to transcribe the data myself was based on having the skills to undertake the task (qualified shorthand/typist) and previous experience of transcribing interview data.

Verbatim transcriptions were done although it is suggested that transcriptions do not have to be verbatim. Verbatim transcriptions are deemed to be useful if data is to be reanalysed considering new information. Also, they can be revisited and shed light on additional themes considering new literature and experience.

5.8 Data analysis

A one-day course (Introduction to Qualitative Data Analysis) was completed at University of Surrey in November 2012 to provide the knowledge required to undertake this analysis.

Due to the sample size, manual as opposed to computerised thematic data analysis was performed. This form of analysis facilitates collation and cross-comparison of participants' responses and involves the creation and application of data codes. Codes are used for data with the same themes and enables patient responses that have the same thematic ideas to be retrieved, collected and examined collectively.

Data can be analysed and interpreted using different approaches which are dependent on the study's purpose. There are three main approaches to qualitative data analysis namely, grounded theory, content analysis and narrative analysis (Flick, 2007). The purpose of this study was not to generate theory or reconstruct biographical processes therefore neither grounded theory nor narrative analysis was chosen. The purpose of this study was to understand the perspectives of a phenomenon therefore content analysis was chosen as the most appropriate approach. Also, the main analytic categories were already known. Priest et al (2002) recommend content analysis if the main categories for questions are already known as do Elo and Kyngas (2008) who advocate content analysis as a means of eliciting meaning from text via the development of emergent themes.

The key concepts in the interview questions formed the master codes, i.e. individual, organisational and structural determinants.

5.8.1 Content analysis

Thematic data analysis was performed following transcription of the recorded interviews. Master and secondary codes (themes) were identified (Table 5.2).

Table 5.2 - Thematic codes

Master (M) Codes	First level (F) Codes	Second level (S) Codes
M1 Individual determinants	F1 Ownership	S1 Responsibility for self S2 Importance of self-management
	F2 Apathy	S3 Family history S4 Don't care S5 Denial
	F3 Commitments	S6 Work S7 Caring for others
	F4 Reliance on others	S8 Family support
	F5 Multiple illnesses	S9 Number of appointments S10 Cost of attending various appointments S11 Isolation/Depression
	F6 Language	S12 Literacy S13 Language support S14 Communication with others
M2 Organisational determinants	F7 Dissatisfaction	S15 Inflexibility S16 Poor communication S17 Administrative issues S18 Waiting times
	F8 Confidence in specialists	S19 Respect and trust S20 Expert knowledge
	F9 Education	S21 Access S22 Choice S23 Type
M3 Structural determinants	F10 Transportation	S24 Access S25 Cost S26 Availability
	F11 Social welfare	S27 Access S28 Knowledge
	F12 Loss of community services	S29 Closure of facilities

5.9 Data presentation: Focus groups

The main aim of the focus groups was to gain an understanding of the factors which influenced an individual's decision to attend or not attend diabetes out-patient appointment. Focus group questions were focused around the individual's general experience of attendance. It was recognised that the focus group members would also talk about their experience of living with diabetes which would provide a richer context for understanding why some individuals attended and others didn't.

Individual and organisational determinants emerged from the focus group discussions as key drivers to attendance (see Table 5.3) .

5.9.1 Individual determinants

In response to the question: "*how important is it for you to attend your appointments",* all participants, irrespective of diagnosis (T1 or T2) expressed strong views that your health was your responsibility and not that of the nurses or doctors. They acknowledged that the doctors and nurses had the specialist knowledge but to get it, "you have to turn up".

Attendance was viewed as a means of improving self-management by gaining the skills and knowledge needed to delay or avoid complications.

Fear was expressed by participants, but fear had different origins. Fear of complications was one driver to maintain attendance and engagement with services. The fear of leaving a dependent child without parental support due to the impact of diabetes complications was also a driver to attendance. The participant who expressed this fear specified that as a parent she has a responsibility to be a healthy and active participant in her child's life. She felt that her daughter should not be negatively affected by the choices she makes in relation to her diabetes management.

The fear and associated embarrassment of having a hypoglycaemic event in public was also expressed as a motivating factor to attend appointments. The participant who express the fear of having a hypoglycaemic episode was asked about her experience of having a hypoglycaemic episode. Her reference was in relation to experiencing this event whilst in public and the humiliation she felt when she became responsive. Her concern was that most people are not aware of diabetes and their impression of her would be that she was not looking after herself and as such deserving of what ever happened. A recently published multi-national study reported that 55.5% of the participants reported being worried about the risk of hypoglycaemic events (Nicolucci et al., 2013).

5.9.2 Organisational determinants

The provision of both patient specific and public education about diabetes prevention, its management and potential complications was deemed to be necessary. Patient/clinician interactions including relationship building, trust, respect and good communication were seen as important drivers of attendance.

Effective education was identified from both an individual and public perspective. There was a consensus that accessing individual education was the individual's responsibility, however, there was a view amongst the focus group participants that sufficient was not being done to improve the public's awareness of the impact of diabetes. Multiple means of accessing education and support were suggested.

There was criticism of past public health awareness programmes which were described as 'a put off'. It was discussed that information should be presented in a form that was useful, appealing, informative and relevant to the local population. The ability to obtain and share knowledge to assist others in their self-management was expressed as a reason to attend appointments. One participant expressed that his attendance at appointments allowed him to be a support mechanism for one of his friends who chose not to attend appointments.

The relationship between patient and clinician particularly confidence in the specialist team (doctors and nurses) was also an important driver of attendance. The emergent themes and some associated quotes are illustrated in table 5.3.

Table 5.3: Focus group's enablers of attendance

ENABLERS OF ENGAGEMENT	**PATIENT RESPONSES**
Individual determinants	
Ownership	*"In diabetes, we are our own doctors. You need to be the one to take care of you".* ***Rita*** *"As a child, it was my mum's responsibility but now it's mine".* ***June*** *"Diabetes is very important. You have to look after yourself. I've seen many people in my family die from diabetes complications."* ***Iqbal***
Fear - of complications	*"Looking after my diabetes is important because I don't want any complications"* ***Roger***
- embarrassment	*"We all try to keep on top of it (diabetes) because it stops you from getting the nasty things that go with it. The embarrassment of having a hypo will make me keep appointments ….."* ***Rita***
- parental responsibilities	*"My fear is that I will have complications and no one will be there to look after my daughter so I know it's important to attend appointments."* ***June***
Organisational determinants	
Education	*"Coming to the appointment, you find out how to look after yourself and what's new. There are new things coming all the time so keeping your appointments - you can get new things".* ***Rita*** *"They say – no one dies from diabetes but they don't realise you die from the complications of*

	diabetes" ***Suni***
Confidence in specialists	*"The hospital doctors are the specialists so they have all the knowledge. You need a big mum or dad to look after you and the hospital doctors are good at doing it. We have back up with the specialist nurse and we can give them a ring. If you have any questions, you can phone one of the nurses. You always got someone to fall back on"* ***Rita***

5.9.3 Reasons for non-attendance

Focus group participants were asked: 'why do you think people don't attend appointments?' and identified five factors which could potentially influence someone's ability to attend appointments. Factors such as language and cultural norms were framed in the context of the demographic composition of the local borough. There was recognition that individuals such as the frail and elderly or anyone who required the support of others would have difficulty attending. Participants were empathetic to patients who were dependent on others to attend.

Apathy was identified as a reason for non-attendance and was linked to the type of diagnosis (T1 or T2) and the quiescent nature of diabetes. The type of diabetes an individual was diagnosed with and their treatment was given as a reason for non-attendance by the participants of the second focus group. There was a recognition that "life gets in the way" sometimes but they felt that individuals with T2 diabetes did not take diabetes seriously particularly if they were only managed with oral medication. This opinion although is a broad generalisation was reported by Tan (2004), whereby the lack of seriousness of diabetes or the perceived susceptibility to complications resulted in poor preventative behaviour.

The influence of culture was discussed as a potential rate limiting factor to attendance. All participants from the second focus group felt that an individual’s culture may influence their ability to attend. When asked to explain what aspects of culture would deter attendance, the perceived role of women as being submissive in South Asian cultures whereby their actions are dependent on either the approval of men and/or families was identified as barriers to attendance by two participants. This statement was stereotypical but was not challenged as the basis of the assumption was not deemed to be essential. Despite the nature of the statement, the influence of gender, decision making and culture has been documented (Barbar, 2004). One participant expressed that in his opinion there was a lack of concern about diabetes in his community (Bangladeshi) so attendance at diabetes appointments was not a priority. When asked to elaborate, he stated that no one takes diabetes seriously because it’s so common in families in his community. There was also recognition by non-minority participants that the prevalence of diabetes in some communities and families may result in individuals not being bothered. The opinion expressed by these participants are consistent with the concept of ‘normalisation’ of diabetes by some communities due to its prevalence which results in a minimisation of the importance of self-management (CEG, 2011).

The demographic characteristics of the local area were discussed and the ethnic diversity of residents was flagged up in the context of language. There was group consensus that language is a barrier to booking and sometimes attending appointments but this was also interwoven with not knowing how the system works.

Themes expressed by focus group participants which were deemed to be potential barriers to engagement are illustrated by direct quotations in table 5.4.

Table 5.4: Focus group's perceived barriers of attendance

BARRIERS TO ENGAGEMENT	**PATIENT RESPONSES**
Individual determinants	
Dependence on others	*"It's understandable for people like that (elderly, frail, language difficulties etc) because their family or friends may not always be able to come with them. They have got their own lives and things to do."* **Focus group two**
Apathy	*"I see people dying in my family (from diabetes). People don't realise that diabetes is like a slow cancer.* ***Iqbal*** *"With diabetes, you don't have pain so diabetes you go (throws pen on the table) – Argh! Diabetes; not important!"* ***June***
Cultural norms	*"You know, for some Asian ladies, they aren't allowed to go out without their husband or a family member so that could be the problem."* ***Rita*** *"It could be culture why some people don't come. Maybe if it's in the family and there's a strong history of it, they may have other ways of looking after it (diabetes)."* ***Focus group two***
Language problems and Lack of knowledge of healthcare	*"This area has a lot of immigrants and language is a barrier especially if you don't know how it works. I've been living here 16 years and I went back home (Portugal) for four years. When I came back, I had to start all over again, everything had changed so I had to try and Figure things out myself."* ***June***
Diagnosis type	*"I think non-insulin dependent diabetic patients don't feel bad as they are only on tablets so they don't think coming is important."* ***Rita***

Prior to concluding each focus group, participants were asked two questions:

1. What do you expect from the service?
2. Is there anything else you would like to tell me?

Service expectations were quite consistently expressed with the following views:

- There is a need for clear and consistent education and support from diagnosis which continues throughout the diabetes journey with a greater focus on lifestyle changes as opposed to medication
- Better communication where patients are listened to and provided with care and information based on their individual needs
- Flexibility in appointment scheduling including the use of technology to enable this
- More specialist nursing support which can be in any format (face-to-face, phone, text)

The information participants felt was most important to inform me of to enable service improvements included:

- Bringing the diabetes specialist nurse to the forefront of care to “use the doctor’s time better”
- Improving public awareness and information so that people know just how serious a condition diabetes
- Working with other organisations such as schools and churches (mosques, gurdwaras etc) to help in the prevention of diabetes

5.10 Interviewees

Ten participants were interviewed and consisted of three men and seven women with an age range of 48 years to 70 years (mean 59 years). The duration of diabetes ranged from one year to 30 years. All participants had a diagnosis of T2 diabetes with five participants who regularly attended appointments and five who were discharged due to non-attendance. The demographics of all ten interviewees are presented in Tables 5.5 and 5.6

Table 5.5

Demographics of regular attendees

Ethnicity	Age (years)	Gender	Duration of diabetes (years)	Pseudonym
Bengali	70	M	8	Ali
White	60	F	13	Rose
Bengali	53	F	24	Nessa
Bengali	65	M	12	Miah
Pakistani	56	F	30	Saeeda

Table 5.6

Demographics of non-attendees

Ethnicity	Age (years)	Gender	Duration of diabetes (years)	Pseudonym
African	53	M	10	Ola
African	64	F	2	Femi
White	55	F	1	Liz
Bengali	68	F	20	Nazma
Bengali	48	F	6	Bibi

5.11 Data presentation: Regular attendees

The themes which emerged from interviews with participants who regularly attended appointments were similar to those of the focus group participants. However, additional themes such as the cost of attending appointments and managing multiple illnesses were identified as potential barriers to attendance.

5.11.1 Individual determinants

The views expressed by the regular attendee participants were similar to those of the focus group participants. The need to take responsibility for attending appointments and self-managing was expressed. It was recognised that the ability to take responsibility for oneself was made easier by the support of family and friends.

The importance of family support was expressed by some participants who were reliant on their family to read letters or accompany them to appointments. It was evident from the participants that their family member(s) were actively engaged in their healthcare.

5.11.2 Organisational determinants

Access to education was directly linked with attendance at appointments. Participants felt that the only way they could learn more about and be able to better manage their diabetes was to attend appointments. Some stated that it was not always easy to attend appointments but *"how else would we find out and learn?".* There was a recognition that reliance on others for information was not always useful and that within some communities, there is persistent misinformation.

Confidence was expressed in interactions with both specialist doctors and nurses irrespective of the type or duration of diabetes. Also access to a specialist was seen as a privilege with two participants expressing frustration in stating that, not attending appointments was not just rude but a waste of a valuable opportunity. These two participants are originally from countries where care is neither universal nor free at the point of access. The emergent themes and some associated quotes are illustrated in table 5.7.

Table 5.7

Regular attendees enablers for attendance

ENABLERS OF ENGAGEMENT	**PATIENT RESPONSES**
Individual determinants	
Ownership	*"I have other problems but I put diabetes first because it affects so much. I was quite shocked to learn the amount of problems it can cause."* ***Rose*** *"My GP told me about the complications so it's very important (to attend) no matter how hard it is. You have to go."* ***Saeeda***
Family support	*"My daughter is very good, she reads all my letters and makes sure that she comes to appointments with me."* ***Miah***
Organisational determinants	
Education	*"You hear all sorts of stories in my community and only because I go to my appointments I know they're talking rubbish".* ***Saeeda*** *"I get to find out new things and ask questions when I come to my appointment."* ***Miah*** *"I learned a lot when I went to the groups (storytelling). That's a really good way to learn."* ***Ali***
Confidence in specialists	*"Those appointments (dnas) could be given to people who care about their health. They are lucky to be seeing a specialist."* ***Ali*** *"I'm glad I'm in a country where people are looked after by a specialist and I'm happy with how I'm treated."* ***Nessa***

5.11.3 Reasons for non-attendance

In response to the question which explored why individuals may not attend, individual, organisational and structural themes were identified.

5.11.3.1 Individual determinants

Three individual components which some interviewees felt may be determinants to non-attendance were: apathy, denial/fear and carer responsibilities. Apathy was borne out of a feeling of resignation and acceptance that whatever is to be, will be. Fearfulness was deemed to be associated with having to accept life-style changes and the possible implications or impact on one's life. Family commitment, particular care giver responsibilities was put forward as a potential barrier to attendance. One interviewee encapsulated these sentiments in one statement which is reported in table 5.6.

5.11.3.2 Organisational determinants

The two organisational components which some interviewees felt may be determinants of non-attendance were waiting times and access to services. Despite an acknowledgement for the pressures and demands on services, areas for improvement were identified by regular attendees. Prolonged waiting times were frowned upon and there was an expression of feeling 'short-changed' by either having a short consultation once seen or by being seen by a junior clinician.

5.11.3.3 Structural determinants

Transportation and social welfare concerns were expressed as possible determinants of non-attendance. The ease of access to transportation in addition to assistance with transportation costs were recognised by one regular attendee who expressed that there should be a means-tested approach to the provision of support. . The emergent themes and some associated quotes are illustrated in table 5.8.

Table 5.8

Regular attendees perceptions of barriers to attendance

BARRIERS TO ENGAGEMENT	**PATIENT RESPONSES**
Individual determinants	
Apathy, denial/fear and care giver responsibilities	*"I understand it to a point (non-attendance). Some people are fearful and may not like to know they have to give up things. They decide, I don't care and if it goes wrong, it goes wrong. People don't like being restricted and think it's time wasting coming to appointments especially if they work full time and have a family to look after."* ***Rose***
Organisational determinants	
Waiting times	*"I know that they are short staffed sometimes but they have to improve the waiting times."* ***Miah*** *"One time I waited two hours but I didn't mind because I got to see the professor and she is the top, top."* ***Ali***
Access to services	*"It's so hard trying to cancel or re-book an appointment."* ***Rose***
Structural determinants	
Transportation access	*"Getting to your appointment is your responsibility and they can't come and pick you up but I think they should help those who are old or too ill to travel on their own."* ***Ali***
Impact of social welfare reform	*"If I couldn't get my freedom pass when I turn 60, that would have been a problem because I was made redundant". "I have a lot of appointments."* ***Rose***

5.12 Data presentation: Non-attendees

Individual, organisational and structural themes emerged from interviewees and are discussed. Two of the five non-attendees were not proficient in English. Interestingly, these individuals did not consider themselves as non-attendees with a common remark being that they attend all the appointments they are told about. Some also remarked that the hospital doctor didn't want to see them anymore so they go to their GP for their diabetes care instead. One patient felt that not being seen at the hospital was a sign of improvement.

5.12.1 Individual determinants

The impact of being a carer was a rate limiting factor for two participants. Being a carer, the health related burden of illness of the affected individual falls on the carer therefore their health needs become less of a priority. Recognition of the role of carers has led to great strides have being made in the last decade to provide the appropriate level of support for carers but there is also evidence that many carers still feel very isolated and unsupported (Schulz 2017). Family commitment in this instance also extends to those who provide support to the individual with diabetes. Feelings of guilt and being a burden were expressed based on the recognition of the sacrifice others are required to make to facilitate their needs.

The need for language support and the assistance of others to enable patients with poor English proficiency and literacy was highlighted as barriers to attendance.

The cost associated with multiple appointments or due to the nature of the journey to the service location was identified as a rate limiting factor to attendance. Recent research conducted in the same geographic setting highlighted the issue of 'rationing' of attendance at appointments due to two factors; cost and multiple illnesses (Greenhlagh et al., 2011). The psychological impact of managing multiple illnesses was highlighted. Additional factors included inflexibility of employers

5.12.2 Organisational determinants

Diabetes is a life-long chronic illness which requires ongoing education and support (DUK 2006). Due to the trajectory of the disease, it is essential that services provided are responsive to the needs of those affected. Relationship building, trust and respect of the clinician were expressed as important factors in non-attendance. Dissatisfaction with the clinician and or service was expressed by most of the five interviewees. A patient who expressed dissatisfaction with the service and hence her disengagement was asked to elaborate on her statement. She felt she had not been spoken to respectfully and having recently moved into the locality, she used her previous diabetes service as the reference point for her expectations and felt the service she received did not meet her expectations.

Prolonged waiting times, lack of consideration and inflexibility by administrative and clinic staff in relation to late attendance was raised as a concern. It was expressed that the service has no regard for patients' time however, no leeway is given despite the challenges and effort that is sometimes required to attend appointments. The duration of appointments were also highlighted particularly after a prolonged waiting time and as such, the value of attending was deemed to be minimal.

For all individuals, whether proficient in English or not, the process of cancelling or rescheduling appointments was difficult. The outcome of this process which was described as hard work and frustrating was highlighted.

5.12.3 Structural determinants

Access to transportation has been a recurrent theme reported in non-attendance literature and the impact of transport poverty has been subject to evaluation (Kavanagh et al., 2005). The effort required by some participants to access services was great and became a deterrent. In addition to public transportation access, knowledge about the criteria for being entitled to hospital transportation was limited.

Health inequalities have been reported to be rooted in society and as such require social change. In areas of deprivation, social circumstances have a direct impact on health and gaps in social care including lack of knowledge on how to access social support were factors identified by some participants. One participant expressed feelings of resignation and frustration as a result of the multiple social workers her family has had over a short space of time. At the time of the interview, she had not had a social worker for four months and felt she had to persevere because she did not know how the 'system works'.

The emergent themes and some associated quotes are illustrated in table 5.9.

Table 5.9

Non-attendees factors influencing non-attendance

BARRIERS TO ENGAGEMENT	**PATIENT RESPONSES**
Individual determinants	
Dependence on others	*"My daughters take turns to go with me but they have their families so it's hard for them too"* **Bibi**
Carer responsibilities	*"I have a disabled daughter to look after. My daughter-in-law helps because she is on maternity leave but she is going back to work in September so then it's just me".* **Nazma**
Language and literacy	*"I can't read English or Bengali but when my husband was alive, he took me to all my appointments. He died eight years ago and now the children tell me when I have an appointment. I don't like to go on my own because of language problems and I get lost".* **Nazma** *"I get my children to read my letters and they tell me when my appointments are"* **Bibi** *"It would be good if there was someone you could*

	go to read your letters and tell you what you need to do" ***Nazma***
Impact of managing multiple illnesses	*"I have a lot of appointments which I find hard to cope with. My partner is good but I feel guilty"* ***Liz*** *"I find it hard and don't have the will power."* ***Nazma***
Financial cost	*"I have a taxi card but I still have to pay £4 one way so when I have to go on my own it cost me £8"* ***Liz***
Inflexible employers	*"I have a lot of appointments and can't always get time off work."* ***Ola***
Organisational determinants	
Waiting times	*"One time I waited two hours and then I was in and out."* ***Ola***
Dissatisfaction with service	*"I was not impressed when I went to my first appointment so I didn't go back".* ***Femi***
Access to services	*"Do you know how hard it is to try and change your appointment?"* ***Bibi***
Inflexible services	*"They could have clinics on a Saturday for people who work."* ***Liz*** *"Sometimes you have so many appointments in different places so you have to keep taking time* *"When you are even a little late, they don't see you but they don't know how hard it is travelling there but it's okay for them to have you waiting for hours."* ***Bibi***
Structural determinants	
Transportation access	"*My husband gets hospital transport but I have to make my own way. I have kidney problems and can't walk far."* ***Bibi*** *"It is hard getting around here (local area). I either*

	have to leave almost two hours early or take a taxi and I can't afford it. "You have a long walk to get to the bus stop and then you have a long wait for the bus." ***Bibi*** *"I have to take three buses to go and come back. You might say it's cheaper but it adds up even with an Oyster"* ***Bibi***
Impact of social welfare reform	*"I know I have to look after my diabetes but they stop our benefits two month ago. When I have to go to appointments, I take three buses or pay £5 to go and £5 to come back by taxi so you tell me how easy it is to get to my appointments?"* ***Bibi***

5.13 Data presentation: Questionnaire

All interviewees were asked to complete an adapted health literacy questionnaire (Chew et al, 2004) which comprised of eight questions (Appendix 11). The purpose of the questionnaire was to provide an objective assessment of literacy on decision making and action. A summary of the questionnaire (Table 5.10) and the results are illustrated (Figure 5.2).

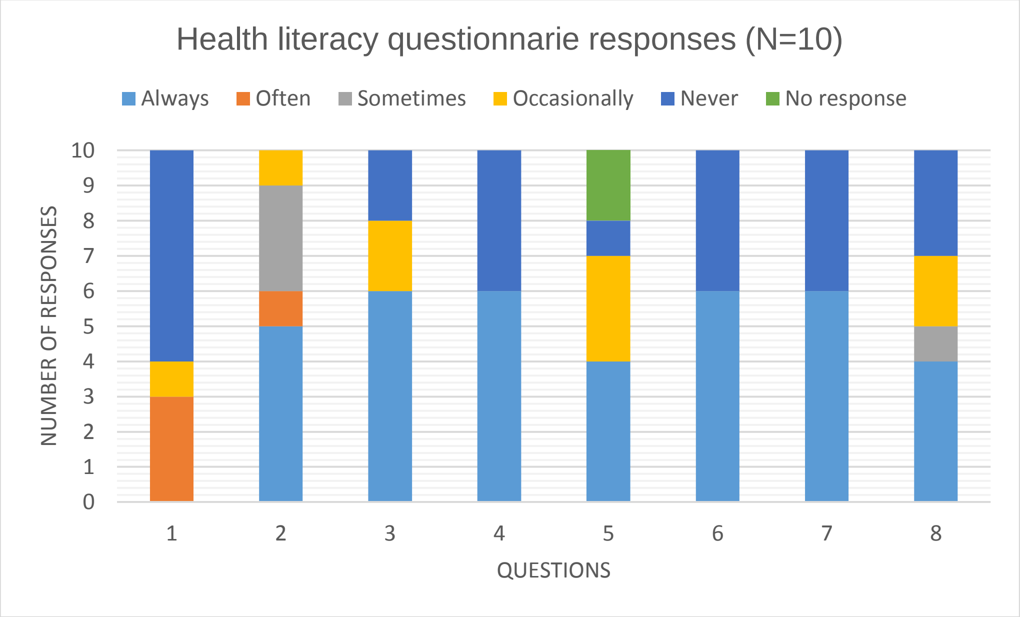
Table 5.10

Summary of the health literacy questionnaire

Questions	Summary of questions
1	Is patient educational material easy to read and understand?
2	Are hospital clinic signs difficult to understand?
3	Are appointment letters difficult to understand?
4	Do you have Difficulty understanding written information given by Health care professionals?
5	Do you have problems getting to clinic appointments due to difficulty understanding written instructions?
6	Do you have problems learning about medical condition because of difficulty understanding written information?
7	Do you have someone read your hospital materials?
8	Do you depends on someone to take you to clinic appointments?

