

Socioeconomic factors influencing equitable access to intensive insulin regimens for adults with type 1 diabetes

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Glossary

Diabetic Ketoacidosis A potentially life-threatening condition resulting from a lack of insulin

Diabetic Nephropathy A long-term complication of diabetes that may result in end stage renal failure

Diabetic Neuropathy A long-term complication of diabetes that causes damage to the peripheral nerves and commonly affects the feet

Diabetic Retinopathy A long-term complication of diabetes affecting the eyes that may result in blindness

HbA1c A measure of average glycaemia over 2 to 3 months

Hyperglycaemia Elevated blood glucose levels

Hypoglycaemia Abnormally low blood glucose levels

Insulin A hormone released into the blood in order to reduce blood glucose to normal levels.

Insulin Regimen Treatment involving an insulin pump or one or more daily injections

Type 1 Diabetes A disease caused by the destruction of β -cells in the pancreatic islets of Langerhans resulting in the loss of insulin production. Insulin replacement therapy is required for survival.

Type 2 Diabetes A progressive disease due to insulin resistance and or decline in insulin secretion.

Abbreviations

CAQDAS	Computer Assisted Qualitative Data Analysis Software
CGMS	Continuous Glucose Monitoring System
CSII	Continuous Subcutaneous Insulin Infusion
DAFNE	Dose Adjustment for Normal Eating
DH	Department of Health
DKA	Diabetic Ketoacidosis
GP	General Practitioner
HbA1c	Haemoglobin A1c
IDDM	Insulin Dependent Diabetes Mellitus
IIR	Intensive Insulin Regimen
MDI	Multiple Daily Injections

NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NS-SEC	National Statistics – Socioeconomic Class
PPI	Patient and Public Involvement
QOF	Quality and Outcomes Framework
ScHARR	School of Health and Related Research
SES	Socioeconomic Status
SMBG	Self-Monitoring of Blood Glucose
TAR	Tape-Assisted Recall
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Abstract

Introduction

Type 1 diabetes is a chronic condition in which self-care is critical to successful outcomes. Intensive insulin regimens can reduce morbidity and mortality associated with the condition. However, socioeconomic inequalities have been demonstrated in both access to treatment and health outcomes for adults with the disease. This study investigates how socioeconomic factors influence access to intensive regimens.

Methods

A qualitative study of a specialist diabetes service was undertaken. Interviews with 28 patients and 6 health care professionals explored factors influencing equity in gaining access to an intensive regimen. Conversation analysis of 25 consultations between patients and specialists explored factors influencing equity in maintaining access. Analysis was framed using the Candidacy theory for access to health care for vulnerable groups.

Findings

Gaining access to intensive regimens was dependent on accessing specialist services. Disparities in the utilisation of specialist services appeared to relate to the permeability of these services, personal social circumstances (low paid work and transport difficulties) and the variable ability of patients to navigate the health care system. Factors diminishing candidacy for intensive regimens were low health literacy, non-alignment with health care professional goals, psychosocial problems and poor quality patient-provider communication. Conversation analysis identified that patient involvement with health care professionals was important for maintaining access. In this sample, 'low involvement' patients were at risk of losing access and were from lower socioeconomic groups. Some barriers to access were modifiable through contact with diabetes specialist nurses, a Structured Education Programme and continuity of care with specialists.

Discussion

Equitable access to intensive regimens was impeded for people from lower socioeconomic groups by a complex mix of factors relating to the permeability of specialist services and patient interactions with health care providers. Efforts to facilitate access to specialist services and to improve the quality of communication could lessen inequities in access to intensive regimens.

Chapter 1. Introduction

1.1 Rationale for the Study

The NHS faces enormous challenges with an ageing population and the increasing prevalence of chronic disease (Liddell et al. 2008). Patient involvement in self-care has been promoted by successive governments and is seen as the optimum way for chronic illness to be managed (Department of Health 2005). Increasingly technology is being incorporated into health care in chronic illness. However, although the use of technology has the potential to counter the increasing demographic burden on NHS resources and the importance of technology in improving health outcomes is acknowledged, it is known that the adoption of health care technology in the NHS is 'often slow and disparate' (Liddell et al. 2008, p. 2).

This thesis focuses on type 1 diabetes as an example of a chronic disease with several treatment options involving technology. In recent years there has been a growth in the use of insulin pumps for the treatment of type 1 diabetes (White et al. 2014). However, the UK lags behind other countries in the use of insulin pumps (White et al. 2014) and concerns have been expressed that patients experience a 'postcode lottery' in terms of access to the technology (Diabetes UK 2011a). Insulin pump technology is more expensive than multiple daily injection therapy (Cummins et al. 2010) and is subject to restrictions on allocation in the NHS (National Institute for Health and Care Excellence 2008).