Figure 5.2

Questionnaire results



Four of the ten patients who completed the questionnaire were proficient in English (two attendees and two non-attendees). All six patients who were not proficient in English required assistance with regard to written information thus demonstrating the extent to which participants who have limited English proficiency are reliant on others for information and the ability to act. Three participants expressed a need to have someone who could read and explain medical information to them in a way they could understand in order to help with their decision making. Some participants who were proficient in English indicated that they occasionally have problems attending clinic due to difficulty understanding the written instructions as well as the fact that some clinic letters are difficult to understand. The negative impact of unmet language need on social exclusion and access to services has highlighted by Aspinall (2005).

5.14 Additional research component

An additional element of the research study proposed was the invitation of members of the multidisciplinary diabetes healthcare team which comprises of doctors, nurses, podiatrists and dieticians to either a focus group discussion or individual interviews. The purpose of this was to ascertain their perceptions of the issue of non-attendance. If this approach was feasible, one focus group lasting approximately one hour would have been conducted and facilitated by an independent researcher. However, due to work commitments and conflicting schedules by most clinicians, neither a focus group nor individual interviews with at least one member from each service (nurse, doctor, dietitian and podiatrist) was feasible to conduct.

5.15 DISCUSSION

The themes which emerged from analysis of the data were consistent with available literature which has identified individual, organisational and structural factors as influencing factors in non-attendance. This research has highlighted that despite over two decades of research, socio-economic deprivation continue to be a pervasive influence on some communities' abilities and willingness to engage with and access healthcare services. The findings of this study are examined from all aspects identified (individual, organisational and structural) as either enablers or barriers to attendance.

Three ethnic groups (African, Bengali and Pakistani) were of interest in this enquiry based on the case study's findings with white British being the comparator. It is widely written in UK literature that these groups identified have poorer access to and utilisation of services and worse diabetes outcomes.

Poor language proficiency was a barrier to information as the ability to receive information was dependent on others. One attempt by organisations to mitigate against poor language proficiency has been translation of information into common languages. This is a valuable resource however, it must be noted that some individuals are illiterate in their mother tongue and in addition, Sylethi is a spoken as opposed to written language. The support of a BHA as an enabler to attendance and understanding of appointments was identified by some participants. It has been highlighted that a key driver to elements such as social exclusion, education, and inequity in access to services is unmet language needs (Aspinall, 2005) thus reinforcing the need for multiple approaches to enable appropriate language support.

The important role of family in decision making and the ability to act by some patient groups has been endorsed by the findings of the research component of this thesis. Family support and assistance was shown to be both a barrier and driver to knowledge of and access to services and is reflected in existing literature (Rosland et al., 2008). There is a body of existing literature that expresses the viewpoint that individuals have ultimate responsibility and ownership for their health (Asimakopoulou 2007, Speight et al., 2012, Tol et al., 2013,). However, this concept appears to be a western viewpoint and does not recognise the importance of reciprocity and responsibility for others in other cultures and other belief systems or diminished autonomy due to factors such as disability, poor language proficiency, poor health literacy and cultural dynamics (Shaikh and Hatcher 2004). In areas where these issues occur, an approach whereby social capital is increased may be an effective means of improving both access to and utilisation of healthcare services.

It is widely accepted that there is a disproportionate incidence of preventable and manageable illnesses in ethnic minority groups. Communication about health messages and support were identified as barriers to attendance. It therefore begs to question whether health messages are reaching vulnerable or disengaged groups and being communicated in both a culturally and linguistically appropriate manner.

Social Capital Refers to the coordination and cooperation for mutual benefit based on the organisation of society in terms of networks, norms and social trust. It is multi-dimensional and includes reciprocity, interpersonal trust, solidarity and cooperation. Social capital is described as having a protective effect as it reduces risky behaviours, psychological distress, stressful conditions and improve self-rated health (Narayan et al., 2000). The philosophical underpinnings of CHWs and Peer support interventions therefore align with increasing social capital for disadvantaged groups.

The Health and Social Care Act (DH 2012) aims to transform healthcare within the National Health Service (NHS). Aspects of the act which resonate with this research study are:

- Empowering patients
- Improving public health
- Facilitating innovation
- Putting the clinician at the heart of commissioning

Conducting this research provided the opportunity to experience the impact of a common structural factor (transportation access) while attending home visits. Despite the proviso in the study’s ethical submission that home interviews would only be conducted in exceptional circumstances, six out of the ten interviews were conducted in this manner. Agreeing to conduct interviews at the patient’s home increased the chances of agreement to participate.

Attending home visits and using public transportation gave an appreciation for the effort required to attend appointments for some individuals.

Restricted transportation access resulted in a ripple effect for some participants whereby the financial impact caused by restricted transportation access significantly influenced their willingness or ability to attend appointments. This was also compounded by some participants who were managing multiple illnesses which affected their mobility but were reliant on public transport with the geographical location of services identified as a barrier to attendance. This was however linked with the ease and access to transportation. Studies on the impacts of geography and transportation on access to services have consistently highlighted the impact of spatial decay whereby the further someone is from a service; the less likely they are to attend (Dusheiko et al. 2009). All participants highlighted that services must be easy to get to, particularly by public transportation. Participants, who did not utilise public transportation to attend appointments, highlighted parking restrictions and insufficient parking around community locations as an inconvenience both in terms of time and cost. One participant stated:

"I drive so I don't have any problems getting there but it's when I get there that's my problem. There's hardly anywhere to park close by, it's expensive and if the clinic is late, I'm worried that I will get a ticket ". **Ola**

These elements highlighted the complex relationship between access and personal engagement with services based solely on the impact of structural factors. The relationship between "transport poverty" (affordability, availability and accessibility) and health has been explored by the Institute of Public Health in Ireland (2005). It concluded that poor access to transportation increased social exclusion, reduced access to services and altered perceptions of services.

Changes made by the Department for Work and Pensions (DWP) in 2012 caused great anxiety for several patients who were managing multiple illnesses and had scarce or limited resources. In particular, the cost associated with attending multiple appointments was identified as a factor which influenced their ability or willingness to attend appointments. One participant who had been made redundant a little while prior to the interview but had multiple appointments was fearful that she would not be entitled to a London Transport freedom pass (providing free transport on buses, underground and overground services in London) upon turning 60 years due to the pension changes. However, following enquiries, she discovered she was eligible for a freedom pass and she said: “I actually can’t wait to turn 60! I won’t have to worry about spending what little money I have on getting to my appointments”. Managing scarce financial resources and its impact on healthcare decision making has been highlighted by Greenhalgh et al (2011). One participant expressed a sense of helplessness with the social conditions of her family and the lack of awareness of how to navigate through the social care system. They had a series of social workers and at the time of the interview had had no contact with a social worker since their previous one left the local council more than six months prior. She indicated that several attempts were made to get help which were unsuccessful because neither her nor her husband were literate and were reliant on their children to complete the forms. Interestingly, despite the frustration expressed, this participant stated that she did not want to be a burden because she felt the social workers had a lot of other important things to do. This interaction drove home the point that for some individuals, health is de-prioritised based on social circumstances with non-attendance being a manifestation of this situation. Existing literature highlights that in marginalised communities, health become a very low priority with a manifestation of reactive care access.

5.15.1 INDIVIDUAL DIMENSIONS

Patient-centred evaluation of health seeking behaviours is commonly conducted in the psycho-social context as opposed to the socio- economic context. A psycho-social evaluation provides an understanding of factors such as motivation, denial, fear, culture, family, perceived severity and threat of an illness on health-related behaviours. A common model used to evaluate the interplay between psycho-social elements and their influence on health-related decision making is the Health Belief Model which has been discussed in chapter one (see Chapter 1, section 1.8.2).

Both focus group and interview participants were asked: "How important is it for you to go to your appointments?" In every instance a high level of importance was attached to attending. However, it soon emerged that the ability to attend was influenced by factors other than motivation or perceived risk or seriousness of disease. Apathy and lack of ownership for one's health have been reported as reasons for non-attendance at appointments (Schafer et al., 2013) and were proposed as reasons for non-attendance focus group attendees. However, a theme which emerged during interviews with non-English speaking participants was the devolution of control to family members. In each instance, a high level of importance was attached to attending appointments but participants knowledge of appointments and ability to attend was dependent firstly on the information being relayed and secondly on their relative's ability to commit to taking them.

Diabetes has been described in public health campaigns as "a silent killer". Recent research has also indicated a 'normalisation' of diabetes by some ethnic minority communities due to the high prevalence within these communities (CEG 2012). Also, due to the insidious nature of diabetes, the impact of both compliance with appointments and ownership for one's health may be minimised when control is transferred to family members who then prioritise health related needs based on their knowledge of diabetes and possible assumptions. Family members are also placed in a situation whereby they must weigh up addressing their immediate family's needs, attending work, school or university against their dependent relative's appointments. This dilemma is compounded when there are multiple illnesses.

The transference of power appeared to be primarily based on issues around language and literacy. One Bengali participant said if letters and information were in her language, she would be OK. Conversely another Bengali participant said she is illiterate so her children must read her letters to her and tell her what they are about. In both instances, both participants were reliant on others for the information they received and their ability to act. The results of the health literacy questionnaire provided an objective assessment and supported the impact that language and literacy have in relation to decision making and action. Ownership for one's health has been shown to be influenced by health literacy.

Speros (2005 p 633) identified health literacy as the factor which:

> "empowers people to act appropriately in new and changing health-related circumstances through the use of advanced cognitive and social skills. It provides the capacity to use information in health care decision-making and successfully function as a healthcare consumer. Consequences of health literacy include improved self-reported health status, lower health care costs, increased health knowledge, shorter hospitalisations, and less frequent use of health care services."

Poor health literacy has a converse effect.

Ownership for one's health has sometime been simplified to publicly made comments such as: 'If they learn English they will be able to take responsibility for their health'. Unfortunately both literacy and health literacy are far more complex than simply learning a language. Two key components to enable effective action are comprehension and applicability. Individuals who are illiterate in their mother tongue will not become literate simply because they are taught English. Also, having command of a language does not indicate the level of proficiency. One participant stated that although her son attends her appointments with her, she prefers to have a BHA because his command of Bengali is not good so:

"I don't think I am told everything because he can't explain it properly, his Bengali isn't very good". (Female Bengali attendee)

From an organisational perspective, one of the Bengali bilingual health advocates (BHAs) highlighted that many patients complain that they find their outpatient letters are confusing especially the ones which are sent to re-

schedule appointments. The outcome of the ‘confusing’ letters is that patients turn up to
appointments which have been re-scheduled and feelings of dis-satisfaction are then expressed.

5.15.2 ORGANISATIONAL DIMENSIONS

A review conducted by the National Advisory Group on the Safety of Patients in England (2013) reinforced the importance of organisations engaging with patients and the public to enable the delivery of safe, appropriate and meaningful health care. The organisational factors which influence non-attendance have been researched and audited by several organisations but further improvement is still required. From an organisational perspective, the results of this study have been reported utilising the Quality, Innovation, Productivity and Prevention (QIPP) programme.

The QIPP programme was developed by the Department of Health to drive forward cost-effective quality improvements in NHS care (DH 2011). QIPP aimed to improve care, lower costs through more productive health services, reduce health inequalities and improve the population’s health by minimising unwarranted variations in healthcare delivery.

Q (quality) – Quality is determined by measurable outcomes and is a direct reflection of how good a product or system is. Health outcome measures are primarily determined by the DH and include dimensions such as mortality rates, referral times, and hospital episodes, length of stay, non-attendance and patient satisfaction. Despite these prescriptive measures of quality, quality is still largely defined by service users and is as good as its users say it is! The ‘family and friends’ survey which was launched in the NHS is a feedback tool to assess quality of care (DH, 2013).

Issues of the lack of confidence about the quality of specialist services provided by GPs were identified in the present study. There were mixed opinions about specialist care being delivered in general practice with some participants expressing satisfaction and others dis-satisfaction. Within general practice, there are GPs with special interests (GPSI) who deliver specialist care for specific illnesses. The push for this change was in care delivery was to provide an up-skilling of GPs to enable care for long term conditions to be delivered closer to home. A review however, questioned the effectiveness of GPSI and reported that specialist care with mixed views about the delivery of specialist care by GPs (Mead 2007).

Patients who highlighted concerns also expressed frustration about not knowing how to gain or re-gain access to specialist services and vocalised a sense of resignation. One patient agreed to participate because she stated:

"I want to see a diabetes nurse". She also remarked that "when I got the letter saying I was discharged, I phoned the number on the letter and asked for an appointment but didn't get one up to now. So I just thought; I have to look after myself. Since then my GP started me on insulin because my sugar is always high but my sugar is still not good. I was in hospital last Friday because they (my sugars) were too high".

There appeared to be a consensus more so by insulin dependent patients that specialist care was best delivered by specialist clinicians as opposed to GPs. One participant stated:

"I was only referred to the hospital after coming to A&E a few times". **Roger**

Another commented that :
"My GP doesn't do anything for me, like he doesn't care about my heart and diabetes and now you're in and out in ten minutes". **June**

When asked about their experience of attending the diabetes clinic, one participant stated that it's much better and another stated:

"the hospital doctors are good at doing it plus we have backup with the specialist nurses. We can give them a ring so you have always got someone to fall back on". **Rita**

Some patients however expressed satisfaction with being cared for by their GP. An African gentleman stated:

"I've been with my GP for over 20 years now and he knows everything about me, so yes, I'm happy with him looking after my diabetes". **Ola**

The consensus was that education should be readily available following diagnosis but some participants expressed that *"there is no backup when you are diagnosed".* One participant stated that:
"I help my neighbour as he is diabetic and always asks me questions. I can do that (help) because I come to appointments". **Roger**

I (innovation) – Innovation requires the creative use of resources to produce, deliver and sustain services which are safe, efficient, cost-effective and fit for purpose. This can be achieved through re-Configuration of services, technological advancements and creative approaches to service delivery.

The use of technology as a means of improving service delivery was highlighted. One patient referenced her experience of healthcare in Portugal whereby the re-scheduling of appointments can be done by the patient via the internet. She felt, *"this would be useful for young people, people who work or people who have to take time off work to take their mother or father to appointments".* **June**

P (productivity) – Productivity requires 'smarter' working through the effective utilisation of resources and the delivery of services which are cost-effective and responsive to the needs of the population served. Factors identified by this study which impacted on productivity were inflexible clinic schedules, waiting times on the day of attendance, dissatisfaction with duration of appointments, difficulty communication with administrative teams to reschedule appointments.

The inflexibility of services was raised by several participants. They asked, *"why can't you do clinics in the evening or even on a Saturday?" Also,*

sometimes you have so many appointments in different places that you forget. I don't mind having a few appointments in the same place on the same day".
Waiting times and the duration of appointment were deterrents to attendance (elaborate)
In support of the views expressed, an observation about the scheduling of appointments was made by the researcher whilst assessing the eligibility of potential participants. During the course of evaluating the attendance profile of patients identified as non-attendees, it was noted that some appointments for doctors and nurses were scheduled in quick succession with the common result being attendance at the doctors' appointment and non-attendance at the nurses' appointments. For example: a patient may have a doctor's appointment and a nurse's appointment scheduled for four hours later or the following day. Failure of the patient to attend the nurse's appointment resulted in the patient being discharged from the DSN clinic due to non-attendance. A discordant scheduling system impacts on both the allocation and utilisation of resources and is an aspect of outpatient service delivery which requires improvement.

One suggestion for better utilisation of the doctor's time was to, *"bring the diabetic nurses to the fore and have good phone support (DSNs)".*

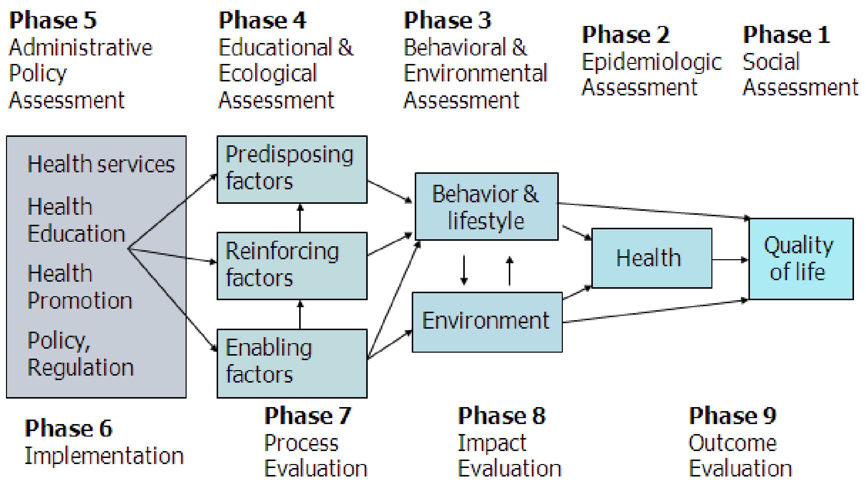
P (prevention) - Prevention is a whole-systems approach to achieving and maintaining good health which involves all key stakeholders for example, communities, local government and voluntary organisations. It requires a comprehensive understanding of local communities through engagement with communities and effective utilisation of health intelligence. Effective dissemination of service information and culturally competent education are enablers of prevention strategies.
Participants who regularly attended appointments highlighted education as the means of reducing the incidence of diabetes, improving attendance and overall diabetes care. There was consensus that *"they (the public) need to realise that diabetes is no joke!"* Jack (2003) emphasised the need for a community based response to diabetes education as a means of reducing the burden of diabetes in communities that are disproportionately affected by it. He

elaborated that if educational methodologies are not improved by healthcare providers, there will continue to be minimal patient improvements and recommended engaging community partners in order to generate public interest, discussion, ownership, and action around diabetes prevention and control. Nutbeam (2000) highlighted that health promotion aspects such as education, social mobilisation and advocacy are crucial components in improving health literacy. Within the context of health promotion, the Precede-Proceed model (Green and Kreuter, 2005) (Figure 5.3) identifies phases involved in health promotion and the inter-relationship between the factors which influence health outcomes.

Figure 5.3

Green and Kreuter, 2005

Precede-Proceed Framework



The Public Health Outcomes Framework (DH 2013) also comprehensively outlines the requirements for improving the wider determinants of health and improving health, health protection and public health. The NICE diabetes prevention pathway (2011) also outlines the framework for action in terms of diabetes prevention and encompasses the key components of care (individual, organisation and structural).

Quotes from participants about the importance of education and public awareness included:

“People don’t understand the importance of it.”

“*People don’t realise that diabetes is a slow cancer.”*

5.15.3 STRUCTURAL DIMENSIONS

Health inequalities are rooted in the wider determinants of health and researchers have consistently highlighted that a reduction in health inequalities lies in social and political reform (Marmot 2012). The results of this research have highlighted the impact of structural issues on an individual’s ability or willingness to engage with healthcare services irrespective of the level of importance they may attach to their illness. Two key factors identified as barriers to access and engagement with services were transportation (access and affordability) and the impact of social welfare reforms.

Transportation - Utilisation of services is directly influenced by both the location of services and transportation access. One Bengali participant said:

“We were tricked (by the council) to move here. They said there would be good transport to get around but all they wanted to do was fill up this area. My husband gets hospital transport to go to most of his appointments but I have to travel. You need to have a car to live here”.

Having made the journey by public transportation, I was able to empathise with this patient’s dilemma. The journey from the local hospital to the participant’s home was an arduous one which took 65 minutes door to door. It required two buses on the onward journey plus a brisk fifteen minute walk. On the return journey via an alternative route, it took three buses plus a brisk five-minute walk. Several participants highlighted the challenges faced in terms of firstly getting to a location where they are then able to obtain public transportation.
Assistance with transportation cost was identified as a factor which could improve attendance. One participant stressed the impracticality of a blanket approach to assistance by saying:

"Well it's your appointment so the government won't pay for the cost of picking you up from your house, is it? But it would be helpful to have transport for older people and those who can't afford it".

Social care – Issues around health and social welfare were highlighted particularly by participants who were categorised as non-attenders. The financial constraints which resulted due to loss of entitlement or delayed entitlement to benefits were a recurrent theme for some participants. This was compounded by the helplessness expressed with regards to their lack of knowledge in seeking appropriate help in order to address the issues of concern.

Structural issues are rooted in how societies are structured. To address these issues requires social reform which is a surmountable task. None-the-less the emergent themes highlight that there is a need for a cohesive health and social care assessment and delivery system whereby unmet needs are identified, assessed and actioned accordingly.

5.16 Limitations

Qualitative research aims to explore the meaning and context of a problem identified hence by nature it is explorative and subjective. To conduct robust research, two key elements required are time and significant funding.

The scope of the intended study was an ambitious undertaking due to the timescale in which it was required to be completed due to the requirements of the funder. The greatest limitations were recruitment of participants, time and the impact of organisational change.

5.16.1 Recruitment

For all participants who agreed to participate and have home interviews, the initial greeting upon arrival was either one of hesitance or in some instances, scrutiny from other family members prior to obtaining consent. In three interviews, family members remained in the room where the interview was conducted which raises questions about responsiveness by the interviewee. In two of the three interviews, the family members were not intrusive and no obvious cues were observed which may have overtly influenced responses. However; in one instance, the interviewee's daughter-in-law insisted on being present despite the interviewee's objection. This lead to a verbal disagreement between the two parties which was resolved by the interviewee's son after approximately five minutes. The result of his intervention being that the daughter-in-law excused herself from the process. The impact of this unforeseen situation was not discussed but there is an appreciation that it may have influenced the level of responsiveness.

Another issue encountered was the disclosure of information and elaboration on questions asked as the BHA and I were about to leave the household. This interaction was not recorded but notes were recorded in a diary. In one instance, the interviewee elaborated on the guilt she feels with having to rely on her children as well as the hopelessness experienced by their family due to issues with social services and not knowing how to access support. Her overwhelming feeling was that their issues were of little importance to social workers who had more important things to do. She stated:

"We've been waiting for two years to have the bathroom moved downstairs. My husband can't get upstairs anymore and my kidney problem is getting worse. We've had four social workers and our last one left about six months ago and we haven't seen anybody since then. We don't want to bother them because they are really busy."

Despite the issues identified, conducting home-based interviews was enlightening as it provided an insight into family dynamics and any real-life issues which may influence an individual's ability or willingness to attend appointments.

5.16.2 Impact of organisational change

During the period of this research, a major organisational merger occurred which impacted on all factors required to enable the smooth undertaking of the study. The uncertainty which occurs with any major organisational changes influenced research and development approval timelines due to departmental restructuring and the access to and availability of BHAs due to increased service demand. Fox et al. (2007, p.121) identified the need for flexible research due to the unpredictable and uncertain world of research. They suggest that despite the best planning, there will be common obstacles such as:

- The changing landscape of the research setting
    - External forces
    - Change of role at work
- Time
    - Underestimated through inexperience
    - The disappearing research participant
    - Research governance and ethics
- Research/life balance
    - Unforeseen life events

The second element of the study which was proposed (clinician's perspectives) was not conducted due to difficulties scheduling a group of clinicians for a focus group. Attempts were also made to schedule individual interviews with at least one clinician from each professional group which made up the multi-disciplinary team (doctor, specialist nurse, dietitian, podiatry). However, due to their clinical commitments and the decision made to focus on patient interviews, this proposed element proved to infeasible.