It appears that issues relating to the allocation of insulin pump technology may be compounded by socioeconomic disparities in access to intensive insulin regimens (IIRs) (see systematic review, Chapter 3). The current study was prompted by a need to ask how and why these disparities might occur. Although initially envisaged as a study aiming to investigate accessibility of insulin pump technology for disadvantaged groups, the primary research was widened to include access to multiple daily injections, based on carbohydrate counting, since both types of regimen offer better health outcomes (DCCT Research Group 1989).

In order to investigate equitable access to an IIR this study combines three areas of research: first, inequalities and equitable access to health care; second, treatment decision-making in relation to an IIR in type 1 diabetes; and finally, the use of technology in chronic disease. The justification for taking this approach was that:

- Type 1 diabetes is a chronic disease in which self-management involving technology is a crucial influence on health outcomes.
- Socioeconomic inequalities in health outcomes persist in adults with type 1 diabetes.
- Access to health care is crucial; however, it is subject to socioeconomic disparities.

1.1.1 Self-Management in Type 1 Diabetes

Type 1 diabetes is a chronic disease in which self-care is critical to successful outcomes (DAFNE Study Group 2002). Central to the management of type 1 diabetes is control of blood glucose levels and adults are advised to maintain their HbA1c within a range consistent with minimising the long term complications of diabetes (National Institute for Health and Care Excellence 2015)¹. Technology supporting diabetes self-management comprises methods of insulin delivery and also equipment to check blood glucose levels. Despite the progress in new forms of technology to treat type 1 diabetes there has not been a commensurate improvement in outcomes (Barnard 2012). Although IIRs offer better health outcomes (DCCT Research Group 1989), it is also known that there are socioeconomic disparities in the uptake of these more complicated regimens (Mühlhauser et al. 1998).

The aim of the current research was to investigate socioeconomic disparities in access to IIRs for adults with type 1 diabetes. Although other inequities such as those relating to race/ethnicity, gender and age are important areas to research, this thesis focuses on socioeconomic inequity.

1.1.2 Inequalities in Health Outcomes in Type 1 Diabetes

This thesis documents evidence of the persistence of socioeconomic inequalities in health outcomes, including: mortality and morbidity; diabetes management; and access to health care, diabetes education and an IIR (see Chapter 3). Socioeconomic inequalities relate to the systematic differences in health outcomes experienced by the affluent in society compared with the less well off (Marmot 2010; Townsend et al. 1988a; Whitehead 1988). Although acknowledged as high profile targets of health care policy, socioeconomic inequalities have proved consistently difficult to eliminate in England's NHS (National Audit Office 2010). It has been postulated that socioeconomic inequalities in health outcomes for individuals with

¹ NICE guideline CG15 was current during the study (National Institute for Health and Care Excellence 2004) but has since been superseded by NICE guideline NG17 (National Institute for Health and Care Excellence 2015).

diabetes may be a result of one or more of the following: the effects of deprivation impacting on health outcomes; the health care behaviours of low socioeconomic status individuals; or poorer access to health care by those in greatest need (the 'Inverse Care Law' (Tudor Hart 1971)) (Edwards et al. 2003).

1.1.3 The Importance of Access to Health Care for Adults with Type 1 Diabetes

Access to health care is one influence amongst many other determinants of health outcomes (National Audit Office 2010) and therefore has the potential both to enable treatment and improve health (Gulliford 2003). Preventive health care is of paramount importance in minimising the onset of diabetes complications (Zgibor et al. 2001) and successful partnerships between patients and health care professionals are essential if improvements in health outcomes are to be achieved for people with diabetes (Health and Social Care Information Centre 2013). This thesis explores the reasons for inequitable access to an IIR for adults with type 1 diabetes since underlying socioeconomic inequalities in health status may be ameliorated by access to good quality care (Büz et al. 2012).

Equitable access to health care has been a goal of the NHS since its establishment in 1948 and remains a stated priority by successive governments. However, it remains difficult to assess the extent of potential inequities (Goddard et al. 2001). This is partly due to the difficulties relating to the concept of access (Gulliford et al. 2003). The complexity of issues related to access to health care and equitable access to health care are a central part of this thesis and the relevant literature is presented in Chapter 3.

1.1.4 Treatment Decision-making in Adults with Type 1 Diabetes

Self-care in type 1 diabetes requires individuals with the condition to be constantly vigilant to ensure that their blood glucose levels neither drop too low (hypoglycaemia) nor are raised too high (hyperglycaemia). The adoption of intensive regimens involving frequent blood glucose testing and insulin injections may assist individuals to achieve near normal blood glucose levels (DCCT Research Group 1989).