The scale and scope of this project was significantly influenced by time and would require further funding to improve aspects such as validity and transferability of findings. Despite the limitations highlighted, this project has served to provide a foundation for further work.

5.17 CONCLUSIONS

This study aimed to explore the factors which influence some BME patients' willingness and ability to attend diabetes outpatient appointments. It has highlighted the impact of individual, organisational and structural influences on an individual's ability to act. Structural and organisational aspects identified such as transportation access, the impact of social welfare reform, service locations, inflexibility of services and ineffective education are tasks for health and social care organisations to address. Addressing these issues are in compliance with the Public Health Outcomes Framework (DH 2013) which provides a context from the local to national level with an ultimate vision of improving and protecting the nation's health and well-being, and improving the health of the poorest fastest.

The findings of this study highlight the complex nature of outpatient attendance particularly in geographic areas where there is high ethnic diversity and economic deprivation. The health outcomes and socio-economic profile for the London Borough of Newham presents a worrying picture and the impact of poor engagement with services is seen daily within the diabetes services in the form of avoidable complications. Healthcare for London (2009) highlighted that poor diabetes service provision and its management within Newham contributed to a reduction in quality of life and life expectancy as well as the increased use of emergency and inpatient services. This highlights the need for a comprehensive examination of the disparities that are evident within diabetes care and a multi-faceted approach to reducing these disparities.

Individual needs are variable however collectively, the core drivers and barriers to attendance have been categorised into individual, organisational and structural elements in concordance with Peek et al (2007). These elements are interdependent and require a cohesive approach to successfully address the issues associated with and the impact of outpatient non-attendance. Therefore, this research has highlighted the need for a local approach to policy making and population based strategies to redress the disparities which are evident.

5.18 RECOMMENDATIONS

Drawing on the analysis described above in Tables 5.2 onwards, the following recommendations arise from this study. There are specific and general recommendations which have been derived from this study and are outlined below (refer to Chapter five, Table 5.2 for thematic codes)

The NHS has been undergoing a period of transformation with austerity measures which aim to drive forward quality improvements. An efficiency savings target of £20 billion was set for the period 2014/15. The British Medical Association (BMA, 2016) has calculated the 2020/21 saving based on the Five year Forward plan is £22 billion. The recommendations which have been proposed because of this study are mindful of the current health economic climate and it is considered that several of the recommendations can be achieved by re-configuring services at a minimal cost. For example, integrated specialist services can be delivered within the community at GP premises which are suitably equipped and have the appropriate infrastructure to deliver a safe and effective service. This approach may be an effective strategy to minimise the impact (cost, time, effort and ease of access) of individual who are managing multiple illnesses. Effective engagement by clinical commissioning groups (CCGs) with local health and well-being boards can facilitate meaningful collaboration and strategies in driving forward local health reform particularly in terms of how and where services are delivered. In addition, engagement with communities can be done at a minimal cost but produce significant yields in terms of understanding the needs of the local population and delivering services which are fit for purpose. The need for support was expressed by some individuals particularly those affected by poor English language proficiency and health literacy.

Commissioners should:

- integrate clinical services which are strategically located and receptive to the needs of the local population (Thematic codes: M1, F5, S10)
- ensure easily accessible education and support following diagnosis which is culturally appropriate/competent (Thematic codes: M1, F1, S1, S2 and M2 S21, S22, S23)

Healthcare Organisations should:

- conduct an evaluation of outpatient scheduling to streamline appointments and simplification of letters (Thematic codes: M2, F7, S17)
- ensure greater flexibility in the delivery of services e.g. provision of out of hours clinics (Thematic codes: M2, S15)
- utilise technology to accommodate people who are in education, employed or are carers e.g. internet based appointments and an appointment management system (Thematic codes: M2, S15)
- increase public awareness of support services available e.g. language support (Thematic codes: M1, F6, S13 and M2, F7, S16)

Local Authorities should:

- develop population-based public health strategies and initiatives in consultation with community stakeholders (Thematic codes: M3, F12, S29)
- ensure a seamless approach to health and social care which enables the effective assessment and provision of support for individuals living with LTCs (Thematic codes: M3, F11, S27, S28)

The results of this study are consistent with existing literature; however, they highlight the slow pace of progression in addressing the pervasive issue of poor outpatient attendance by some BME groups. Several researchers have highlighted the need for public engagement, cultural competence by health care organisations and professionals and the use of community link workers as means of addressing non-attendance by some BME groups (Gatrad 1999, Ogeah 2003 and Zeh et al. 2012). Therefore, further recommendations which require collaborative efforts include:

- Multi-agency working to improve engagement and education within communities
- Specialist link workers to facilitate a comprehensive health and social care needs assessment for patients with LTCs and multiple illnesses who may not be typically categorised as ‘vulnerable’

Health inequalities have been described as pervasive, difficult to shift and expensive to address. However, based on the projected prevalence, poorer outcomes and issues of non-attendance within Newham, a shift in focus is essential with a greater emphasis on preventative strategies.

5.19 LINKAGE

Stage two research rationale

During the study conduct both organisational and operational challenges impacted on recruitment targets. The major challenges experienced included; access to potential study participants, resource intensive efforts to recruit the target population but most importantly, the impact of organisational change which resulted in a protracted R&D approval period. In response to the difficulties encountered in achieving the target sample, discussions were conducted with my academic supervisors to determine the most appropriate way forward in building on the work completed. Two options were proposed with the first option being to either extend the recruitment period until a point of saturation or when the target sample had been achieved. In addition, in relation to the second option it was proposed to revisit the findings of the interview and focus group findings and identify an important theme which could be researched following exploration of existing literature.

Due to the resource-intensive nature of extending recruitment particularly within restricted timelines, the second option was chosen. Ownership for one’s health (see Table 5.2) was chosen as the theme to further explore and for it to be framed in the context of empowerment. It was agreed that an evaluation of empowerment could be a meaningful way of objectively identifying unmet needs in patients who do not access services and thereby inform patient engagement and self-management strategies.

A second stage of research was agreed and will be described in the following chapter (6).

CHAPTER 6: Phase II research report

The role of patient activation in non-attendance of black and minority ethnic (BME) patients at an Inner London diabetes outpatient service: a pilot study

6.1 Rationale for study

This study builds upon the case study which was conducted in 2011 and subsequent qualitative research study which was conducted in 2013 and published in 2016 (see Appendix 11). The case study quantified the extent of non-attendance, identified demographic characteristics of non-attendees and determined the significance of additional predictors of attendance such as geography and deprivation. The initial qualitative research study provided evidence of the individual, organisational and structural factors which influence both access to and use of diabetes out-patient services. These findings were consistent with existing literature which identified factors such as transportation access, financial cost of attendance, inflexibility of services and administrative difficulties as rate limiting factors to attendance. Additional factors which emerged as barriers to attendance were limited English proficiency, reliance on others and poor health literacy. These factors, highlighted the complex nature of the concept of non-attendance and brought to the forefront, the question of ownership for one’s health. If for some individuals, the ability to make decisions and take action about their health is directly influenced by the decisions and actions of others then how much and to what extent do they have ownership for their health?

There is a synergistic relationship between empowerment, ownership for one’s health and health literacy. Engagement is a concept of reciprocity which facilitates patient interaction with healthcare organisations (Schoenbaum and Audet 2005) with key elements being empowerment, equity, participation and self-determination. The National Service Framework for Diabetes (2001) highlighted empowerment as a means of improving self-management in individuals with diabetes. Empowerment and its measurement, is an emerging area of research with a recent articles posing the question: are we ready to test empowerment (Asimakopoulou 2007, Barelle 2012)? A criticism of measures such as empowerment and health literacy scales/questionnaires is that they are limited in their assessment of all aspect which contribute to better self-management (knowledge, skills and confidence) (Hibbard et al., 2004) and are usually measured in conjunction with other questionnaires which when used in diverse cultures and in the presence of limited language and literacy skills can be problematic.

Based on participants' and BHA's feedback obtained during previous research studied conducted within the diabetes service, it was determined that multiple questionnaires and those which had extensive questions were not well received by patients. Empirical evidence indicates that multiple questionnaires are used in studies conducted to provide a more robust understanding of these issues. However, being mindful of language and literacy as potential rate limiting factors in questionnaire completion within the sample population, I sought a tool which could provide a single comprehensive assessment of the various components of empowerment which was supported by robust empirical evidence, would be practicable for the demographic group, fulfil the aims of the study and provide the data required in a timely and resourceful manner.

As such, a literature review was undertaken to establish whether there was a questionnaire which could measure all dimensions of empowerment, was not exhaustive and could be used in isolation. The patient activation measure questionnaire (Hibbard et al, 2004) was assessed and determined to be an appropriate measure. It has been reported that patient activation is a 'unique measure of engagement and empowerment' (Kings Fund, 2014; pg. 4). Its uses include but are not limited to: more effective allocation of resources, stratification of interventions, program evaluation, predictive modelling, personalisation of information and goal setting for patients (Kings Fund, 2014). The thirteen-point Patient Activated Measure (PAM) (see Appendix 12), developed by Hibbard et al (2004) was identified and selected due to its ability to measure both knowledge and empowerment (skills and confidence) and to be an effective and acceptable measure in an ethnically diverse demographic.

There is currently a lack of UK specific literature about the use of the PAM in an out-patient setting as well as its use in clinical care. This study was therefore designed and conducted as a pilot to establish the feasibility and applicability of using the PAM in an out-patient clinical setting. Due to the lack of PAM literature which could inform the sample size for a pilot study, a post hoc sample size calculation was proposed to inform future studies of this nature.

6.2 Introduction

Ownership is universally defined as "the act, state or right of possessing something" (Webster dictionaries (2008 p. 346). Ownership in the context of health refers to responsibility of decision-making and action in relation to one's health. All individuals who are deemed to be competent to have the mental capacity to make informed decisions and choices, are considered to be capable of ownership for their health. In the process of conducting the literature review which was aimed at informing this study, it was evident that there was a paucity of literature which explicitly examined ownership for one's health by competent individuals. However, there was ample literature about diabetes self-management and mental illness or generally about decision-making and individuals with diminished capacity.

All patients within the initial qualitative study expressed that diabetes care was very important to them, however, for non-attendees there was clearly a disconnection between beliefs and action. This therefore raised the question: could lack of action be a result of dis-empowerment? Speros (2005) identified that there is a synergistic relationship between ownership for one's health and empowerment. In addition, Rose and Harris (2013) highlighted the relationship between the minimization of diabetes and its impact by family and friends and self-management practices.

The WHO (1998) suggests that empowerment involves behaviours which allow people to achieve greater control over their own decisions and practices affecting their health. Empowerment in chronic illness is said to be governed by three fundamental aspects: choice, control and consequences (Funnell et al., 2007). It is widely recognised that improved self-management is a means of reducing both the personal and societal costs of diabetes. In the Five Year Forward view, NHS England advocates the empowerment of individuals to take charge of their own care by improving their understanding of diabetes and its impact on them. It recommends the use of multiple interventions and models which are fit for purpose i.e. responsive to the individual's health and support needs with the primary focus being to improve knowledge, skills and confidence to self-manage (DH 2015).

One of the core standards within the National Service Framework for Diabetes (DH 2001, p 21) lists: 'Empowering children, young people and adults with diabetes' as one of the core components to improving standards:
"All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process." (DH 2001; pg. 5)

Based on these requirements of shared care planning and empowerment, the Patient Activated Measure (PAM) (13-point questionnaire) was chosen (Hibbard 2004). This measure has been robustly validated in diverse clinical setting and ethnic groups with ample empirical evidence that supports its effectiveness in evaluating both empowerment and health literacy (Hibbard and Greene, 2013, Cunningham et al., 2011, Bolen et al., 2014). Patient activation refers to the level of competence (knowledge, skills and confidence) an individual has which will enable effective and sustained self-management. There are four progressive stages of activation:
Level 1: The belief that your role as a patient is important
Level 2: Having the knowledge and confidence necessary to act
Level 3: The transformational process of acting required to improve and maintain one's health
Level 4: Sustainability of improvement even during periods of stress

The scoring matrix provided for PAM's use also provided scores ranging from 0 – 100, which are associate with the respective level of activation. Due to PAM's progressive nature, there are different requirements based on the stages of activation. Interventions targeted at increasing knowledge about the medical condition and associated treatments are required for patients in the lower stages of activation whereas patients who are in the later stages of activation require interventions which will increase skills and confidence in self-management.

Ownership for one's health is the driver for this research element. Self-ownership is defined as taking responsibility for one's health which involves making day to day choices which affect an individual's health and well-being. The patient has the ultimate control and decision-making power. Asimakopoulou (2007) stated that the consequences of the choices a patient makes, lies with themselves therefore patients are in control of their illness therefore are responsible for it. However, the ability to have ownership for one's health is dependent on patients having the appropriate knowledge, skills and confidence to self-manage. Having the appropriate knowledge, skills and confidence to effectively self-manage is defined as empowerment which highlights the interdependent relationship between ownership and empowerment. In the context of this study, ownership has been measured using patient activation (PAM) because it examines knowledge, skills and confidence to self-manage which are core components of empowerment.

6.3 Aims

This study aimed to objectively assess whether there is a quantifiable difference in patient activation between specific groups of diabetes patients who attend and do not attend diabetes out-patient appointments. The primary research question proposed was:

How effective Is PAM in predicting non-attendance in a diabetes outpatient setting?

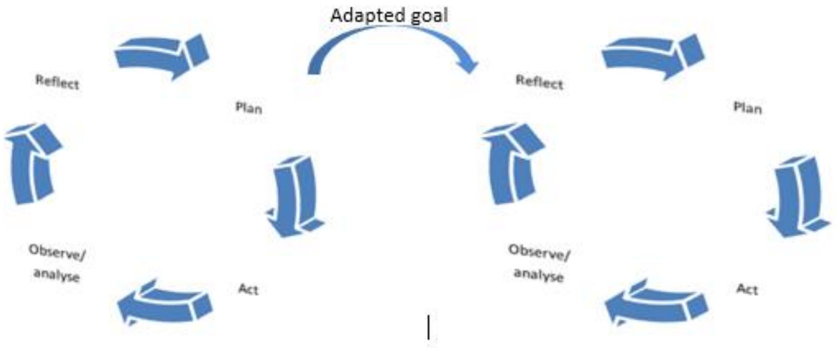
Secondary questions posed by this study were:

1. Do patients who do not attend appointment have a lower level of patient activation than those who attend?
2. Can patient activation scores be used to identify specific unmet needs of non-attendees?
3. Can patient activation be used to predict the likelihood of attendance?
4. What sample size would be needed to detect differences in activation levels between patients who attend and do not attend appointments?

6.4 Research Approach

Upon reflection, this additional research phase was consistent with the action research cycle as described by Vallenga et al (2009) (see Figure 6.1) and demonstrated that practitioner research requires flexibility which is borne out of reflexivity.

Figure 6.1: Action research cycle
Vallenga et al., 2009



The data were revisited from the Case Study and Phase I and a search of literature was conducted to help establish how best to develop the research study. It was agreed that a quantitative method would be most appropriate utilising a validated tool which has clinical relevance, is comprehensive, has a high level of sensitivity, acceptable to both clinician and patient and not resource intensive. As discussed above the tool chosen for the Phase II study was the PAM (Hibbard et al., 2004) (see Appendix 13)

The PAM was brought to my attention in July of 2014 and suggested as a robust assessment tool to comprehensively measure self-management whilst involved in a project whose primary focus was to establish and evaluate a Peer support programme for young adults (16 to 25 years old) living with diabetes.

To establish a sample size calculation for this study, I reviewed existing literature on the PAM and established that there was a lack of studies which evaluated its use in the context of out-patient non-attendance. In the UK, the Health Foundation was tasked with the roll-out of the PAM therefore I enquired from the programme director about evidence (published or unpublished) of its use in evaluating out-patient non-attendance. I was subsequently invited to a one-day seminar on the use and evaluation of PAM in the UK context which was hosted by the Health Foundation and facilitated by Dr Judith Hibbard and the Insignia team which developed the PAM (see Appendix14). At the seminar, there were no additional studies identified which specifically evaluated out-patient non-attendance.

6.4.1 Setting

Diabetes out-patient service in Newham, London, U.K

6.4.2 Inclusion criteria

Adults over 25 years of age diagnosed with Type 2 diabetes from Bengali, Pakistani, African and white British ethnic groups who have either/or:

1 - Attend routine diabetes follow-up appointments in the Newham diabetes out-patient service

2 - Failed to attend for routine diabetes follow-up appointments in the Newham diabetes out-patient service and have been referred back to their General Practitioner

6.4.3 Exclusion criteria

Adults over 25 years of age diagnosed with Type 2 diabetes from Bengali, Pakistani, African and white British ethnic groups who are either/or:

1 - Unable to give consent due to cognitive impairment

2 - Unwilling to give informed consent.

6.4.4 Recruitment

Non-attendees:

A retrospective clinic attendance report was obtained in the first instance to identify patients who were discharged due to non-attendance as per the Trust non-attendance policy. Updated reports were obtained prospectively of patients who were discharged due to non-attendance.

Regular attendees:

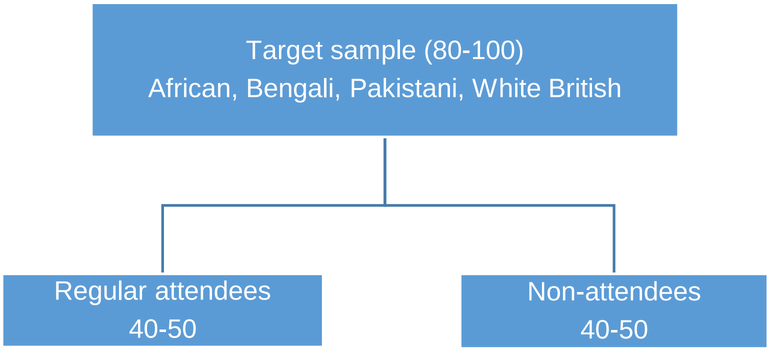
Patients who attend appointments were identified during the course of clinic consultations by the diabetes specialist nurses and doctors.

6.4.5 Sample size

Following discussions with the former School of Health Science's statistician, a sample size calculation was not deemed to be practical based on the scope of this study (pilot), the time available and the lack of studies which could be used to inform a sample size calculation. The general guidance reported for determining the sample size of a small study is 10 percent of the sample requirement of a full study (Hertzog, 2008). In the absence of suitable studies, a pragmatic sample size of 80 to 100 patients was proposed (see Figure 6.2) which was primarily based on the scale of the study proposed, time constraints and potential for recruitment based on outpatient attendance figures. It was determined that a post-hoc sample size calculation should be done based on this study's results to inform future studies of this nature.

Figure 6.2

Proposed recruitment structure



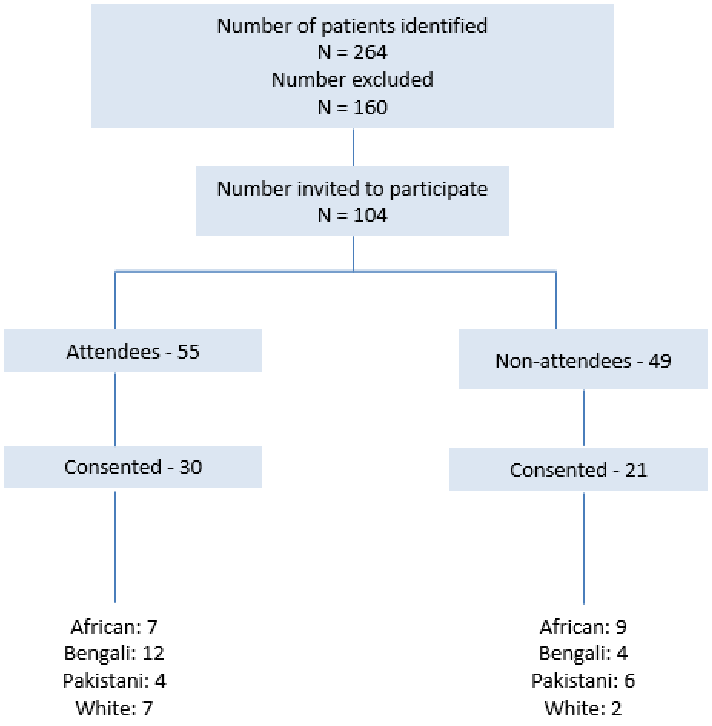
6.4.6 Method of recruitment

A list of patients who were discharged due to non-attendance was obtained from the clinic administrator. A letter inviting them to participate and a patient information sheet was posted with a follow-up call made one week later to establish the patient's willingness to participate. BHAs were used to facilitate communication where it was established that a patient has limited English proficiency.

Patients who regularly attended appointments were identified by either the diabetes specialist nurse or doctor. The risks with this study were minimal therefore patients were given the option to be recruited face to face in their own time (> 1 hour after they have been given the information sheet or had the study explained). The option of having a letter inviting them to participate and a patient information sheet was also given. A follow-up call was made within one week of postage for patients who prefer to have the information sent. During the follow-up call, verbal consent was obtained for all patients who agreed to participate and the questionnaire was completed. BHAs were used to further explain the study's purpose and gain informed consent for patient with limited English proficiency. The recruitment sampling process is detailed (see Figure 6.3)

Figure 6.3

Recruitment of participants



6.4.7 Service User Involvement

In accordance with research governance, advice was sought from the local Diabetes UK representatives about the acceptability of the project methods.

6.5 METHODS

6.5.1 Data Collection

Demographic details such as age, gender, ethnicity, date of diagnosis were obtained from the diabetes data management system (DIAMOND). Questionnaires were completed either via telephone or in person with three additional questions asked upon completion of the questionnaire to establish ease of access and possible reliance on others. The additional questions asked were:

- How easy is it to attend your appointments?
- Do you or a family member read your clinic letters?

- Do you need a friend/family/carer to attend appointments with you?

6.5.2 Data management

All data captured was anonymised and stored in accordance with Barts Health NHS Trust Data Protection, Research and Information Governance policies.

6.5.3 Data analysis

A scoring matrix is supplied upon purchase of PAM questionnaires by Insignia health (www.insigniahealth.com) which calculates both activation levels (1-4) and scores (0-100). All data obtained were analysed using version 20 of the statistical software SPSS and were examined using descriptive statistics and logistic regression.

6.6 RESULTS

6.6.1 Demographic and clinical data

Descriptive statistics were used to illustrate the characteristics of the demographic variables (age, gender and ethnicity) and clinical variables of attendees and non-attendees. The total number of questionnaires completed was N=51 (30 attendees and 21 non-attendees). However, after consultation with my academic supervisors, a sample size of 51 was deemed to be suitable for the conduct of this pilot study considering sample size calculation was an integral part of its evaluation.

Age

The age range for this patient population was 25 to 81years with a mean of 51.90 ± SD 15.46. CI 47.55 – 56.25. Due to the sample size, the median was also obtained to ascertain the likelihood of normal distribution. The median age was 55 years which is similar to the mean therefore indication normality of distribution. The Kolmogorov-Smirnov test was also done which provided a significance of p=0.186. A significance >0.05 indicate normality of distribution.

Gender

The distribution of appointments recorded indicated a gender difference. There were a greater number of females 56.9 % (n-29) as opposed to males 43.1 % (n=21).

Ethnicity

The focus of this study was four ethnic groups (African, Bengali, Pakistani and White British). The distribution based on ethnicity was as follow (Table 6.1):

Table 6.1 – Summary of interview participants

Ethnicity	Number	Non-attendees	Attendees	Percentage %
African	**16**	**9**	**7**	**31**
Bengali	**16**	**4**	**12**	**31**
Pakistani	**10**	**6**	**4**	**20**
White	**9**	**2**	**7**	**18**

Co-morbidities

76.5% of the participants had one or more recorded co-morbidities. Co-morbidities included cardiac, renal, hepatic, auto-immune, vascular, obesity and mental ill-health.