In contrast to multiple daily injection therapy, insulin pumps are subject to restrictions in terms of eligibility (National Institute for Health and Care Excellence 2008). This is despite their growing popularity (Diabetes UK 2011a) and the known advantages for some patients who use them (Misso et al. 2010). In principle there are guidelines for the allocation of particular regimens (National Institute for Health and Care Excellence 2015). In practice, however, there

is a lack of evidence on how decisions are made regarding the choice of treatment regimens incorporating technology and the respective parts played by individuals with type 1 diabetes and health care professionals involved in their care. For type 1 diabetes, guidelines are used to determine patient suitability for insulin pumps (National Institute for Health and Care Excellence 2008). However, health care professionals also play a key role in selecting patients for this technology. There is a lack of research addressing what is involved in this decision-making process and how individuals are selected for this technology. One of the objectives of the current research was to investigate the role and influence of health care encounters in relation to these decisions.

Adults with type 1 diabetes

Insulin pumps are used by both adults and children in the UK and researching equity of access is equally important in both. Although some quantitative research has been conducted in the USA investigating socioeconomic disparities in access to insulin pump therapy for children (Cortina et al. 2010; Wood et al. 2013), to my knowledge no research has been carried out for adults with type 1 diabetes in the UK investigating socioeconomic disparities. This study focused on adults in order to address this gap in the research.

1.2 Research Question

In order that future self-care technologies can optimise health care outcomes for all groups in society, research is required that examines how regimen candidacy decisions are reached and the influencing factors from both the patient and the health care professional perspective. The majority of research reviewed in Chapter 3 relating to socioeconomic inequalities in health outcomes and disparities in access to health care in type 1 diabetes was quantitative and there was a lack of research explaining how and why individuals access an IIR. The current study addressed this gap in the research by exploring the perspectives of both patients and health care professionals on the factors involved in accessing an IIR.

1.3 Methods

Qualitative methods were chosen to explore the socioeconomic factors influencing equitable access to an IIR. The primary focus of the study was a specialist service situated in secondary care. This was supplemented with the perspectives of a small sample of patients and health care professionals in primary care. Qualitative interviews with 28 patients and 6 health care professionals explored factors influencing equity in gaining access to an IIR. Conversation

analysis of 25 consultations between patients and specialists explored factors influencing equity in maintaining access. Analysis was framed using the Candidacy theory for access to health care for vulnerable groups (Dixon-Woods et al. 2005; Dixon-Woods et al. 2006). The term ‘vulnerable groups’, used throughout this thesis, is synonymous with socioeconomically disadvantaged people (Dixon-Woods et al. 2006).

1.4 Thesis Structure

Chapter 2 provides the background to type 1 diabetes and its treatment. Chapter 3 provides a review of three main bodies of literature relevant to the thesis. First, a systematic review of the evidence of associations of socioeconomic status with health outcomes and diabetes management for adults with type 1 diabetes is presented. This reveals that whilst socioeconomic inequalities persist there is a paucity of research explaining the causal pathways. Second, the wider literature on access to health care is reviewed in order to gain a better understanding of the issues involved in inequitable access. Finally, a review of the literature on patient-provider communication relating to the thesis is presented. Overall the review identifies a lack of research relating to the decision-making processes involved in the adoption of an IIR from the perspective of equitable access. Following the review the chapter concludes with the thesis aims and objectives.

Chapter 4 addresses the rationale for the methods adopted in the study and provides details of the approach to sample selection, recruitment, data collection, and data analysis. This chapter describes how Candidacy theory (Dixon-Woods et al. 2005; Dixon-Woods et al. 2006) was used to frame the findings. The researcher’s ontological stance as a subtle realist is also outlined in this chapter. Chapter 5 presents the findings of the interviews with patients and health care professionals in relation to accessing an IIR. Chapter 6 focuses on the findings in relation to maintaining access to an IIR using the techniques of conversation analysis. Chapter 7 draws together the findings presented in Chapters 5 and 6 and these are discussed within a framework of equitable access to health care. The thesis concludes with: reflections on the strengths and limitations of the study; implications for policy and practice; and finally recommendations for future research.

Chapter 2. Background

2.1 Diabetes

Diabetes is a complex chronic condition with profound implications in terms of health impact and treatment on the lives of those with the condition and their families (Weinger et al. 2009). Global prevalence is increasing with an expectation that by 2030 numbers will approach 366 million (Wild et al. 2004; World Health Organisation et al. 2006). In 2008, 2.1 million individuals in England (4.1%) were registered with diabetes. However estimates put the true prevalence closer to 3.1 million, or 7.4% of the population aged 16 and over (Holman et al. 2011). Type 1 diabetes, formerly known as insulin-dependent diabetes mellitus (IDDM) or juvenile onset diabetes, accounts for approximately 5-10% of cases (American Diabetic Association 2010) and is estimated to affect over 370,000 adults in the UK (National Institute for Health and Care Excellence 2015).