Duration of diabetes

The minimum recorded duration of diabetes was 0.66 years with a maximum of 36 years. The mean duration of diabetes was 10.40 years ±SD 7.77

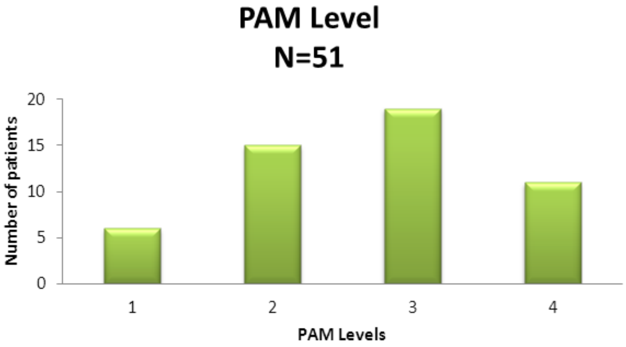
HbA1c

The minimum recording was 41 mmol/mol with a maximum of 106 mmol/mol. The mean HbA1c was 68.16 mmol/mol (Figure 6.4).

PAM Levels

For valid PAM levels to be obtained, ten out of the thirteen questions had to be completed. Values were obtained for all fifty-one participants with the distribution illustrated in figure 6.4. 41.2 percent of participants fell within levels 1 and 2 whereas 55.8 percent fell within levels 3 and 4.

Figure 6.4 –PAM Levels distribution



PAM Scores

The minimum recorded score was 39.4 with a maximum of 100. The mean recorded score was 59.58 ±SD 13.88 (Table 6.2).

Additionally, an independent sample T-test was performed to compare the mean PAM levels between attendees and non-attendees. A marginally significant difference of p=0.056 between those who attend and did not attend was observed.

Table 6.2

Comparison of PAM scores (attendees and non-attendees)

	Attend	N	Mean	Std. Deviation	Std. Error Mean
PAM Score 0-100	Attend	30	62.732	14.9083	2.6776
	DNA	21	54.690	10.7059	2.3939

Multivariable analyses (MVA)

MVA was used to determine the likelihood of attendance (dependent variable) occurring using either PAM levels or scores as the independent variable. The first analysis examined the relationship between the likelihood of attendance based on PAM scores, duration of diabetes and co-morbidities (see table 6.3).

Table 6.3

MVA of likelihood of attendance (PAM score, duration of diabetes and co-morbidities)

			95% C.I.for OR	
	Sig.	Odds ratio	Lower	Upper
Duration	0.496	1.031	0.944	1.126
PAM score	0.055	1.056	0.999	1.116
Comorbidities	0.521	1.613	0.374	6.951
Constant	0.058	.034		

When all factors were considered, the only variable which had marginal significance (p=0.055), OR 1.056 was PAM score. Individuals with co-morbidities were 1.6 times more likely to attend appointments however this finding did not achieve statistical significance (p=0.52) OR 1.61.

The second analysis examined the relationship between the likelihood of attendance based on PAM levels and the demographic characteristics of age, gender and ethnicity (see table 6.4).

Table 6.4

MVA of likelihood of attendance (PAM level, age, gender and ethnicity)

Variable	Sig.	Odds ratio	95% C.I.for EXP(B)	
			Lower	Upper
Age	0.029	1.097	1.009	1.192
Female	0.169	3.529	0.584	21.314
White	0.00			
African	0.073	0.058	0.003	1.299
Bengali	0.557	0.400	0.019	8.533
Pakistani	0.010	0.003	0.000	0.256
PAMLevel 1	0.00			
PAMLevel 2	0.030	32.266	1.411	737.668
PAMLeve 3	0.034	33.855	1.306	877.894
PAMLevel 4	0.002	898.231	11.086	72775.118
Constant	0.036	0.002		

When all factors were considered, three factors (age, ethnicity and PAM level) were statistically significant predictors of attendance. Despite women being 3.5 times more likely to attend than men, this finding was not statistically significant (p>0.05).

With 95 per cent certainty, the likelihood of attendance increases by 1.1 times for every one year older an individual is (p<0.05), OR 1.09, CI (1.01 – 1.19).

Ethnicity was a statistically significant predictor of attendance. African, Bengali and Pakistani individuals were less likely to attend (OR <1) compared to Whites. However, only Pakistani patients were significantly less likely to attend (p=0.01). Statistical significance was not achieved for African and Bengali individuals (p>0.05).

PAM levels were statistically significant predictors of attendance whereby individuals with higher levels of activation were more likely to attend than those with lover activation levels. Individuals who attained a PAM level 4 score had a highly significant likelihood of attendance (p=0.002) as oppose to Levels 2 and 3 (p=0.30 and p=0.034) respectively as illustrated in table 6.4.

6.6.2 Supplementary question responses

Three additional questions were posed to all participants following completion of the PAM questionnaire. These questions were chosen following the findings of the qualitative review which identified factors such as transportation access, reliance on others to attend appointments or to read and inform individuals of the content of appointment letters. The questions asked were:

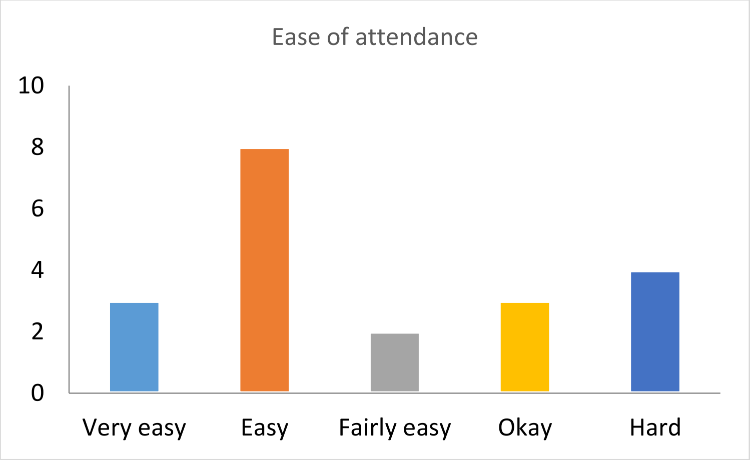
1. How easy is it to attend your appointments?
2. Do you or a family member read your clinic letters?
3. Do you need a friend, family or carer to attend appointments with you?

The method of analysis for these open questions was not pre-determined and was decided based on the nature of the responses provided. O'Cathain and Thomas (2004) describe open question as problematic due to the ambiguity associated with their analysis and reporting. They highlighted that there should be a clear purpose for these questions and recommend that they can be interpreted quantitatively or qualitatively. These additional questions were posed to provide a further understanding to potential rate limiting factors which could influence the participant's ability to engage, irrespective of the level of activation achieved. Upon examination of all the responses, a descriptive form of analysis was deemed to be most appropriate and are illustrated in figures 6.5 to 6.10. However, additional comments provided by participants to the questions posed were subsequently grouped into themes and are illustrated in tables 6.5 and 6.6.

6.6.2.1 Non-attendee responses

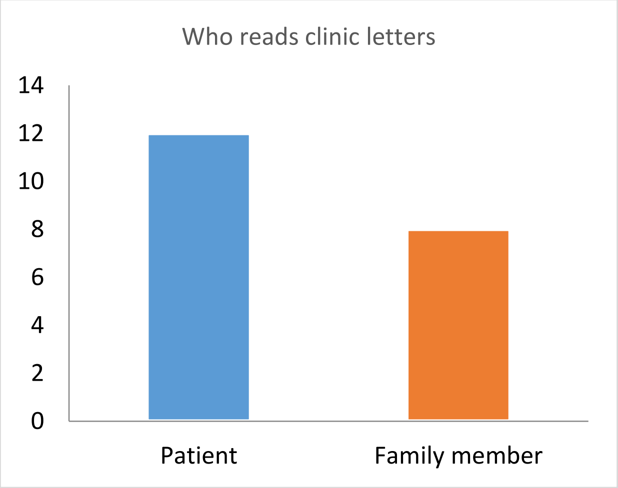
Question 1(Figure 6.5)

How easy is it to attend your appointments?



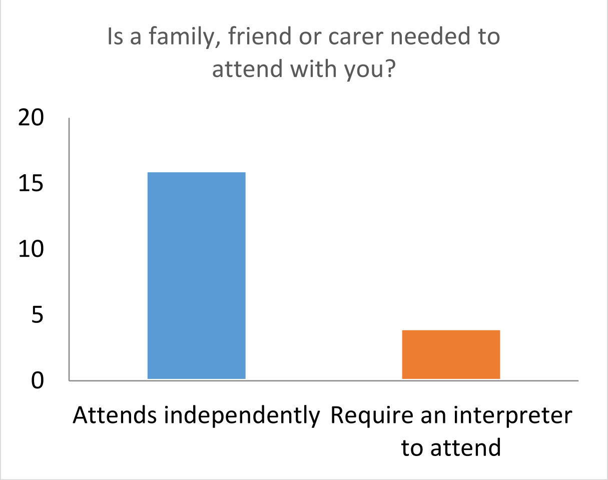
Question 2 (Figure 6.6)

Do you or a family member read your clinic letters?



Question 3 (Figure 6.7)

Do you need a family, friend or carer to attend appointments with you?



Despite being a non-attendee, appointments were deemed easy to attend due to easy access to transportation and residing near the appointment venue. However, barriers to attendance included factors such as reliance on family members, denial, dissatisfaction with clinicians, inability to get time off work, inflexible appointment times, multiple appointments, forgetfulness and the impact of multiple illnesses.

Additional comments to the questions posed have been grouped into themes with illustrative comments (see Table 6.5)

Table 6.5

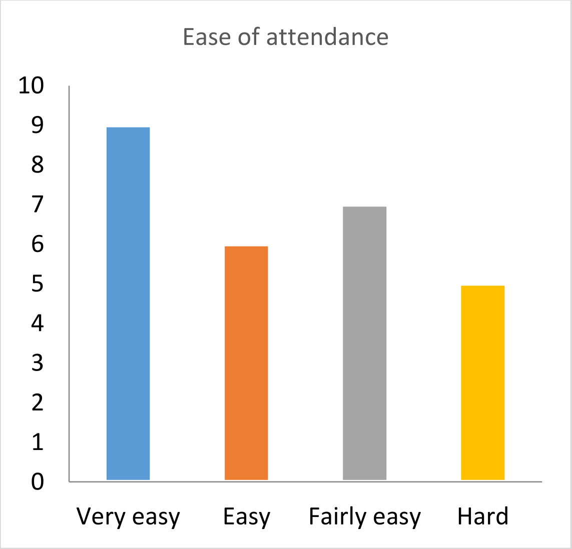
Factors influencing engagement by non-attendees

BARRIERS TO ENGAGEMENT	**PATIENT RESPONSES**
Individual determinants	
Denial	*"If I'm honest, I was in denial about my diabetes.*
Dependence on others	"*I have no family in this country so I would not be able to attend without an interpreter"*
Managing multiple illnesses	"*It's easy to attend abut I have a lot of medical problems and can't always come. Sometimes I forget too"* "*It's not easy to attend because I have other medical problems which makes it hard"*
Forgetfulness	"*It's okay coming but sometimes I forget them"*
Organisational determinants	
Inflexibility of services	
Multiple appointments	
Poor patient/clinician relationship	"*I decided to stop coming to my appointments because of the way the doctor used to speak* *to me. She never listened."*
Structural determinants	
Employment constraints	*"I have to work and can't always get time off"*
ENABLERS OF ENGAGEMENT	**PATIENT RESPONSES**
Individual determinants	
Acceptance	*"It's only recently I started taking my diabetes seriously because I have a lot of complications (eyes, kidneys and feet) and I have a three-year-old daughter*"
Structural determinants	
Good transportation access	
Close geographic proximity to service location	

6.6.2.2 Regular attendees

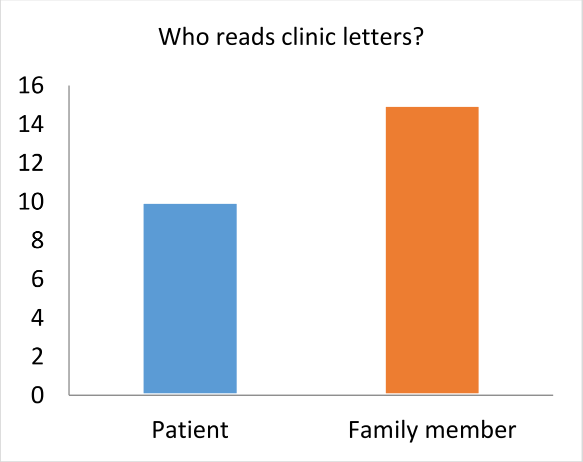
Question 1 (Figure 6.8)

How easy is it to attend your appointments?



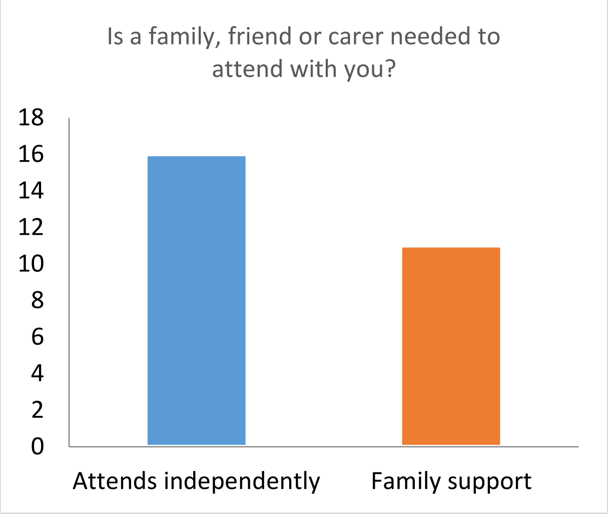
Question 2 (Figure 6.9)

Do you or a family member read your clinic letters?



Question 3 (Figure 6.10)

Do you need a family, friend or carer to attend appointments with you?



Approximately seventy percent of regular attendees found appointments were easy to attend and attributed support of family members, easy access to transportation and residing close to the appointment venue as enablers to attendance. For individuals with poor English proficiency who were otherwise capable of attending independently, language support was a key enabler to attendance.

Additional comments to the questions posed have been grouped into themes with illustrative comments (see Table 6.6)

Table 6.6

Factors influencing engagement by attendees

BARRIERS TO ENGAGEMENT	**PATIENT RESPONSES**
Individual determinants	
Carer responsibilities	*"Caring for my elderly parents have affected my ability to attend"*
Deteriorating health and dependence on others (2 participants)	*"It used to be easy but now it's difficult to attend because of pain in my legs. Now I need someone to attend with me"* "*I used to attend independently but my health has deteriorated so I rely on my family now to bring me to appointments"*
Organisational determinants	
Inflexibility of services (clinic times)	"I*f I can book an appointment before or after work its fine. I work 9-5"*
Multiple appointments	"*It is not always easy as I do have to attend a lot of appointments. I constantly have to ask for time off work to be able to attend them which make things difficult"*
Structural determinants	
Employment constraints (3 participants)	"*It not that easy as I have to take time off from work so I have to book annual leave.* "*Not easy to attend as I'm not always able to take time off from work.* "*It's mostly okay/easy to attend. Things that have affected my ability to attend have been work commitments."*
ENABLERS OF ENGAGEMENT	**PATIENT RESPONSES**
Individual determinants	
Ownership for one's health (2 participants)	"*My health is very important to me. This is the only valuable thing we have"*

	"*I am old and I go across London even if it takes me an hour. Why don't people go? It's their health and it's very important"*
Support of others (family or language) (3 participants)	"*My appointments are easy to attend. I can come on my own but I need to be informed well in advance and I need a health advocate when I attend. I rely on their input"* *I don't have family in this country so I need a Bengali advocate for my appointments"* "*It's very easy to attend because I have a lot of support"*
Structural determinants	
Good transportation access	"*Sometimes it's easy to attend depending on transport. I have to take a bus and then walk"*
Close geographic proximity to service location	"*It's within walking distance so it's very easy for me to attend my appointments"*

6.7 Post-hoc sample size calculation

A post-hoc sample size calculation was deemed to be important to inform future studies of this nature. A pragmatic sample size of 80 was proposed for this pilot study due to a lack of research studies which evaluated the use of PAM and out-patient attendance. Pot-hoc sample size calculation was performed using the statistical software STATA and was derived by the pooling of variance using the observed means between attendees (mean 62.7, Std dev 14.9) and not attendees (mean 54.7, Std dev 10.7) with parameters of 80 % (alpha levels) power at $p<0.05$ (beta levels). It was calculated that a sample size of 86 (43 in each group) would be needed to demonstrate statistically significant differences in activation between attendees and non-attendees.

6.8 Discussion

This study was conducted as a pilot to examine whether there was a relationship between patient activation and outpatient non-attendance utilising the PAM questionnaire. Multiple logistic regression adjustments were made for factors such as age, gender and ethnicity and these significantly demonstrated for every one-point increase in PAM score, a patient is more likely to attend an appointment. Therefore, the more activated an individual is, the more likely they are to attend appointments. This study also demonstrated that the PAM can be used as a predictor of non-attendance and requires a sample size of 86 to detect significance at $p< 0.05$ with 80% power.

Activation is influenced by many factors and this study has demonstrated the complex nature of ownership and as such empowerment. It has highlighted that despite the concept of self-determination as an important driver of ownership which in this context refers to self-management, factors such as language, literacy and family support are key enablers to facilitate ownership of one’s health.

The results of the analyses have also been examined in the context of the clinical use of PAM. NHS England (2015) identified that there is little information about how PAM can improve care and commissioning in the UK and highlighted the need to find out how to optimise its use, what value it has and the challenges.

To explore the clinical effectiveness of PAM in clinical care, the relationship between variables such as HbA1c, co-morbidities, PAM levels and scores were examined in the context of non-attendance from data recorded on the patient information system. Twenty-four per cent of the participants had between one and three co-morbidities and fifteen per cent had four or more co-morbidities. Co-morbidities were diverse, but a higher incidence of coronary heart disease, renal disease, depression and obesity was observed. Co-morbidities were factored into the analysis on a basis of whether they existed or not. This decision was made because too many assumptions would have to be made in isolation about the impact of co-morbidities on an individual’s functional capacity. However, the analysis demonstrated that whilst activation was a significant predictor of attendance, neither co-morbidities nor HbA1c were achieved statistical significance as predictors of attendance.

Despite co-morbidities not having a significant influence on attendance, the incidence of depression amongst the sample population was an interesting observation as one in five of the sample population had a diagnosis of depression. The negative impact of depression on diabetes self-management though well documented is thought to be under-reported. It has been reported that the burden of living with diabetes and the influence of factors external to the condition may increase the emotional and psychological support needs for individuals. Depression, anxiety, eating disorders or phobias are potential psychological outcomes linked to the daily responsibility of self-managing diabetes. It was reported that the prevalence of depression in people with diabetes is approximately twice as high than in the general population (Katon et al., 2004, Mommersteeg et al.,2013).

Usability of the questionnaire was identified as an issue of concern with patients who were less proficient in English. The patient group comprised of people of diverse ethnicities with variable levels of English proficiency. Therefore, Bilingual health advocates were used to translate the questionnaires for participants as required. A common concern with translating information is the potential impact of loss of meaning and integrity following translation. This issue of concern was discussed by Hibbard et al (2008) and following the use and translation of PAM in diverse ethnic and language groups they reported that the validity of the questionnaire is not adversely affected. Despite this level of reassurance, a recurrent feedback from the BHAs within this study was that some patients found some questions difficult to relate to or understand. The Bengali and Arabic speaking BHAs also stated that it was difficult to translate some questions without altering their structure and potential meaning because some words did not have a direct translation.

Analyses were done based on both PAM levels (1-4) and scores (1-100). Existing literature indicate that patients who have longer hospital stays, poorer health outcomes and greater consumers of health resources usually have an activation score of 1-2. In accordance PAM categorisation, the functional ability of patients is as follow:

Level 1: Patients who are disengaged and overwhelmed
Level 2: Patients who are becoming aware but struggling
Level 3: Patients who possess knowledge and are developing their self-management skills
Level 4: Patients who have knowledge, skills and confidence for self-management but may require assistance to manage during times of change or stress.

Whilst conducting this analysis, it was observed that there were wide minimum and maximum scoring ranges within each activation level. This inter-level variability meant that two patients could be assessed as having the same Level of activation however, they could be at opposites of the score range. For example one patient could score 55.6 and another 70.3 within Level 3. Therefore, raising the question: how similar or different are their individual needs? From a perspective of the PAM, both Level 3 patients would be defined as patients who possess knowledge and are developing their self-management skills. However, to what extent is this true for the patient with the lower score of 55.6?

Also, there were Level 1 patients who from a clinical perspective were very well managed and highly engaged with services whereas some Level 4 patients were not well managed clinically and had disengaged with services. This observation highlighted the need for a context to enhance the interpretation and usefulness of PAM in clinical practice.

How useful is PAM in a diabetes out-patient setting if the wider determinants of health are identified as rate limiting factors? What can secondary care organisations do to mitigate against the disconnect between health and social care?

The PAM's broad categorisation of Levels may serve the purpose of providing collective data to inform 'Level specific' interventions and pre/post evaluations as the literature highlights. However, Level specific data can be limited in interpretation and value for example:

- An individual who scores on the lower spectrum of PAM level 3 (55.6) pre-intervention may have an improved score post intervention for example 66.2 but remains within Level 3.

In this instance, minimisation of not just collective improvement but more importantly, individual gains can occur when using PAM levels as the measure of an intervention's effectiveness. A focus solely on the PAM level of attainment has the potential to become a de-motivating factor for some individuals. If individual improvement is to be assessed, PAM scores would be a more meaningful means to evaluate an intervention's effectiveness. This approach would involve reviewing the questions to determine patient specific needs and would be both resource and time intensive. Despite the time and resource implications, PAM can be useful as a starting point for planning individualized care as it objectively identifies the perceived gaps from both a self-management and service perspective. Unfortunately, the use of PAM has an associated cost and raised the question of whether there is added value in its use if compared to enhanced communication skill for clinicians or motivational interviewing.

Instances as detailed above highlight the need for individual examination of PAM questionnaires if meaningful clinical dialogue is to be made and appropriate goals set.

Despite the results demonstrating the correlation between levels of activation and attendance, there were individuals who achieved maximum activation (Level 4) who were non-attendees. For some individuals, the decision to attend appointments is an informed choice irrespective of the level of activation (perceived or measured). It has been stated that ultimately, patients are the ones who decide what choices they will make, advice they will follow or ignore and what modifications they will make if any (Asimakopoulou, 2007). This statement may be true for individuals whose ability to act is not subject to the influence of others due to poor language proficiency, limited health-literacy and other factors such as multiple co-morbidities and no employment rights.

The ease of attending appointments and the reliance on others to enable attendance also provides a holistic context which can influence clinician/patient dialogue and self-care recommendations. Interestingly, individuals who did not attend appointments viewed reliance on family members as a barrier to attendance whereas regular attendees viewed reliance on family members as an enabler to attendance. This highlights the supportive element of care which is required to facilitate engagement and the fact that patients cannot be assessed in isolation. The supportive information provided by participants in relation to the additional questions posed reinforced the impact of factors such as multiple illnesses, language support, relationship with illness (i.e. denial), employment, inflexibility of services and being a carer.

Language support has been a recurrent need for individuals who are less proficient in English. Dependence on others for information was evident in both elements of this research component with it being the rate limiting factor for even those who could attend independently. Within recent years Bilingual Health Advocacy services have been de-commissioned by some NHS organisations with a shift to the use of translation only (telephone) services. BHAs are employed by healthcare organisations and have working knowledge of both the NHS and the communities they serve. Their primary functions are to enable impartial communication between a clinician and the patient but most importantly to be the patient's advocate. The use of BHA was deemed to be essential in the delivery of healthcare in ethnically diverse locations where there is limited English proficiency. Full BHA services are a means of quality assurance for organisations by mitigating against the moral and ethical dilemma of using friends and family to facilitate clinician/patient interactions. One interview participant highlighted that although her son attended appointments with her, she was not confident in the quality and accuracy of the information relayed to her because his command of Bengali was not good in her opinion. Factors such as difficulty navigating through and knowledge of healthcare systems were identified by research participants but also in existing literature (Greenhalgh et al., 2011). BHAs assist patients in navigating healthcare systems and are a means to increase permeability of services thereby improving patients' ability to both access and utilise services. The

NHS is undergoing a period of significant financial pressures and austerity measures of which the de-commissioning of BHAs and the use of telephone interpretation services may be viewed as a cost-effective measure. The risk associated with de-commissioning services is a reduction in the overall quality of healthcare interactions and a potential increase in dis-engagement with services.

6.9 Challenges

Accessing study populations and participation in research by BME individuals:
The response rate to written information was negligible with only five responses from 104 letters which were posted. The method of telephone completion of the questionnaire was chosen to increase access to potential participants in a resourceful manner. Despite the time-consuming nature of telephone contact due to repeated attempts to establish contact with potential participants this approach proved to be more fruitful with 41 of the 51 participants recruited by such means.

The approach of telephone or mail contact were limited in levels of success. It has been noted that the response rate to questionnaires generally is quite low in the general population and greatly reduced in disadvantaged groups due to multiple factors such as literacy and the psychosocial impact of illness or deprivation (Griffin 1998). Recruitment of patients who are deemed ‘hard to reach’ therefore requires time, effort, resources and local knowledge.
Mistrust was a recurrent problem encountered with potential participants despite both written (Patient information sheet) and verbal reassurance. Some individuals declined to participate as they were not convinced that their responses would be anonymous and therefore might have a negative impact on their care. This expression of mistrust was identified amongst South Asians as barriers to research participation by Hussain-Gambles et al. (2004). An unpublished service audit which explored ‘Barriers to Research Participation’ which was conducted at Newham University Hospital in 2010 as part of a Comprehensive Local Research Network (CLRN) funded initiative to improve research awareness and recruitment by BAME communities also identified

factors such as the ethnicity of the researcher and the benefits for the individual and their community as influencing factors to research participation.

Due to multiple factors such as delayed R&D approval, reluctance of some individuals to participate during Ramadan, difficulties accessing potential participants and a finite timeframe, the recruitment target was not met. Cultural sensitivity and an awareness of religious holidays are critical elements which must be factored into research time frames (Khunti et al.2009). In both stages of the research study, the period of Ramadan fell with the recruitment period which proved quite challenging for targeting Bengali and some Pakistani individuals. A recurrent response from patients when contacted by telephone was that they would prefer to be contacted after Ramadan as research was viewed as a non-essential endeavour.

6.10 Limitations of PAM

From an individualised care perspective, the clinical usefulness of PAM required knowledge of a patient's activation score alongside other influencing factors such as ease of attendance, reliance on others to obtain information such as having clinic letters read and assistance by others to aid clinic attendance. In addition, the PAM questionnaire does not provide an insight into service gaps from a patient's perspective which may have a significant influence on their decision making with regards to attendance. For example, question six asks:

Question 6*: I am confident that I can tell a doctor concerns I have even when he or she does not ask.*

This question could be very relevant in identifying training needs for clinicians particularly in terms of communication bearing in mind that lack of a rapport with clinicians following diagnosis and not being heard were identified as reasons for dis-engagement by some participants.

6.11 Conclusion

A PAM assessment in isolation is limited in its clinical applicability due to the lack of an individualised context. Non-attendance has been demonstrated to be multi-factorial and the PAM questionnaire alone did not provide a context for non-attendance. Also, based on the lack of any statistically significant differences between level of activation and factors such as duration of diabetes, co-morbidities and HbA1c, the question of clinical appropriateness and cost-effectiveness of PAM can be raised.

Despite its assessed value in existing literature, the use of PAM questionnaires is potentially a costly means of conducting individualised assessment. The use of PAM requires purchasing of a licence plus a cost per questionnaire. It can be argued that enhanced communication skills training for clinicians and a psychological approach such as motivational interviewing (MI) would be more sensitive to individualised needs as it provides context and meaning, effectively aids goal setting and helps to build rapport between the individual and clinician and be more cost-effective. All members of the clinical team can be trained in MI techniques and this training can be delivered in a cost-effective manner by a clinical psychologist who in accordance with NICE recommendations (2003) should be a core member of a diabetes multi-disciplinary team. In addition, MI's use has also been recommended in a recent report into diabetes education (DUK, 2016). The effectiveness of this approach can be measured in a cost-effective manner by evaluating individualised goals which would have been set, clinical and biochemical measures and attendance trends at pre-determined timepoints.

However, despite these limitations and due to the predictive ability of PAM, there is potential for its use in both primary and secondary care in relation to evaluating self-management interventions and predictive modelling. Knowledge of PAM levels in General Practice could inform interventions designed to enhance patient preparedness prior to referral to specialists in secondary care. A PAM assessment as part of the specialist referral pathway could also be of value to outpatient predictive modelling.

This pilot study has demonstrated that patients who are less activated are less likely to attend out-patient appointments therefore patient activation levels could be one of the variables which is added to out-patient scheduling predictive models. Out-patient non-attendance predictive models have used variables such as demographics, appointment characteristics, co-morbidities, risk factors to maximise out-patient scheduling (Ramsey et al., 2008, Huang 2014). The variables selected are specified by organisations based on observed trends.

The multi methods approach used to investigate the phenomenon of diabetes out-patient non-attendance was very appropriate as it provided a comprehensive and rich evaluation. The sequential use of qualitative and quantitative methods provided context and enabled a meaningful interpretation of results.

6.12 Linkage

A component of the professional doctorate is the production of a dissemination artefact. Based on the explorative nature of this thesis, it was deemed that an article for publication would be the most appropriate form of dissemination. The following chapter provides details about the dissemination artefact, a dissemination plan in addition to the article which has been submitted for publication (see 7.4).

CHAPTER 7: THE ARTEFACT

7.1 Introduction

A component of this thesis is a dissemination artefact. The artefact is an article for publication based on one aspect of the findings of the case study evaluation which was submitted to the journal Health and Place on July 24th, 2017. Health and Place is an international peer reviewed journal that encourages submissions from multiple disciplines which examine the influence of location on health and healthcare.

7.2 Artefact description

There were multiple evaluations and findings of the case study. Findings such as differences in non-attendance based on clinician or clinic location provide local evidence which may not be reflected in other geographical areas with a similar population profile. However, the findings which demonstrated the relationship between demographic characteristics, deprivation and geography have greater scope for generalisability therefore was chosen as the focus for the dissemination article.

7.3 Dissemination plan

During the conduct of this thesis, dissemination of finding has been ongoing in the form of seminar and poster presentations (nationally and internationally) in addition to publication of an article from Phase I of the research study. Information disseminated to date include:

7.3.1 Case study

July 2011	Seminar presentation at the local NHS Trust multi-professional educational session
October 2012	SAPC poster presentation (see Appendix 13)

November 2012	Seminar presentation at City University

7.3.2 Research studies

March 2014	Poster presentation of Phase I findings (Royal College of Nursing Research Conference) Glasgow UK (see Appendix 14)
May 2014	Poster presentation of the combined findings of case study and Phase I findings (Canadian Public Health Association) Toronto (see Appendix 15)
February 2016	Publication of Phase I findings: The Journal of Diabetes Nursing Volume 20

7.4 Dissemination Artefact

The article included in this chapter was submitted to the journal Health and Place for publication.

Title: Diabetes out-patient non-attendance (DNA) in an ethnically diverse Inner urban area in the United Kingdom

ABSTRACT

Background: The likelihood of non-attendance was examined based on local geography and deprivation in a UK Inner London diabetes outpatient service. The borough within which the service sits, has a high diabetes outpatient non-attendance rate, is one of the most ethnically diverse and deprived in the UK (LBN 2010), has the third highest prevalence of diabetes in the UK (YHPHO 2010), poor engagement with services and worse diabetes outcomes compared to the rest of England (Healthcare for London 2008).

Method: A retrospective geodemographic analysis of 35997 appointment was conducted to evaluate non-attendance trends for all patients over 16 years of age for the period 2004-2009 who had scheduled appointments with a diabetes doctor, specialist nurse or dietitian. A further analysis was conducted on 31864 appointments for only patient who resided locally to examine the relationship between local geography, deprivation and attendance. Data were analysed using SPSS V 18 using descriptive analysis and logistic regression.

Results: Key findings included a significantly higher non-attendance rate of 25% in comparison to the national average of 11%. Significant differences were seen in non-attendance rates based on clinic location, clinician seen and service delivered. Ethnicity, deprivation, gender and age were found to be significant predictors of attendance ($P<0.05$). with African, Bengali and Pakistani being significantly more likely to not attend in comparison to White British patients. Patients residing in more deprived locations were significantly more likely to not attend appointments. Men were significantly more likely to not attend appointments than women and for every 1 year older a patient is, they are more likely to attend appointments ($p<0.05$). The mean age was 54.3 years ± 16 years (std deviation).

Conclusions: The results demonstrated the usefulness of evaluating readily available out-patient data to understand attendance trends and establish the predictors of attendance.

INTRODUCTION

Diabetes is a long-term disease which is characterised by elevated blood glucose levels which over time can result in multi-organ damage and premature death if poorly managed. There are two types of diabetes Type 1 (T1) and Type 2 (T2). T1 accounts for 3% of the total diagnosed cases and is due to the absence of insulin production. T2 is characterised by the sub-optimal production or utilisation of insulin and is linked to factors such as heredity, diet and lifestyle choices. It is one of the non-communicable diseases (NCD) which has a significant global burden of illness. It has been projected that there will be 380 million people with diabetes globally by 2025 (DUK 2010). The direct and indirect cost implication of diabetes in England and

Wales for the period 2010/2011 was calculated at £23.7 billion. Direct cost was associated with the management of avoidable complications however indirect costs included sickness, loss of productivity and informal care (Hex et al. 2012).

There is a higher prevalence of T2 diabetes amongst South Asians, Afro-Caribbeans and individuals who are socio-economically deprived. Based on ethnicity South Asians are six times more likely and Afro-Caribbeans four times more likely to develop diabetes than Caucasians (APPG 2006). In addition, the most deprived in the UK are 2.5 times more likely to have diabetes and diabetes related complications are 3.5 times higher in the lower socio-economic groups (DUK 2010).

Individuals from socio-economically deprived and some minority ethnic groups in the UK have been found to dis-engage with healthcare services and report poorer health(APPG 2006). Dis-engagement which routinely manifests in non-attendance has been shown to be multi-faceted. However, some contributory factors have included: inflexibility of services, difficult to access service locations, lack of culturally sensitive services and difficulty navigating healthcare systems (Greenhalgh et al 2011). Organisational enablers and barriers to the access and utilisation of services have also been examined in the context of porosity and permeability of services (Dixon Woods 2005). Services which require minimal effort and negotiation to use are deemed to have high permeability whereas services which require greater effort and negotiation to enter and maintain engagement with are deemed to be less permeable. High non-attendance is thought to be indicative of services which are less permeable (Dixon Woods 2005). Non-attendance is measured in two ways: from the Department of Health quarterly activity return or by using aggregated data from secondary used services for example out-patient encounters. Outpatient data is felt to provide a more accurate picture of non-attendance than quarterly returns. The estimated cost to the National Health Service (NHS) in 2001 because of outpatient non-attendance was £300m (Tham et al., 2002).

METHODS

The evaluation was considered to have fulfilled the criteria for a clinical audit (National Institute of Clinical Excellence (NICE) 2003) therefore ethical approval was not required. Written permission to utilise the data was obtained from the Trust's Information Governance Department. It was determined that patient confidentiality would not be compromised and the scope of this audit fulfilled the remit of the NHS Equality Delivery System (EDS) which endorses the use of routinely collected equality monitoring data as a means of supporting targeted service improvements.

Out-patient data comprising of all scheduled routine appointments (new or follow-up) for the doctors, specialist nurses and dieticians for patients ≥ 16 years of age was obtained for the period 2004-2009. The sample population included all patients with a diagnosis of Type 1, Type 2 or gestational diabetes (GDM). SPSS (Version 18) was used to conduct the analyses for this audit.

The17 (16+1) National Health Service (NHS) ethnic categories were subsequently recoded into the six (5+1) recommended categories (ONS 2001) to conduct the geographic and deprivation analyses.

Geographic analyses were performed on both a mid-level super output area (MSOA) and lower-level super output area (LSOA). Deprivation was analysed using Noble's indices of multiple deprivation (IMD) (Noble 2007)

Firstly, descriptive analyses were performed on the entire dataset (N= 39957) to gain an overview of attendance trends.

Secondly, the dataset was revised to include appointments for patients with a local residential postcode only (N= 31837) prior to undertaking the geographic and deprivation analyses. The unpaired t-test was used to see if there were differences in age between attenders and non-attenders and single and multivariable logistic regression was performed to look at differences in attendance/non-attendance by ethnicity, gender, geography and deprivation.

RESULTS

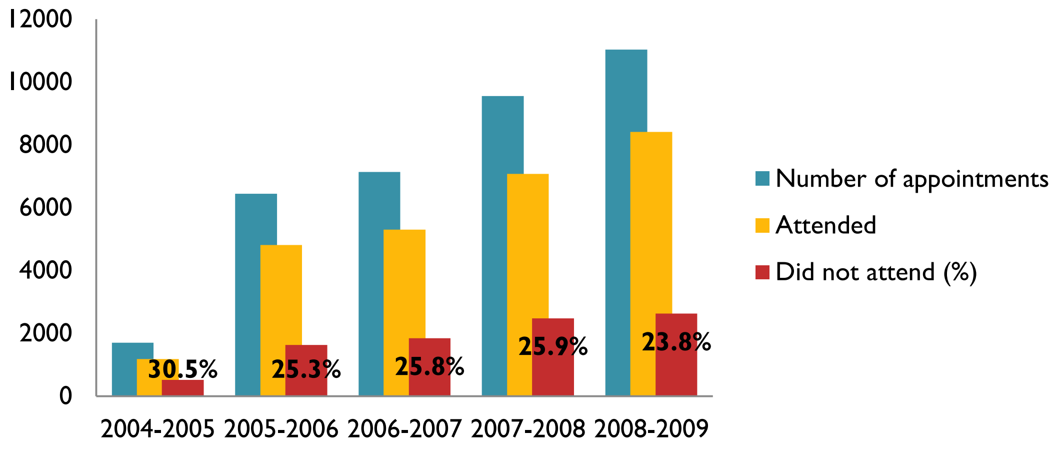
During the period covered by this audit, routine outpatient diabetes appointments were delivered at four locations within the community with the primary clinic location being location 1. Table 1 illustrates the respective sites, the percentage of appointments, percentage non-attendance rates and type of appointment. Eighty percent of the overall number of appointments were conducted at the diabetes centre (location 1) with an overall DNA rate of 26%. Two percent of overall routine appointments were conducted at location 4, with an overall DNA rate of 36%.

Overall, there was a year on year increase in the number of diabetic appointments with an average non-attendance rate of 25% (Figure 1) for three consecutive years (April 2005-March 2008). However, a reduction of 2% was seen for the period April 2008 – March 2009. The year 2004-2005 illustrated the highest non-attendance rate but this was due to a shorter data recording time (6 months). This shorter time was due to the transition in moving from one data system to another. The reduced numbers for this time frame therefore created wider confidence intervals and do not provide an accurate reflection of that year’s non-attendance rate.

Table 1 - Non-attendance rates (2004-2009) per outpatient department (OPD) location

OPD Centre Location	Percentage of appointments (%)	Rate of non-attendance (%)	Appointment category
1	80	26	Routine care
2	16	18	Gestational care
3	2	41	Young adult care
4	2	36	Routine care

Figure 1 - Overall non-attendance trends 2004-2009



Age

The age range for the sample population was 16 to 96 years old. Age was normally distributed with a mean age of 54.3 years (SD 16). A significant difference was observed between patients who did not attend and those who attended, with those attending being on average 2.24 years older (95% CI: C.I 1.85 – 2.63), P=0.005.

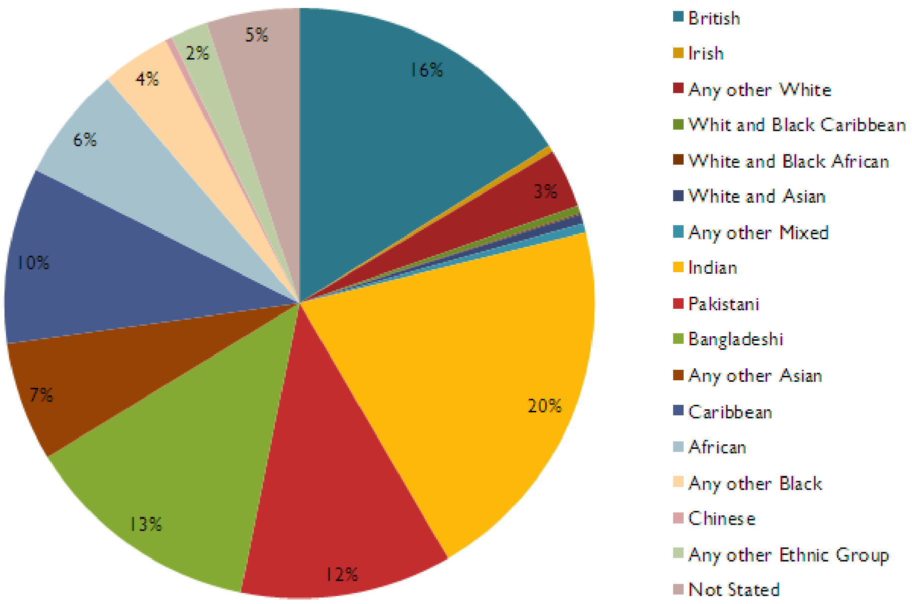
Gender

Females accounted for 56.2% of appointments. Men had a significantly higher non-attendance rate (27.5%) compared to women (23.7 %), p<0.001

Ethnicity

A descriptive analysis was conducted to examine the distribution of appointments per ethnic group (see Figure 2).

Figure 2 - Dis-aggregated ethnicity (distribution of appointments)



Dis-aggregated ethnicity

Descriptive analyses were initially conducted using the nationally accepted National Health Service (NHS) ethnic categories (16+1) to gain an insight into the rates of non-attendance that demonstrated significant variations in non-attendance across ethnic groups. The results are presented as a percentage of the total number of appointments per ethnic group and whether there is a significant difference in the DNA rates for each ethnic group compared to all other ethnicities (see Table 2).

Table 2 – Cross tabulation of non-attendance rates

Ethnicity	Number of booked appointments	DNA (%)	P value
British	5756	23.1	<0.001
Irish	128	24.2	<0.001
Any other white	1159	28.7	<0.001
White and Black Caribbean	146	23.3	<0.001
White and Black African	30	33.3	<0.001

White and Asian	184	16.3	<0.001
Any other mixed	179	30.7	<0.001
Indian	7336	23.3	<0.001
Pakistani	4163	27.2	<0.001
Bangladeshi	4691	24.9	<0.001
Any other Asian	2343	25.7	<0.001
Caribbean	3458	23	<0.001
African	2254	25.6	<0.001
Any other Black	1334	29	<0.001
Chinese	143	14	<0.001
Any other ethnic group	727	33.7	<0.001
Refused or not stated	1829	33.7	<0.001

Multivariable logistic regression analysis showed that after adjusting for age patients categorised as Mixed (White and Asian) were more likely to attend appointments compared to White British. However, those categorised as Mixed other were significantly more likely to not attend appointments. Pakistani (OR 1.288, CI (1.173-1.414)), Bengali (OR 7.154, CI (1.052-1.265)) and African (OR 1.154, CI (1.028-1.295) patients were significantly more likely to not attend appointments than White British patients. Chinese patient (OR 0.57, CI 0.354-0.923) were more likely to attend appointments compared to White British patients. However, patients categorised as Other and Not stated had a highly significant likelihood of not attending appointments (OR 1.564, CI 1.321-1.855 and OR 1.636, CI 1.457-1.841 respectively)

Ethnic categories were also aggregated based on ONS categorisation (5+1) Aggregation of ethnicity is standard practice for statistical evaluations particularly when handling large data sets (CEG 2011). The distribution of appointments per ethnic group is illustrated in Table 3.

Table 3 - Aggregated ethnicity

Category	Group composition	Percentage of overall appointments (2004-2009)
White	White British, White Irish, Scottish, Welsh, Eastern European, White other	20
Black	African, Caribbean, Black British, Somali, Black other	20
Asian	Indian, Pakistani, Bangladeshi, Other Asian	52
Mixed	Black/White, Asian/White, Other Mixed	1
Other	Arab, Middle Eastern, Chinese, Vietnamese, Other,	2
Not stated	Not stated, Not asked and Refused	5

Geography

The local borough had 37 MSOAs with each MSOA comprising of a population of 5000 persons or 2000 households (ONS 2004A single variable analysis (cross-tabulation) was done to evaluate the non-attendance rate per geographic location.

A multivariable logistic regression was undertaken to find out if age, gender, ethnicity and geographic location were significantly related to non-attendance. MSOA location 37 chosen as the comparator for this analysis due to its geographic size in addition to it having a low local IMD score (second least deprived). The results can be seen in Table 4 and show that patients residing in four MSOA locations 3, 7, 10 and 24 were significantly more likely to attend appointments than patients in MSOA 37.

For each year older a person is, they are 1.01 times more likely to attend their appointment. Men were significantly more likely to not attend appointments than women. Asian, other ethnicity or not stated ethnicity were significantly more likely to not attend their appointments than Whites.

Table 4 - MVA summary of likelihood of non-attendance

Variable		Odds ratio	95% CI		P value
			Lower	Upper	
Age		0.992	0.990	0.994	<0.001
Gender	Male	1.301	1.234	1.372	<0.001
	Female	1.000			
MSOA locations	37	1.000			
	3	0.707	0.545	0.980	0.009
	7	0.721	0.555	0.937	0.015
	10	0.721	0.574	0.904	0.005
	24	0.763	0.593	0.983	0.037
Ethnicity	White	1.000			
	Mixed	0.896	0.709	1.132	0.358
	Asian	1.114	1.033	1.200	0.005
	Black	1.083	0.995	1.178	0.066
	Other	1.482	1.235	1.778	<0.001
	Not Stated	1.622	1.430	1.839	<0.001

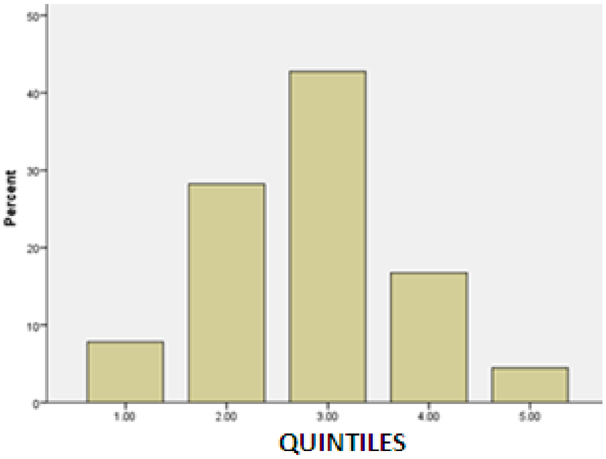
Deprivation

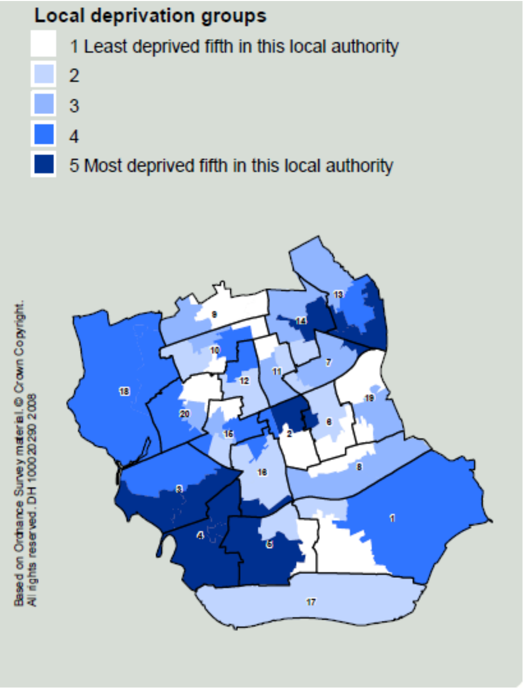
In England, the Indices of Multiple Deprivation (IMD) is produced and reported on a Lower Super Output Area level (LSOA) with associated deprivation scores and ranking (1 to 5), with 1 being the least deprived and 5 the most deprived

There were 159 LSOAs within the local borough for this study, each comprising a minimum population size of 1000 – 1500 persons (400 households). To establish the relationship between deprivation and attendance, analyses were conducted on a LSOA level.

Descriptive analyses of the sample population evaluated the deprivation ranking both in comparison to both England and the local IMD ranking (Noble 2007). When compared to England, ninety percent of the sample population ranked in the most deprived fifth and ten percent in the fourth most deprived. Further analysis of the local deprivation profile for the sample population demonstrated results which were also consistent with the nationally published health profile of the local borough (see Figure 3).

Figure 3 - IMD comparison (sample population IMD scores vs Local Health Profiles 2008)





A single variable logistic regression using LSOA as the independent variable was performed to identify micro-level geographic locations with a greater or lesser likelihood of non-attendance. The analysis identified with 95% certainty, patients residing in LSOA E01003490, E01003540 and E01003547 were significantly less likely to attend.

A further multivariable logistic regression was undertaken looking at whether deprivation was related to non-attendance. The variables age, gender, ethnicity and deprivation quintile) were used in this analysis to (see Table 5)

Table 5 - Multivariate analysis of likelihood of non-attendance (LSOA, deprivation quintile, age, gender and ethnicity)

Variable		Odds ratio	95% CI		P value
			Lower	Upper	
Age		0.991	0.990	0.993	<0.001
Gender	Male	1.300	1.240	1.370	<0.001
	Female	1.000			
Ethnicity	White	1.000			
	Mixed	0.901	0.714	1.136	0.378
	Asian	1.064	0.991	1.142	0.087
	Black	1.070	0.984	1.163	0.115
	Other	1.440	1.201	1.726	<0.001
	Not Stated	1.550	1.370	1.754	<0.001
Quintiles of deprivation	1 – least deprived	0.798	0.688	0.926	0.003
	2	0.889	0.783	1.009	0.068
	3	0.810	0.716	0.917	0.001
	4	0.908	0.796	1.036	0.153
	5 – most deprived	1.000			

The results for age, ethnicity and gender are like the previous analysis with LSOA. For deprivation those in the least deprived quintiles were significantly more likely to attend their appointments than those patients in the most deprived quintiles

DISCUSSION

The average yearly non-attendance rate for the entire sample population was 25%. The national non-attendance rate for all outpatient clinics during 2008 was approximately 11 percent which was only a one percent reduction when compared to the period 1996-1997 (DH 1997, HSJ 2009).

This audit quantified the extent of non-attendance over a five-year period; identified trends in non-attendance based on socio-demographic characteristics of patients and framed it in the context of local geography. It identified the significantly higher than national average rate of out-patient non-attendance and demonstrated the significant disparities based on gender, age and ethnicity and the relationship to local geography and deprivation. The findings are consistent with existing literature which highlights the influence of demographic and socio-economic factors on access and utilisation of healthcare services (Karlsen et al 2007, DUK 2006). This audit has however attempted to address the question of which factor(s) are more precise predictors of attendance (demographic, geographic or socio-economic)?

Demographically, the likelihood of non-attendance was significantly decreased with increasing age and if you were female. Based on ethnicity, Chinese were significantly less likely to not attend appointments whereas the likelihood of non-attendance was significantly greater if African, Bengali and Pakistani. Interestingly, the Improvement and Development Agency report (IDA 2010) indicated that African, Bengali and Pakistani patients report worse health outcomes whereas Chinese people report better health than the white British population.

Geographic precision was achieved by examining the likelihood of attendance not only on a MSOA level but on a smaller scale by using LSOAs. During the period within which this audit was conducted, 80 percent of routine diabetes out-patient appointments were conducted at the Diabetes Unit which is in a community based facility. The diabetes unit is deemed to be centrally located and relatively accessible with reasonable public transportation (bus and underground) links to the location. However, the further away you move from the unit, the more difficult the journey. For patients who do not reside within close proximity to the location, transportation as well as the associated travel costs may have an impact on their ability or willingness to attend appointments. The results of demonstrated a significant difference in non-attendance rates for the diabetes unit and the other location where routine appointments were held (26 and 36 percent respectively). Accessibility of transportation has repeatedly been shown to be a rate limiting factor in the public's ability to access services. The relationship between "transport poverty" (affordability, availability and accessibility) and health has been explored by the institute of public health in Ireland (Kavanagh et al. 2005). It concluded that poor access to transportation increased social exclusion, reduced access to services and altered perceptions of services. Also, the impact of spatial decay has been demonstrated to be a barrier to attendance whereby the further away someone is from a service; the more likely they are not to attend (Dusheiko 2009). The relationship between the effort required, travel time and distance can impact on a person's willingness to attend appointments. For example: using a transport route planner to illustrate ease of access, a seven-mile journey via public transport from one of the geographic areas where patients were more likely to not attend to the diabetes unit can take more than an hour due to at least two bus changes and walking time. The effort required to utilise public transportation may therefore be a deterrent particularly for individuals who are employed and may have difficulty obtaining time off to attend appointments, those with young children and limited mobility (Salway 2007). The NHS London Reconfiguration Programme Guide (NHS London and TFL 2008) highlighted the need for a detailed travel time analysis to determine the potential effect of new or reconfigured sites on accessibility, both for existing populations and for future forecasts. It specified that the impact on patients, visitors and staff should be considered.

There is a wealth of evidence about the impact of ethnicity and deprivation on health inequalities and it is widely agreed that people living in the poorest and most deprived areas have the worst health and poorest outcomes (Post 2007, Salway 2007, DUK 2010). Deprivation and its associated factors such as unemployment, poor housing, and education have been shown to be significant determinants of health seeking behaviours of which non-attendance is a manifestation. It has been reported that in areas of deprivation, managing health becomes less of a priority due to competing socio-economic factors (Scheppers et al. 2006, Greenhalgh et al. 2011). This audit identified specific geographical areas with a significant likelihood of non- in relation to a larger geography (MSOAs) and smaller geography (LSOA). In the context of deprivation, the IMD scores for the sample population when compared to the UK indicated that 90% per cent were in the most deprived quintile and 10% in the fourth most deprived quintile. However, when the sample population was examined based on the borough's IMD scores, those who resided in the most deprived areas were significantly more likely to not attend appointments. Therefore, a plausible argument for non-attendance may be the compound effect of deprivation, the psychosocial impact of living with a long-term illness and accessibility of services (APPG 2006, Salway 2007).

Examination of deprivation on a LSOA level demonstrated that when factors such as age, gender and ethnicity were accounted for, in areas of the least levels of deprivation (quintiles 1 and 3), the likelihood of non-attendance was significantly lower in comparison to the most deprived area (quintile 5). However, interpretation of these finding should be done cautiously as factors such as proximity to the nearest clinic location, transportation access and the impact of co-morbidities are potential influencing factors. With multiple illnesses, attendance may be further influenced by either the individual's ability to access services due to restricted mobility, social isolation, psycho-social difficulties or their reliance on a carer. Examination of non-attendance on a LSOA level provides a foundation for further exploratory undertakings in an informed manner as specific areas of interest can be identified. Identification of these areas can inform both health and social care strategies aimed at reducing health disparities.

The limited scope of this audit is acknowledged as there may be several confounding variables which may only be ascertained by undertaking further research.

CONCLUSION

This audit highlighted the complexity of deconstructing the phenomenon of non-attendance particularly in areas of socio-economic deprivation.

Geo-demographic profiling utilising non-specialist methods was used as an explorative tool and provided a foundation for identifying trends in a geographical context. This is therefore a worthwhile approach as it can provide conclusive information based on real time data which can then be used as part of an approach for strategic healthcare planning and service delivery.

Using easily available analytical software (SPSS), the analysis demonstrated the relationship between geographical location and deprivation on non-attendance. This is a cost-effective approach that can be used to provide a foundation for not simply informing service re-design but a means of geographically identifying area that may require targeted approaches for health interventions. Due to the finite resources of the NHS, any remedial undertakings to improve the accuracy of health intelligence information would require innovation and greater multi-agency collaboration to reduce the cost burden of chronic illness.

The need for robust, accurate and up to date health intelligence information as a means of identifying and tackling health inequalities is required if the pervasive problem of non-attendance is to be effectively addressed. This approach has been advocated in recent research (Scheepers et al. 2006, Roos et al. 2010). Roos et al., highlighted that significant investment and organisational collaboration is required to enable such a strategy as it links an individual's area of residence to census and health data. A criticism of the UK with regards to data which is utilised to inform policy is that it is reliant on Census data which is only updated every ten years.

Overall, this study has provided a better understanding of the non-attendance trends of local diabetes out-patient service users at both a MSOA and LSOA level and in relation to demographic factors. These findings can be utilised to inform health strategies which are aimed at optimising access and utilisation of services by groups which may be defined as disengaged, hard to reach or marginalised.

Limitations:

Geo-demographic profiling is limited in the context of health intelligence as it does not answer questions such as why and how. Therefore, problems such as dis-engagement (non-attendance) should be examined within its broadest context (quantitative and/or qualitative).

This analysis was conducted using SPSS which is readily available and relatively inexpensive. However, it's use for in-depth geographic analyses is limited. Examination of factors such as spatial decay and its relationship with attendance would require specialist input and software. Within the NHS, specialist input usually requires commissioning and can be costly. Considering the current focus of efficiency savings within the NHS, a case can be made for closer clinical/academic collaborations as a means of undertaking specialist analyses in a cost-effective manner.

7.5 Chapter summary

This chapter detailed the form of artefact which was chosen for dissemination and included the steps which have been taken to disseminate findings of this thesis on an on-going basis.

CHAPTER 8

Thesis discussion

8.1 Introduction

This final chapter provides a review of key findings from the individual components (case study, literature review and research study) of this Doctoral thesis. This chapter will also review the recommendations that have been made.

8.2 Key findings: the case study

The case study was conducted during the period 2010 to 2011 and utilised a standard statistical software (SPSS) to perform the analysis. It is recognised that during this study, there has been an increasing use of specialist geographic mapping tools and techniques (heat maps, chloropeth maps and data visualisation) in the UK to evaluate health related data, particularly in public health departments. However, despite the lack of specialist tools and techniques, the software used, methods of analysis and results were robust.

The finding reported are relative to the time the analysis was undertaken however following a review of the host organisation in 2015 by the Care Quality Commission (CQC), the high rate of non-attendance and lack of a reduction strategy was highlighted. Subsequently, a report produced by the organisation’s public health department in July 2017 in response to the high non-attendance rates, demonstrated similar findings to those reported in this case study thereby validating the findings of the case study.

The conclusions drawn included the usefulness of data mining of routinely collected hospital episode data as a means of enhancing local health intelligence and informing strategic planning. Two key recommendations were the need for an in-depth geographical analysis to explore the influence of distance on access to services and a qualitative analysis of the factors which influence engagement. The need for a qualitative understanding was also highlighted in the organisation’s non-attendance report in 2017.

8.3 Key findings: the literature review

The literature review was first developed in February 2013 and proposed to examine public health strategies used to redress diabetes health disparities. However, based on emerging themes during the first stage of the research study which was undertaken during May to September 2013, the proposed topic was re-visited and modified. A review which focused on specific interventions aimed at improving patient engagement and outcomes was then developed and written in 2015/2016.

It is recognised that there is an increasing body of literature on the use of CHWs and Peer supporters in diabetes educational interventions which continue to report on their clinical effectiveness. However, the progress with studies evaluating their cost-effectiveness and sustainability has not matched that of clinical effectiveness studies.

The literature examined was heterogeneous in terms of study design, methods types of interventions and evaluation which makes drawing definitive conclusions difficult. However, despite the heterogeneity observed, the use of these interventions was evaluated to be clinically effective and cost-effective with varying degrees of significance. This is supported by a wide body of evidence which includes systematic reviews that has consistently concluded that CHW and Peer Support interventions are clinically and cost-effective in the short and medium term.

The usefulness and cost-effectiveness of CHW and Peer support initiatives was consistently demonstrated particularly in countries where healthcare and financial resources are scarce. These interventions have been gaining traction in resource rich countries however, a challenge continues to be the lack of integration into healthcare policy.

A recommendation posed by this review is the need for embedding these interventions into healthcare policy as a means of tackling health inequalities which is supported by recommendations in the wider body of literature.

8.4 Key findings: the research report

The findings of the case study informed the development of the research undertaken as the question of ‘why and how’ needed to be addressed. The research report was conducted in two stages at different time points. However, the overall aim of the combined research studies was to primarily explore the factors which influence engagement at diabetes out-patient services with the outcome measure being attendance.

The main conclusion from the combined studies was that individual and wider determinants of health are significant rate limiting factors in an individual’s willingness or ability to engage with diabetes out-patient services. In each research component, individual, organisational and structural determinants were identified as both enablers or barriers to engagement. In addition, an objective measure of empowerment was piloted (PAM) which demonstrated its predictive ability in the likelihood of engagement (attendance). Due to its predictive ability, a potential use may be its integration as a variable in predictive models used for maximisation of out-patient scheduling.

Key recommendations of the research include a more efficient alignment of health and social care, transformation and co-designing of services, use of innovation and technology to improve service delivery and improved community engagement.

Health inequalities have been described as pervasive, costly and difficult to fix. However, in the presence of a high burden of disease, deprivation and dis-engagement, there are significant clinical, financial and societal implications associated with inaction by all factions (individual, organisational and structural).

8.5 Relationship of findings to existing literature

A critical analysis of non-attendance that would provide greater insight into non-attendance to enable the development of non-attendance reduction strategies has been suggested (Heneghan et al., 2007).

This thesis adds to the body of knowledge concerning non-engagement through examining the problem of patient dis-engagement within diabetes services. It has been reported that local solutions are required to address health inequalities, and this begins with an evidence-based understanding of the problems. The comprehensive examination of engagement with services undertaken and reported in this thesis provides a holistic context which is mindful of both health inequalities and psychosocial frameworks. This thesis has demonstrated the influence of individual, organisational and structural influences on engagement and, as such, the findings have both clinical and policy implications.

The value of the trend analysis undertaken in the case study moves beyond the clinical context and extends to preventative public health due to its geo-demographic specificity. From an organisational perspective, the variable location-based attendance profile highlighted the need for service re-configuration which should be done in consultation with service users, local councils and transport organisations to ensure accessibility and acceptability of proposed changes.

The qualitative exploration of factors which influence engagement were consistent with existing literature with common barriers being language and literacy, family commitment, transportation access, cost of attendance, impact of social welfare changes, dissatisfaction with and inflexibility of services and enablers such as family support, effective education, confidence in specialists and fear of complications reported. Interestingly, this form of enquiry highlighted the complexity of the concept of ownership for one's health which was subsequently explored in the context of activation.

There is currently a paucity of UK specific literature around the use of the patient activated measure (PAM) questionnaire in relation to its clinical use and applicability in an out-patient settings. PAM was designed to assess a patient's activation/empowerment by measuring their knowledge, skills and confidence to self-manage. This multi-dimensional validated measure was chosen to objectively evaluate the relationship between activation and attendance. The results demonstrated a correlation between activation and attendance whereby individuals who were significantly less likely to attend appointments had lower levels of activation.

The PAM questionnaire as a standalone measure of empowerment was deemed to be limited in its clinical use as a patient specific context is required to maximise its interpretation. Logistic regression was undertaken to determine the predictive ability of PAM in relation to attendance and demonstrated that individuals who are more activated are significantly more likely to attend appointments. Based on the predictive ability of PAM, there may be an argument for the use of PAM assessment in referral pathways from primary care to secondary care services. PAM scoring could potentially be used as one of the predictive factor for out-patient predictive modelling programmes. Despite this evidence, of the predictive value of PAM, its clinical relevance and cost-effectiveness is subject to debate.

The increasing prevalence of diabetes globally is a public health concern (see chapter 1.3). Globally, health inequalities in diabetes are evident with significant variations in outcomes such as morbidity and mortality based on ethnicity and deprivation (UKPDS 1994, APPG 2006, Walker et al 2011). Health inequalities affect the poorest and most vulnerable and have been described as pervasive and difficult to shift. In the UK, reducing health inequalities, improving access to care and diabetes related outcomes are key elements of the National Service Framework (NSF) for Diabetes (DH 2001). This framework acts as a policy driver to improve diabetes services by setting standards aimed at improving quality and addressing variations in care.

Out-patient non-attendance is a characteristic of inequitable access to care and subsequent dis-engagement which is complex and multi-factorial and include factors such as the impact of the wider determinants of health, poor health literacy and disempowerment. Empirical evidence on diabetes non-attendance has consistently identified three core drivers of health inequalities which are individual, organisational and structural factors (see chapter 5.). A recurrent recommendation of studies is that a better understanding is needed about the reasons for non-attendance particularly in vulnerable or hard to reach groups (Dixon-Woods 2005, Akhter et al 2012).

8.6 Strengths and weaknesses

8.6.1 Case study

Use of real-time data is a valuable means of providing timely answers to problems identified. However, the analysis of any study utilising a database is constrained by the data, or lack of data and its accuracy.

During the data cleansing aspect of the case study, discrepancies were observed with factors such as nationality being recorded instead of ethnicity and missing or incomplete data such as postcodes or appointment outcome (attended or not-attended). Therefore, the data analysed is as accurate a representation as was feasible based on the data available. Despite these observations, a great strength of the case study is the granular evaluation of attendance based on factors such as service level delivery (locations and clinicians), geo-demography and deprivation.

An observation made whilst conducting the case study was the lack of an integrated data capture systems with stand-alone databases. To enable seamless and efficient analysis of hospital episode data, integrated IT systems would be beneficial. Integration of IT data systems may be a costly undertaking for NHS organisations but an exemplar of the effectiveness of integrated data capture systems has been demonstrated in Canadian literature (Cauch-Dudek et al., 2013). It highlighted that an information rich environment is essential as it provides real-time health intelligence information required to tackle health inequalities.

A useful finding, which has organisational relevance, was the non-attendance trends based on clinicians. A higher incidence of non-attendance was recorded for DSNs (26%) and dieticians (51%) in comparison to doctors (23%). This finding makes a case for the possibility of re-configuring some aspects of service delivery, for example, a combined dietician and DSN clinic.

8.6.2 Literature review

This was not a systematic literature review which would have a robust framework for its conduct. However, a critical narrative review was performed utilising systematic review guidance. A criticism of the CHW review is that most articles selected were from studies conducted in the USA which has a privatised healthcare model and as such, may not be representative of the wider body of literature. The peer support literature identified and selected was more geographically diverse, however, it was observed that several peer support studies selected for the review were funded by one organisation (Peers for Progress). This raises the issue of selection bias which influences the impartiality of the review conducted.

8.6.3 Research report

The initial research is particularly limited by sample size which impacts on its external generalisability which refers to conclusions that extend beyond the group, setting, time or context (Maxwell 1992). The focus of qualitative research is not generalisability of findings but it has been reported that generalisability should not be discounted as analytic generalisations can be made (Miles and Huberman 1994).

The data analysis was influenced by time due to delays in the research approval processes and funding specifications for which a submitted report at twelve months from the date of the award was the primary output. Funding is an important factor in undertaking some research activities, however, in this instance, the requirements of the funders had an impact on both the conduct and analysis of the initial qualitative study undertaken. Challenges such as funding, time constraints and accessing patients for recruitment, necessitated a pragmatic approach in relation to sample size and depth of qualitative analysis. However, Flick (2009) reported that “deviations from the maximum requirements of precision and completeness of such methods” (Flick 2009, p.

132) are deemed to be justifiable when a research question must be answered but there are funding and time constraints.

The second stage of the research used a validated questionnaire as the primary data collection method with three additional questions which aimed to assess the ease of attendance and reliance on others. On reflection, the additional questions could have been designed in a more probative manner to yield more informative information. The target recruitment was also not achieved due to time and resource constraints. However, as a pilot study, the sample size was assessed to be sufficient for analysis in addition to determining a post hoc sample size calculation which could inform future research undertakings.

The findings of the combined components of this thesis (case study, literature review and research study) provide evidence which can be used to support a chase for change with regards to non-attendance reduction strategies service re-design and redressing diabetes disparities. The influence and impact of the wider determinants of health and support (family and community) has been illustrated thus highlighting the need for greater community involvement, innovation and multi-agency collaboration as a means of minimising the phenomenon of dis-engagement as demonstrated by non-attendance. However, it is recognised that a rate limiting factor to change, may be the level of bureaucracy within organisations which is subject to influences such as political and policy decisions. It has been reported that bureaucracy within the NHS delays the extent of organisational collaborations and rate of progress (Fox et al., 2007).

8.7 Recommendations

The main recommendations of this thesis are structural cohesion and health and social care policy reform. Structural cohesion in this instance refers to factors such as transportation access, strategic planning and location of services. As illustrated in Barton and Grant’s (2006) health map for the local habitat (Chapter 4, figure 4.1), these factors are influenced by the macro economy and politics.

One major concern I have had whilst undertaking this thesis was the relevance of its findings upon completion given the pace at which changes occur within the NHS and the constant realignment of strategic priorities. In 2015, following the Care Quality Commission's review of the host NHS Trust, non-attendance reduction was identified as a strategic priority for the organisation (CQC 2015) thus endorsing the relevance of the undertakings of this thesis. In addition, it was stated in the summary report that*:*

"there was little evidence to demonstrate that information about the local population's needs was used to inform the planning and delivery of services and that the services provided did not reflect the need of the population served." (CQC, 2015)

The evidence provided in this thesis is of value to the host organisation and other healthcare organisations with a similar demographic and non-attendance profile to inform service re-design and population strategies.

8.8 Future plans

Non-attendance reduction strategies are a priority for the organisation where I am employed. A mapping exercise which evaluated non-attendance trends across the organisation based on geo-demography and deprivation was conducted which also demonstrated variations based on ethnicity, geographic location and deprivation which were representative of the findings of this thesis. A recommendation was made by the board that in addition to the quantitative findings, a qualitative understanding is required.

The findings of this thesis can contribute to baseline data to inform the organisation's non-attendance reduction strategies as well as provide the foundation for a comparative analysis over time. There is increasing interest in primary care and the work undertaken in this thesis has been used to provide guidance in the potential use of PAM in clinical settings in the community services.

This thesis has provided a foundation for future research undertakings such as a prospective clinical and cost-effectiveness evaluation of non-attendance and health outcomes. It is my intention to seek post-graduate funding to develop a research proposal to undertake an outcome study.

As a practitioner researcher, the scope for nursing specific research is evident from the qualitative findings. A significant and quantifiable disparity in attendance trends between doctors and specialist nurses was observed whereby patients would attend doctors' appointments more readily than specialist nurses' appointments. The specialist nurses' role was introduced to provide continuity and support for patients with specific conditions. The specialist nurse role has been reported as an invaluable component of clinical care and is an enabler to attendance by some interview participants. The observed disparity in non-attendance between doctors and nurses can in part be attributed to inefficient appointment scheduling however, this observation has the potential for future exploration to establish:

- What are patient's perceptions of the role and value of a specialist nurse?
- Does ethnicity or culture influence patients' perception of the role of the specialist nurse?

8.9 Reflections of a Practitioner researcher

It is recommended that a critical element of being a practitioner researcher is reflection and reflexivity. The process of reflection involves exploring and clarifying experiences to develop a new understanding whereas reflexivity involves understanding the relationship between your position as a researcher and how it affects outcomes (Fox et al., 2007). Undertaking this thesis has been a learning opportunity for a novice academic researcher.

I registered for the PhD in February of 2010 with a proposed completion of February 2017 (see Figure 1.1). This course of study was funded by the organisation with which I am employed and the timescale for completion was 1st February 2017. It was anticipated that this thesis would have been completed in the specified time however the ability to fulfil this requirement was influenced by multiple factors (single-handed working, major life crises and significant organisational change) which necessitated an extension of six months. The learning achieved during this course of study is identified and based on personal, professional and academic reflections.

8.9.1 Personal

The personal reflections relate to the emotional aspects of becoming an academic researcher and the acceptance of embracing uncertainty and change. Accepting that research requires flexibility and changes may occur in study design due to either unforeseen challenges or emerging evidence. Recognising the importance of self-determination and emotional resilience in the face of uncertainty and the efforts required to ensure a good work-life balance.

The decision to pursue this course of study was motivated by a longstanding interest in health inequalities and a desire to add to the body of knowledge about the influence of ethnicity and deprivation on diabetes outcomes. Having worked in clinical research for a significant period and more recently in clinical/academic projects which focused on diverse aspects of health improvement initiatives (clinical and organisational) my passion for exploring inequalities was re-ignited.

8.9.2 Professional

The professional reflections account for the impact of undertaking a professional doctorate as a lone worker.

The impact of being a lone worker and completing a PhD was under-estimated. My work schedule throughout this thesis was part-time (4 days per week) but being a lone researcher, a recurrent challenge was gaining a work/study balance. Prior to commencing this course of study, an informal agreement of having one day per week was proposed. However, this was not feasible in practice due to competing work priorities. Attempts to undertake additional training offered at the university proved difficult due to the course requirements and fixed day-time course modules which hindered my ability to attend.

Concerns related to my professional development and uncertainty about my career trajectory were at times demotivating factors. However, being a research student as opposed to a research enabler has enhanced my professional knowledge, skills and abilities. Despite the limitations of both phases of research, valuable learning was gained with regards to application for funding, research and ethical approval processes and the practicalities and challenges of conduction ‘own’ research.

8.9.3 Academic

The academic reflections include research learning, development of critical thinking, networking with specialists and the ability to access evidence.

New learning was gained through undertaking the critical review of literature and undertaking/evaluating a qualitative research project. Significant lessons learnt have been a greater understanding of and an appreciation for the research processes (funding, approvals and study deign). As a research nurse, my primary function is undertaking all aspects of research management for diabetes studies and ensuring compliance with all regulatory frameworks. By nature, the ethical and research and development processes are the responsibility of the principal investigator therefore I had no hands-on experience of undertaking these processes. These processes were time-consuming and at time arduous. Non-the-less, understanding the ethics and R&D processes and potential pitfalls gained during submission of stage one of the research element provided vital learning and made the second submission more seamless.

The scope for future research in two areas (organisational and nursing) has been identified.

8.10 Conclusion

The guidelines for submission of this type of Doctorate specifies that the thesis should contain one or more reflective accounts of case study work, a critical review of literature, a main research topic and a dissemination artefact and plan. Each of these components have been undertaken separately but have been written up cohesively as a whole. The primary aim of this thesis was to comprehensively evaluate the phenomenon of engagement of individuals with a healthcare service using non-attendance as the measure of engagement. This has been achieved through multiple methods of enquiry.

If engagement is better understood, more effective strategies can be designed which could help to minimise health disparities, improve health outcomes and lessen the significant burden of illness associated with diabetes.

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APPENDICES

APPENDIX 1

LBN MSOAs and local geographic locations

MSOA CODE	MAP LOCATION
E02000714	Newham 001
E02000715	Newham 002
E02000716	Newham 003
E02000717	Newham 004
E02000718	Newham 005
E02000719	Newham 006
E02000720	Newham 007
E02000721	Newham 008
E02000722	Newham 009
E02000723	Newham 010
E02000724	Newham 011
E02000725	Newham 012
E02000726	Newham 013
E02000727	Newham 014
E02000728	Newham 015
E02000729	Newham 016
E02000730	Newham 017
E02000731	Newham 018
E02000732	Newham 019
E02000733	Newham 020
E02000734	Newham 021
E02000735	Newham 022
E02000736	Newham 023
E02000737	Newham 024
E02000738	Newham 025
E02000739	Newham 026
E02000740	Newham 027
E02000741	Newham 028
E02000742	Newham 029
E02000743	Newham 030
E02000744	Newham 031
E02000745	Newham 032
E02000746	Newham 033
E0000747	Newham 034
E02000748	Newham 035
E02000749	Newham 036
E02000750	Newham 037

APPENDIX 2

Cross tabulation of geographic location and attendance

Question: No of appointments not attended			
Location	Percentage	Appointments per location (N=)	P value
1	26.2% (145)	554	<0.00
2	24.0% (283)	1178	
3	21.1% (19)	912	
4	25.0% (369)	1474	
5	25.4% (258)	1016	
6	26.5% (114)	431	
7	21.3% (118)	881	
8	25.0% (324)	1295	
9	23.1% (130)	562	
10	21.7% (578)	2668	
11	24.2% (372)	1536	
12	24.6% (79)	321	
13	24.6% (114)	464	
14	27.7% (291)	1052	
15	24.4% (307)	1260	
16	26.4% (212)	804	
17	25.0% (426)	1707	
18	25.0% (396)	1583	
19	24.2% (238)	984	
20	29.4% (288)	978	
21	23.6% (149)	631	
22	23.3% (211)	906	
23	26.9% (206)	767	
24	22.9% (226)	986	
25	24.6% (190)	773	
26	26.2% (168)	641	
27	25.4% (139)	547	
28	23.0% (162)	704	
29	24.8% (149)	602	
30	27.3% (121)	443	
31	25.5% (128)	502	
32	29.6% (149)	503	
33	31.0% (148)	478	
34	29.8% (142)	476	
35	31.1% (79)	354	
36	30.8% (154)	500	
37	28.0 % (130)	464	

APPENDIX 3

Logistic regression of geographic location and attendance

Variable (Geographic location)	Odds Ratio	95% CI Lower	 Upper	P value
37	1.0			
1	1.098	.832	1.449	.509
2	1.231	.966	1.569	.093
3	1.460	1.128	1.889	.004
4	1.166	.922	1.473	.200
5	1.144	.893	1.464	.287
6	1.082	.806	1.453	.599
7	1.435	1.107	1.859	.006
8	1.166	.919	1.481	.206
9	1.293	.976	1.715	.074
10	1.407	1.127	1.758	.003
11	1.218	.964	1.539	.098
12	1.192	.862	1.650	.289
13	1.195	.892	1.601	.233
14	1.018	.798	1.299	.887
15	1.208	.950	1.536	.122
16	1.087	.841	1.404	.524
17	1.170	.930	1.474	.181
18	1.167	.925	1.472	.193
19	1.220	.950	1.566	.119
20	.933	.730	1.191	.576
21	1.259	.958	1.655	.099
22	1.282	.994	1.654	.056
23	1.060	.819	1.372	.658
24	1.309	1.018	1.683	.036
25	1.194	.920	1.550	.182
26	1.096	.838	1.433	.504
27	1.142	.864	1.511	.350
28	1.302	.996	1.703	.054
29	1.183	.899	1.557	.229
30	1.036	.774	1.386	.813
31	1.137	.855	1.513	.377
32	.925	.700	1.222	.582
33	.868	.656	1.149	.322

34	.915	.690	1.214	.540
35	.862	.617	1.204	.384
36	.874	.662	1.154	.344

APPENDIX 4

Logistic regression of LSOAs and non-attendance

Variable		P value	Odds Ratio	95% Confidence Interval for Exp(B)	
				Lower Bound	Upper Bound
Not Attend	Intercept	.000			
	[LSOA=E01003479]	.069	.541	.279	1.050
	[LSOA=E01003480]	.315	.743	.417	1.326
	[LSOA=E01003481]	.438	1.311	.662	2.598
	[LSOA=E01003482]	.771	.918	.515	1.636
	[LSOA=E01003483]	.246	.711	.400	1.265
	[LSOA=E01003484]	.116	.613	.333	1.128
	[LSOA=E01003485]	.743	.897	.470	1.713
	[LSOA=E01003486]	.331	.773	.459	1.300
	[LSOA=E01003487]	.346	.756	.422	1.353
	[LSOA=E01003488]	.997	1.001	.621	1.612
	[LSOA=E01003489]	.335	1.310	.756	2.271
	[LSOA=E01003490]	.032	1.833	1.054	3.188
	[LSOA=E01003491]	.385	1.233	.769	1.980
	[LSOA=E01003492]	.601	1.153	.676	1.968
	[LSOA=E01003493]	.854	1.048	.635	1.731
	[LSOA=E01003494]	.978	.993	.596	1.655
	[LSOA=E01003495]	.461	1.226	.713	2.106
	[LSOA=E01003496]	.399	1.294	.711	2.355
	[LSOA=E01003497]	.462	.810	.462	1.421
	[LSOA=E01003498]	.170	.673	.382	1.186
	[LSOA=E01003499]	.702	1.110	.650	1.896
	[LSOA=E01003500]	.581	.849	.474	1.519
	[LSOA=E01003501]	.568	.849	.485	1.488
	[LSOA=E01003502]	.239	1.481	.771	2.848
	[LSOA=E01003503]	.017	.451	.235	.867
	[LSOA=E01003504]	.445	.810	.472	1.390
	[LSOA=E01003505]	.146	.569	.266	1.217

[LSOA=E01003506]	.541	1.234	.629	2.420
[LSOA=E01003507]	.990	1.003	.592	1.701
[LSOA=E01003508]	.206	.672	.362	1.244
[LSOA=E01003509]	.201	1.511	.803	2.844
[LSOA=E01003510]	.490	.814	.454	1.460
[LSOA=E01003511]	.734	.889	.451	1.753
[LSOA=E01003512]	.924	.971	.531	1.776
[LSOA=E01003513]	.074	.524	.258	1.064
[LSOA=E01003514]	.915	.969	.539	1.741
[LSOA=E01003515]	.050	.590	.348	1.001
[LSOA=E01003516]	.368	1.282	.747	2.200
[LSOA=E01003517]	.467	.800	.439	1.459
[LSOA=E01003518]	.094	.610	.341	1.089
[LSOA=E01003519]	.865	1.067	.506	2.249
[LSOA=E01003520]	.643	1.119	.697	1.797
[LSOA=E01003521]	.654	.899	.565	1.430
[LSOA=E01003522]	.574	1.146	.713	1.841
[LSOA=E01003523]	.472	.818	.473	1.415
[LSOA=E01003524]	.612	.885	.552	1.418
[LSOA=E01003525]	.265	1.333	.804	2.212
[LSOA=E01003526]	.893	.968	.600	1.562
[LSOA=E01003527]	.089	1.600	.931	2.750
[LSOA=E01003528]	.749	1.086	.655	1.800
[LSOA=E01003529]	.116	1.427	.916	2.223
[LSOA=E01003530]	.083	1.497	.949	2.362
[LSOA=E01003531]	.929	1.021	.645	1.615
[LSOA=E01003532]	.180	1.371	.864	2.174
[LSOA=E01003533]	.211	1.381	.833	2.290
[LSOA=E01003534]	.644	1.112	.709	1.746
[LSOA=E01003535]	.953	1.016	.605	1.706
[LSOA=E01003536]	.743	.910	.517	1.602
[LSOA=E01003537]	.506	1.185	.719	1.955
[LSOA=E01003538]	.850	1.052	.624	1.772

[LSOA=E01003539]	.230	.711	.407	1.241
[LSOA=E01003540]	.052	1.733	.996	3.018
[LSOA=E01003541]	.771	.918	.515	1.636
[LSOA=E01003542]	.843	1.053	.631	1.756
[LSOA=E01003543]	.350	1.287	.758	2.183
[LSOA=E01003544]	.035	.522	.286	.955
[LSOA=E01003545]	.616	1.185	.610	2.301
[LSOA=E01003546]	.821	.939	.544	1.622
[LSOA=E01003547]	.018	2.222	1.144	4.318
[LSOA=E01003548]	.532	1.244	.626	2.473
[LSOA=E01003549]	.987	1.004	.585	1.725
[LSOA=E01003550]	.548	1.189	.676	2.091
[LSOA=E01003551]	.368	1.313	.726	2.373
[LSOA=E01003552]	.572	.860	.511	1.449
[LSOA=E01003553]	.606	1.165	.653	2.079
[LSOA=E01003554]	.436	1.226	.734	2.050
[LSOA=E01003555]	.423	1.231	.741	2.045
[LSOA=E01003556]	.712	1.116	.624	1.994
[LSOA=E01003557]	.381	.782	.451	1.356
[LSOA=E01003558]	.432	.818	.496	1.349
[LSOA=E01003559]	.960	.985	.539	1.800
[LSOA=E01003560]	.119	1.485	.904	2.439
[LSOA=E01003561]	.644	1.118	.697	1.794
[LSOA=E01003562]	.849	.955	.595	1.533
[LSOA=E01003563]	.366	1.250	.771	2.025
[LSOA=E01003564]	.791	.935	.571	1.533
[LSOA=E01003565]	.938	1.019	.633	1.639
[LSOA=E01003566]	.292	.760	.457	1.266
[LSOA=E01003567]	.169	1.461	.851	2.507
[LSOA=E01003568]	.960	1.012	.638	1.605
[LSOA=E01003569]	.500	1.179	.731	1.902
[LSOA=E01003570]	.801	1.063	.663	1.703
[LSOA=E01003571]	.520	1.167	.729	1.869

[LSOA=E01003572]	.557	1.160	.707	1.903
[LSOA=E01003573]	.495	1.170	.745	1.840
[LSOA=E01003574]	.838	.954	.607	1.499
[LSOA=E01003575]	.238	1.343	.823	2.192
[LSOA=E01003576]	.775	.931	.572	1.516
[LSOA=E01003577]	.880	1.037	.646	1.665
[LSOA=E01003578]	.302	1.304	.788	2.156
[LSOA=E01003579]	.487	1.184	.736	1.904
[LSOA=E01003580]	.143	.679	.405	1.139
[LSOA=E01003581]	.975	.992	.621	1.586
[LSOA=E01003582]	.302	1.317	.781	2.222
[LSOA=E01003583]	.218	1.348	.838	2.168
[LSOA=E01003584]	.246	1.364	.807	2.306
[LSOA=E01003585]	.990	.997	.626	1.588
[LSOA=E01003586]	.012	2.015	1.165	3.483
[LSOA=E01003587]	.144	1.447	.882	2.374
[LSOA=E01003588]	.195	.728	.450	1.177
[LSOA=E01003589]	.994	.998	.631	1.579
[LSOA=E01003590]	.920	.975	.593	1.603
[LSOA=E01003591]	.577	.880	.561	1.380
[LSOA=E01003592]	.342	1.345	.730	2.479
[LSOA=E01003593]	.272	1.337	.796	2.245
[LSOA=E01003594]	.408	.798	.467	1.362
[LSOA=E01003595]	.348	.779	.463	1.311
[LSOA=E01003596]	.880	.961	.577	1.601
[LSOA=E01003597]	.271	1.314	.808	2.138
[LSOA=E01003598]	.649	1.149	.632	2.086
[LSOA=E01003599]	.804	1.067	.641	1.775
[LSOA=E01003600]	.373	1.258	.760	2.082
[LSOA=E01003601]	.742	1.099	.626	1.929
[LSOA=E01003602]	.062	1.659	.975	2.823
[LSOA=E01003603]	.594	1.149	.690	1.912
[LSOA=E01003604]	.744	1.096	.632	1.903

[LSOA=E01003605]	.528	1.183	.702	1.991
[LSOA=E01003606]	.696	1.106	.666	1.836
[LSOA=E01003607]	.566	.844	.474	1.504
[LSOA=E01003608]	.280	1.365	.776	2.401
[LSOA=E01003609]	.116	.658	.391	1.110
[LSOA=E01003610]	.467	.800	.439	1.459
[LSOA=E01003611]	.156	1.503	.856	2.636
[LSOA=E01003612]	.615	.837	.417	1.678
[LSOA=E01003613]	.900	1.036	.594	1.808
[LSOA=E01003614]	.119	2.133	.822	5.537
[LSOA=E01003615]	.577	1.181	.658	2.118
[LSOA=E01003616]	.830	.924	.450	1.898
[LSOA=E01003617]	.224	1.411	.810	2.460
[LSOA=E01003618]	.474	.774	.384	1.561
[LSOA=E01003619]	.755	.889	.424	1.862
[LSOA=E01003620]	.820	.940	.554	1.597
[LSOA=E01003621]	.593	1.167	.663	2.053
[LSOA=E01003622]	.683	.893	.520	1.536
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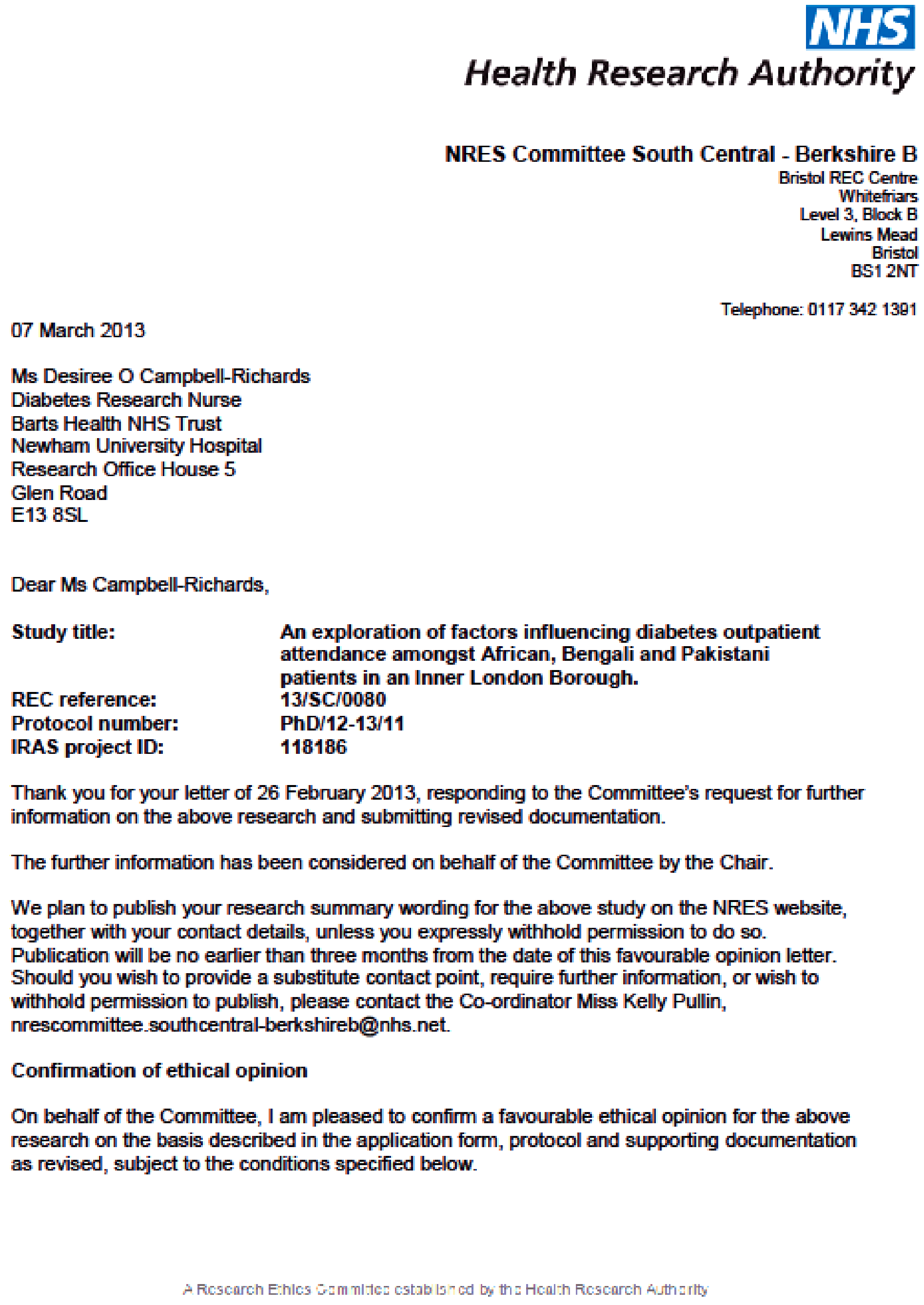
[LSOA=E01003637]	.	.	.	.

APPENDIX 5

Ethics approval letter Phase I



NHS
Health Research Authority

NRES Committee South Central - Berkshire B
Bristol REC Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1391

07 March 2013

Ms Desiree O Campbell-Richards
Diabetes Research Nurse
Barts Health NHS Trust
Newham University Hospital
Research Office House 5
Glen Road
E13 8SL

Dear Ms Campbell-Richards,

Study title: **An exploration of factors influencing diabetes outpatient attendance amongst African, Bengali and Pakistani patients in an Inner London Borough.**
REC reference: **13/SC/0080**
Protocol number: **PhD/12-13/11**
IRAS project ID: **118186**

Thank you for your letter of 26 February 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

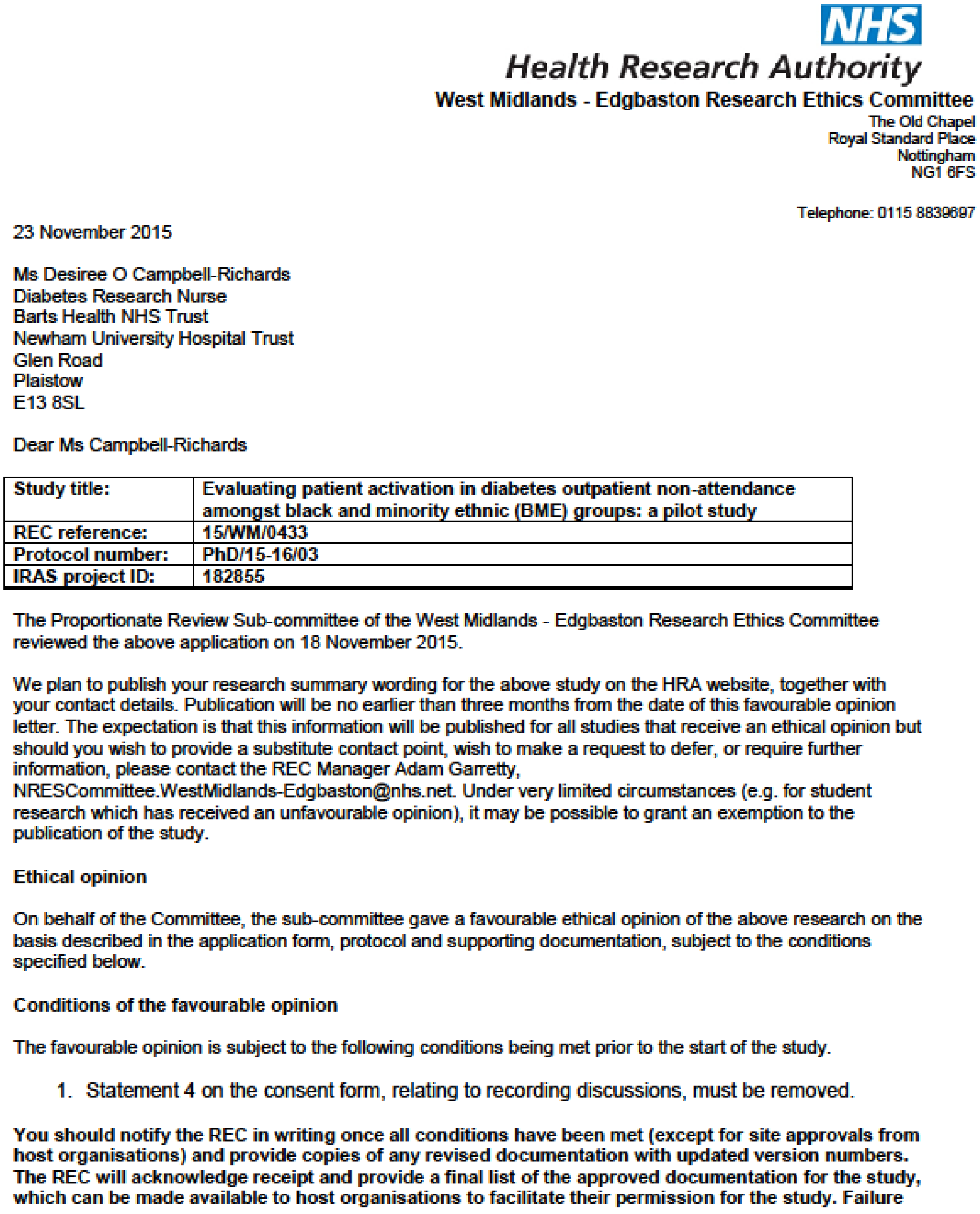
We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Kelly Pullin, nrescommittee.southcentral-berkshireb@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

APPENDIX 6

Ethics approval letter Phase II



NHS
Health Research Authority
West Midlands - Edgbaston Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839697

23 November 2015

Ms Desiree O Campbell-Richards
Diabetes Research Nurse
Barts Health NHS Trust
Newham University Hospital Trust
Glen Road
Plaistow
E13 8SL

Dear Ms Campbell-Richards

Study title:	**Evaluating patient activation in diabetes outpatient non-attendance amongst black and minority ethnic (BME) groups: a pilot study**
REC reference:	**15/WM/0433**
Protocol number:	**PhD/15-16/03**
IRAS project ID:	**182855**

The Proportionate Review Sub-committee of the West Midlands - Edgbaston Research Ethics Committee reviewed the above application on 18 November 2015.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Adam Garretty, NRESCommittee.WestMidlands-Edgbaston@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

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

Conditions of the favourable opinion

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

1. Statement 4 on the consent form, relating to recording discussions, must be removed.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure

APPENDIX 7

Focus group flyer

CITY UNIVERSITY LONDON

MARY SEACOLE

Barts Health NHS

NHS Trust

Get Involved
Diabetes Focus Groups

Have your say and play an active part in shaping your future diabetes services

You are invited to attend a focus group to look at your experiences of attending diabetes outpatient appointments

Date: June 17th (1:00 – 3:00pm)
Venue: Discussion Room 3
Newham University Hospital

To take part in this focus group, please contact:
Desirée Campbell-Richards on [redacted]

As a token of appreciation, you will be provided with a £10 voucher

Diabetes Department (Newham University Hospital)
Version 1: 16/01/13

APPENDIX 8

Focus group topic guide

CITY UNIVERSITY LONDON

MARY SEACOLE 1805-1881

Barts Health NHS Trust

Version 1 07.11.12

Topic guide for focus group participants

After explaining study, answering any questions, and gaining informed consent

1. Please tell me about your experience attending clinic appointments. How often do you attend?
2. How easy is it for you to get to your appointments?
3. How important is it for you to attend your appointments?
4. What do you expect from the diabetes service?
5. Do you have any thought on why people do not attend appointments?
6. What would you suggest as a solution to non-attendance?
7. Is there anything else you would like to tell me?
8. Is there anything you would like to ask me?

APPENDIX 9

Interview topic guide

CITY UNIVERSITY LONDON

MARY SEACOLE 1805–1881

Barts Health NHS
NHS Trust

Version 1 07.11.12

Topic guide for qualitative interview with participants

Date:
Time:
Ethnicity:
BHA:
Gender:
Category:

After explaining study, answering any questions, and gaining informed consent

1. How long have you had diabetes?
2. How often do you attend?
3. How easy is it for you to get to your appointments?
4. What if anything is likely to affect your ability to attend appointments?
5. Please tell me about your experience of attending appointments –
6. Do you think it's important you to attend your diabetes appointments?
7. Why do you think people don't attend appointments?
8. How can we encourage patients to attend?
9. Do you have any suggestions about how we can improve diabetes services?
10. Is there anything you would like to ask me?
11. Is there anything else you would like to tell me?

APPENDIX 10

Adapted health literacy screening questionnaire

Questions adapted from Health Literacy Screen Questions (Chew L. D. et al 2004)

1) How often are patient educational materials written in a way that is easy to read and understand?
   1) Always 2) Often 3) Sometimes 4) Occasionally 5) Never

2) How often are hospital or clinic signs difficult to understand?
   1) Always 2) Often 3) Sometimes 4) Occasionally 5) Never

3) How often are appointment letters difficult to understand?
   1) Always 2) Often 3) Sometimes 4) Occasionally 5) Never

4) How often do you have difficulty understanding written information your health care provider (like a doctor, nurse, nurse practitioner) gives you?
   1) Always 2) Often 3) Sometimes 4) Occasionally 5) Never

5) How often do you have problems getting to your clinic appointments at the right time because of difficulty understanding written instructions?
   1) Always 2) Often 3) Sometimes 4) Occasionally 5) Never

6) How often do you have problems learning about your medical condition because of difficulty understanding written information?
   1) Always 2) Often 3) Sometimes 4) Occasionally 5) Never

7) How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you to read hospital materials?
   1) Always 2) Often 3) Sometimes 4) Occasionally 5) Never

8) How often do you have problems getting to your clinic appointments because you depend on someone (family member, friend or caregiver) to take you?
   1) Always 2) Often 3) Sometimes 4) Occasionally 5) Never

APPENDIX 11

Published article of Phase I research study

[redacted]

APPENDIX 12

PAM questionnaire

[redacted]

APPENDIX 13

Health Foundation PAM seminar correspondence

From: Adrian Sieff [[redacted]]
Sent: 13 March 2015 17:25
Subject: Invitation: Judith Hibbard and Chris Delaney in conversation with the Patient Activation Measure Learning-set

Invitation: Judith Hibbard and Chris Delaney in conversation with the Patient Activation Measure Learning-set

The Health Foundation and NHS England are hosting a unique opportunity to learn about how the NHS is supporting patients with long term conditions. Patient Activation is the skills, confidence and knowledge a person has to manage their health and care. A learning-set of five CCGs and the renal registry is being supported and evaluated to understand how the measurement of Patient Activation can improve how health services can better support patients to manage their own health.

This event will see the learning-set present how they are using the Patient Activation Measure to Dr Judith Hibbard, who designed the Patient Activation Measure (PAM) and Chris Delaney, Chief Executive of Insignia Health, who own and support use of the PAM . Sites will have the opportunity to ask Judith questions about their work to date. Attendees will be able to observe the conversation and also be given the opportunity to ask questions of Judith, Chris and the learning-set.

The event will be held at the Health Foundation, 90 Long Acre, London, WC2E 9RA from 10.00am on Friday 10th April. A light lunch will be available at the end of the meeting.

We do hope that you will be able to join us. Please RSVP to [redacted] by Monday 23rd March.

Kind regards

Alf Collins

Clinical Associate

The Health Foundation

APPENDIX 14

Society for Academic Primary Care (SAPC) poster (2012) – Case study

Diabetes Outpatient Attendance

A Retrospective geo-demographic analysis

Desirée Campbell-Richards[1], Fiona Warburton[2]
(1) Newham University Hospital/City University, (2) Institute of Psychiatry, Kings College London

BACKGROUND

During the conduct of a diabetes research study at Newham University Hospital (2006-2009), a non-attendance rate of approximately forty percent was recorded. This high non-attendance rate was not isolated to research and was highlighted as a longstanding area of concern within the multi-disciplinary team. A retrospective audit of outpatient attendance was deemed to be appropriate in order to gain an insight into attendance trends as a means of informing and improving services delivered.

A survey commissioned by the local Primary Care Trust was conducted by IPSOS MORI in 2009 highlighted that poor engagement with services and lack of flexibility of services contributed to poor self management by patient with diabetes.

VITAL STATISTICS

London Borough of Newham

- 260, 000 population
- Second most diverse population in the UK (70% from Black and Minority Ethnic (BME) groups)
- 86% of residents live in areas classed amongst the fifth most deprived areas in England (Health Profiles 2010)
- 3rd highest estimated total diabetes prevalence in England(YHPHO 2010)
- High diabetes non-attendance (DNA) rates of 23 to 41 percent depending on age)
- Largest antenatal diabetes clinic in England

AIMS

- Explore attendance trends
- Explore attendance based on demographic characteristics
- Explore attendance in the context of local geography and deprivation

DATA

- Period Nov 2004 to March 2009
- 35997 diabetes outpatient appointments (Doctors, Specialist Nurses & Dietitians)
- Outcome - Attended or did not attend (DNA)
- Four clinic locations within the borough
- Age > 16 years
- Type 1, Type 2 and Gestational diabetes

DATA ANALYSIS

- SPSS Version 18
- Descriptive analysis to describe characteristics of participants
- Single and multivariable logistic regression

① Appointment profile 2004-2009

ATTENDANCE PROFILE 2004-2009
Clinic locations and services delivered

Clinic location	Services delivered	Clinicans
Shrewsbury	Routine appointments	Doctors, DSN
NUHT	Ante/Postnatal and inpatient appointments	Doctors, DSN, Dietician
Church Rd	Young adult appointments (≥ 16 years up to 25years)	DSN
Appleby	Routine appointments	DSN

② **ETHNICITY PROFILE**

Aggregated ethnicity 2004-2009

Category	Composition
White	White British, White Irish, Scottish, Welsh, Eastern European, White other
Black	African, Caribbean, Black British, Somali, Black other
Asian	Indian, Pakistani, Bangladeshi, Other Asian
Mixed	Black/White, Asian/White, Other Mixed
Other	Arab, Middle Eastern, Chinese, Vietnamese, Other,
Not stated	Not stated, Not asked and Refused

GEOGRAPHIC ATTENDANCE TRENDS 2004-2009
MVA (age, gender, ethnicity, geographic location)

Clinic locations (•)
Green areas – significantly more likely to attend (p<0.05)
Un-shaded areas – more likely to attend (p>0.1)
Red areas – more likely **not** to attend (p>0.1)

③ **Main Findings**

1. The likelihood of attendance significantly increased with age. Mean age: 54 years (SD 16 years)
2. Women comprised 56.2% of appointments and were significantly more likely to attend appointments than men.
3. No difference in attendance between white and mixed ethnicity.
4. Asian, Black, Other and unknown ethnicity were significantly less likely to attend appointments compared to whites.
5. Within individual groups; Pakistani, Bengali, African and other Black patients were significantly less likely to attend appointments than whites. However, Chinese patients were significantly more likely to attend than whites.
6. Geographic location of clinics and services were determinants of attendance. Patients were 3 times more likely to attend appointments at the local hospital and twice as likely at Shrewsbury Centre compared to Appleby Centre.
7. 5 of the 6 Mid Super Output Areas (MSOAs) where patients were less likely to attend appointments were located within the most deprived 5th of the local authority according to the Indices of Multiple Deprivation 2007

Conclusion

These findings are useful to inform strategies aimed at improving access and utilisation of services and reducing health inequalities.

Next Steps

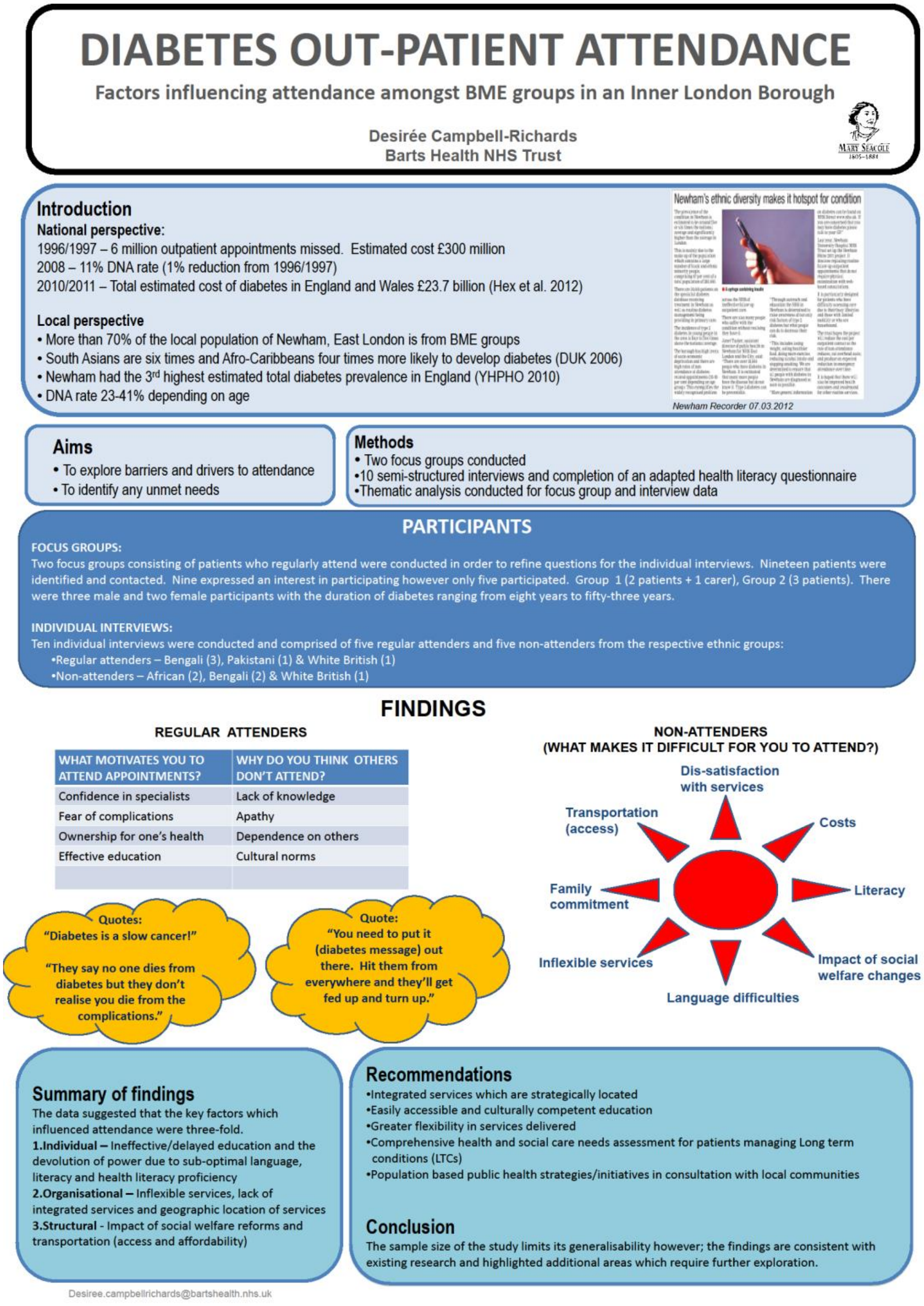
1. A qualitative study to explore Drivers and Barriers to diabetes outpatient attendance
2. An in depth geographical analysis to explore relationships between transportation and deprivation on attendance.

REFERENCES

Department for Communities and Local Government; The English Indices of Deprivation 2007
London Health Observatory (2010). Health Inequalities overview
Newham Joint Strategic Needs Assessment 2010; London Borough of Newham – Key Statistics
Yorkshire and Humber Public Health Observatory 2010; APHO diabetes prevalence model: Key findings for England

APPENDIX 15

Royal College of Nursing (RCN) poster (2014) – Phase 1



DIABETES OUT-PATIENT ATTENDANCE

Factors influencing attendance amongst BME groups in an Inner London Borough

Desirée Campbell-Richards
Barts Health NHS Trust

Introduction

National perspective:

1996/1997 – 6 million outpatient appointments missed. Estimated cost £300 million
2008 – 11% DNA rate (1% reduction from 1996/1997)
2010/2011 – Total estimated cost of diabetes in England and Wales £23.7 billion (Hex et al. 2012)

Local perspective

- More than 70% of the local population of Newham, East London is from BME groups
- South Asians are six times and Afro-Caribbeans four times more likely to develop diabetes (DUK 2006)
- Newham had the 3rd highest estimated total diabetes prevalence in England (YHPHO 2010)
- DNA rate 23-41% depending on age

Newham's ethnic diversity makes it hotspot for condition

Newham Recorder 07.03.2012

Aims

- To explore barriers and drivers to attendance
- To identify any unmet needs

Methods

- Two focus groups conducted
- 10 semi-structured interviews and completion of an adapted health literacy questionnaire
- Thematic analysis conducted for focus group and interview data

PARTICIPANTS

FOCUS GROUPS:

Two focus groups consisting of patients who regularly attend were conducted in order to refine questions for the individual interviews. Nineteen patients were identified and contacted. Nine expressed an interest in participating however only five participated. Group 1 (2 patients + 1 carer), Group 2 (3 patients). There were three male and two female participants with the duration of diabetes ranging from eight years to fifty-three years.

INDIVIDUAL INTERVIEWS:

Ten individual interviews were conducted and comprised of five regular attenders and five non-attenders from the respective ethnic groups:

- Regular attenders – Bengali (3), Pakistani (1) & White British (1)
- Non-attenders – African (2), Bengali (2) & White British (1)

FINDINGS

REGULAR ATTENDERS

WHAT MOTIVATES YOU TO ATTEND APPOINTMENTS?	WHY DO YOU THINK OTHERS DON'T ATTEND?
Confidence in specialists	Lack of knowledge
Fear of complications	Apathy
Ownership for one's health	Dependence on others
Effective education	Cultural norms

Quotes:
"Diabetes is a slow cancer!"

"They say no one dies from diabetes but they don't realise you die from the complications."

Quote:
"You need to put it (diabetes message) out there. Hit them from everywhere and they'll get fed up and turn up."

NON-ATTENDERS
(WHAT MAKES IT DIFFICULT FOR YOU TO ATTEND?)

- Dis-satisfaction with services
- Costs
- Literacy
- Impact of social welfare changes
- Language difficulties
- Inflexible services
- Family commitment
- Transportation (access)

Summary of findings

The data suggested that the key factors which influenced attendance were three-fold.

1.Individual – Ineffective/delayed education and the devolution of power due to sub-optimal language, literacy and health literacy proficiency

2.Organisational – Inflexible services, lack of integrated services and geographic location of services

3.Structural - Impact of social welfare reforms and transportation (access and affordability)

Recommendations

- Integrated services which are strategically located
- Easily accessible and culturally competent education
- Greater flexibility in services delivered
- Comprehensive health and social care needs assessment for patients managing Long term conditions (LTCs)
- Population based public health strategies/initiatives in consultation with local communities

Conclusion

The sample size of the study limits its generalisability however; the findings are consistent with existing research and highlighted additional areas which require further exploration.

Desiree.campbellrichards@bartshealth.nhs.uk

APPENDIX 16

Canadian Public Health Association (CPHA) Poster (2014) – Combined case study and Phase I

CITY UNIVERSITY LONDON


MARY SEACOLE 1805–1881

Barts Health NHS Trust

DIABETES OUT-PATIENT ATTENDANCE IN A DEPRIVED URBAN AREA:
a comprehensive evaluation

Desirée Campbell-Richards[1], Fiona Warburton[2]
[1]Barts Health NHS Trust/City University, [2]Institute of Psychiatry, Kings College London

BACKGROUND

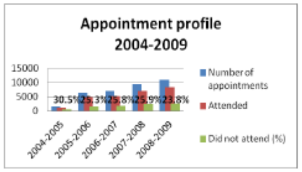
UK National perspective

The total estimated cost (direct/indirect) of diabetes in England and Wales has been reported as £23.7 billion (Hex et al., 2012). The estimated cost of non- attendance (DNA)at outpatient appointments in England (1996/1997) was £300 million. However in 2008 there was only a marginal reduction of 1% in non-attendance with a rate of 11%. Non-attendance poses a significant challenge for organisations and has a significant cost implications for health economies.

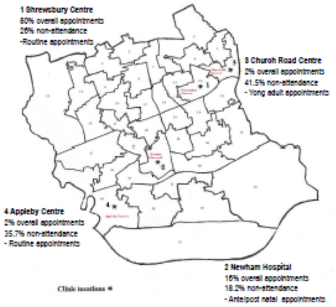
Local perspective (London Borough of Newham)

- More than 70% of the local population of Newham, East London is from black and minority ethnic (BME) groups
- Newham had the 3rd highest estimated total diabetes prevalence in England (YHPHO 2010)
- 86% of residents reside in the fifth most deprived areas in England (Health Profile 2010)
- DNA rate for diabetes services range between 23-41% depending on age
- Largest antenatal diabetes clinic in England

OVERVIEW OF ATTENDANCE



NON-ATTENDANCE PROFILE 2004-2009: Clinic locations



1 Shrewsbury Centre
80% overall appointments
26% non-attendance
-Routine appointments

3 Church Road Centre
2% overall appointments
41.5% non-attendance
- Yong adult appointments

4 Appleby Centre
2% overall appointments
35.7% non-attendance
- Routine appointments

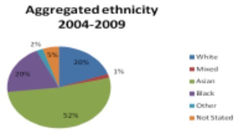
2 Newham Hospital
16% overall appointments
18.2% non-attendance
- Ante/post natal appointments

Clinic locations ✱

SAMPLE POPULATION

Gender – 56.2% female/43.8% male

Mean age – 64 years ± 16 years



Deprivation - Indices of Multiple Deprivation for England 2007

•90% of appointment were located in geographical areas in quintile 5 (most deprived) and 10 % in quintile 4 when compared to England
•Local deprivation profile calculated and categorised in quintiles

Percentage of appointments	Deprivation quintile	Deprivation ranking
8	1st (Q1)	Least deprived
27	2nd (Q2)	
43	3rd (Q3)	
17	4th (Q4)	
5	5th (Q4)	Most deprived

METHODS

Quantitative:

- 35897 diabetes out-patient appointments for doctors, specialist nurses and dietitian retrospectively analysed in SPSS using descriptive statistics and logistic regression (single and multivariate analysis)
- Analyses were conducted based on demographic characteristics, geographic location and deprivation profiles

Qualitative:

- Two focus groups and 10 semi-structured interviews were conducted and thematically analysed to:
  - Explore barriers and drivers to attendence
  - Identify any unmet needs

PARTICIPANTS

FOCUS GROUPS:

Two focus groups consisting of patients who regularly attend were conducted in order to refine questions for the individual interviews. Nineteen patients were identified and contacted. Nine expressed an interest in participating however only five participated. Group 1 (2 patients + 1 carer), Group 2 (3 patients). There were three male and two female participants with the duration of diabetes ranging from eight years to fifty-three years.

INDIVIDUAL INTERVIEWS:

Ten individual interviews were conducted and comprised of five regular attendees and five non-attendees from specifically chosen ethnic groups:

•Regular attendees – Bengali (3), Pakistani (1) & White British (1)
•Non-attendees – African (2), Bengali (2) & White British (1)

QUANTITATIVE RESULTS

Non-attendance rates

- The average yearly DNA rate of 25 percent was significantly higher than the national average of 11 percent
- DNA rates were significantly variable depending on the clinician ($p<0.001$)
  - Doctor DNA rates – 23 percent
  - Diabetes Specialist Nurses DNA rates – 25 percent
  - Dietician DNA rates – 51 percent

Demographics

- The likelihood of non-attendance significantly decreases with age (OR <1)
- Women were significantly less likely to DNA appointments than men ($p<0.001$)
- Ethnicity was observed to be a significant determinant of attendance both across and within ethnic categories

Across ethnic categories (8 categories) – Office of National Statistics 2004

- No significant difference in DNA was observed between White and Mixed ethnicity
- Asian, Black, Other and unknown ethnicities were significantly more likely to DNA appointments in comparison to White ($p<0.05$)

Within ethnic categories (17 categories) – Office of National Statistics 2004

- Pakistani and Bangladeshi patients were significantly more likely to DNA appointments than Indians
- African patients were significantly more likely to DNA appointments than Caribbean
- Chinese patients were significantly less likely to DNA appointments within the category Other

Geography

- The geographic location of clinics was a significant determinant of attendance ($p<0.001$)
- Patients were significantly less likely to DNA appointments at clinic location 2 than clinic location 4
- Patients were significantly less likely to DNA appointments at clinic location 1 in comparison to clinic location 4
- No significant difference was observed in attendance between clinic locations 3 and 4

Deprivation

Local deprivation was shown to be a determinant of attendance with variations both across and within geographical areas. Geographical areas are defined based on mid layer super output areas (2000 households) and lower layer super output areas (400)

- MSAO (37 geographically defined areas)
  - Patients residing in four of the least deprived MSOAs were significantly less likely to DNA appointments ($p < 0.05$)
- LSOA (159 geographically defined areas within MSOAs)
  - Patients residing in the least deprived (Q1) and in areas of average deprivation (Q3) were significantly less likely to DNA appointments than those in the most deprived areas (Q5) ($p<.005$)

QUALITATIVE FINDINGS

REGULAR ATTENDEES

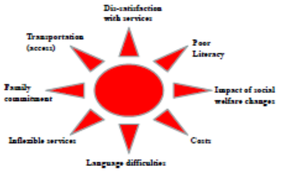
WHAT MOTIVATES YOU TO ATTEND APPOINTMENTS?	WHY DO YOU THINK OTHERS DON'T ATTEND?
Confidence in specialists	Lack of knowledge
Fear of complications	Apathy
Ownership for one's health	Dependence on others
Effective education	Cultural norms

Quotes:
"Diabetes is a slow cancer!"

"They (patients) say no one dies from diabetes but they don't realise you die from the complications."

Quote:
"You need to put it (diabetes message) out there. Hit them from everywhere and they'll get fed up and turn up."

NON-ATTENDEES
(WHAT MAKES IT DIFFICULT FOR YOU TO ATTEND APPOINTMENTS?)



CONCLUSIONS

Non-attendance at diabetes services is a complex phenomena which requires:

- Flexible and innovative models of healthcare delivery
- Integrated and strategically located services
- Easily accessible and culturally competent education
- Population based public health strategies/initiatives done in consultation with local communities
- Comprehensive health and social care needs assessment for patients managing long term conditions (LTC)

Acknowledgement
Funded in part by the Department of Health (Mary Seacole Development award 2012/2013)

For additional information please contact:
Desirée Campbell-Richards: Desiree.campbellrichards@bartshealth.nhs.uk