2.1.1 The Financial Costs of Diabetes Incurred by the NHS

Direct costs associated with diabetes are estimated to comprise 9% of the total NHS budget (Krentz et al. 2005), whereas inpatient costs are estimated to be 10% of the total budget (Department of Health et al. 2002). Prescriptions related to diabetes are increasing in both volume and cost and represent the highest single expenditure within the NHS prescribing budget (The Information Centre et al. 2007). The costs of medication for type 1 diabetes are difficult to extricate since insulin is prescribed to some individuals with type 2 diabetes.

2.1.2 The Impact of Complications for Individuals with Diabetes

Individuals with diabetes have reduced average life expectancy due to microvascular and macrovascular complications (Department of Health et al. 2002). In England, end stage renal failure arising from type 1 diabetes increased between 2003-04 to 2008-09 (from 0.78% to 1.27%) implying that approximately 2500 individuals with the condition require transplants or renal dialysis (The Information Centre for Health and Social Care 2010). Additionally the percentage of people with type 1 diabetes experiencing an episode of Diabetic Ketoacidosis (DKA) in England increased by 10% over five years from 2003-04 (The Information Centre for Health and Social Care 2010) .

2.2 Type 1 and Type 2 Diabetes

The aetiology and natural history of type 1 diabetes is very different from type 2 diabetes. Table 2.1 provides the contrasting characteristics of type 1 and type 2 diabetes. Type 1 diabetes arises because of β -cell destruction in the pancreas determined by a combination of genetic and environmental factors. These cells produce a hormone, insulin, which regulates blood glucose levels. Since production of insulin is in very small quantities or not all, these patients require lifelong treatment with insulin (National Institute for Health and Care Excellence 2008). Onset of type 1 diabetes is generally before the age of forty (National Audit Office 2012) and most often in childhood, teenage years or early adulthood (Department of Health 2001). Although insulin is always a necessary treatment in Type 1 diabetes, it may also become necessary for individuals with type 2 diabetes if medication fails to control the condition.

Table 2.1 Different characteristics of type 1 and type 2 diabetes (Watkins 2003)

Type 1 diabetes	Type 2 diabetes
Incidence and causes	
<ul style="list-style-type: none"> • Peak incidence is between 10-12 years • Small male predominance • Occurs under 40 years of age in approximately 70% of cases 	<ul style="list-style-type: none"> • Most common between 50-70 years of age • Both sexes affected equally • Some children have type 2 diabetes
<ul style="list-style-type: none"> • Loss of insulin production • Destruction of islet β -cells 	<ul style="list-style-type: none"> • Decreasing insulin secretion or increasing insulin resistance
Risk factors	
<ul style="list-style-type: none"> • A combination of environmental and genetic factors trigger an autoimmune attack on β-cells in the pancreas leading to a loss of insulin production 	<ul style="list-style-type: none"> • Obese individuals • People over the age of 40 • Asian or African-Caribbean ethnic origin • Family history of diabetes • History of gestational diabetes • History of a large baby (birth weight > 4kg)
Treatment	
<ul style="list-style-type: none"> • Insulin in conjunction with diet and exercise 	<ul style="list-style-type: none"> • Diet and exercise • Oral hypoglycaemic agents (OGLAs) if diet and exercise has failed • Insulin if OGLAs fail to achieve control

2.3 Treatment Objectives in Type 1 Diabetes

NICE recommends treatment focusing on the management of blood glucose levels to prevent both short- and long-term complications (National Institute for Health and Care Excellence 2015). This involves technologies for insulin delivery and self-monitoring of blood glucose (SMBG) levels. Treatment for type 1 diabetes includes the following: 1, 2 or 3 daily (insulin) injections; multiple daily injections (MDI); or continuous subcutaneous insulin infusion (CSII), also known as insulin pump therapy. This follows the NICE guideline CG15 which was current during the study (National Institute for Health and Care Excellence 2004) but has since been superseded by NICE guideline NG17 (National Institute for Health and Care Excellence 2015)². Two key changes in the guidelines are that:

- Multiple daily injections have replaced twice daily injections as the treatment of choice and newly diagnosed adults with type 1 diabetes should not be offered non-basal-bolus regimens
- Patients are now advised to aim for a target HbA1c level at least as low as 48 mmol/mol (6.5%) (the previous target was 58 mmol/mol (7.5%)).

Current policy focuses on assisting individuals in self-managing their chronic conditions (Department of Health 2009; Diabetes UK 2009). However, despite the known benefits of tight glycaemic control (DCCT Research Group 1989) a recent audit in England found that less than 25% of individuals with diabetes (type 1 and type 2) reached the treatment standards required to minimise long term complications of the disease (National Audit Office 2012).

A key objective in the treatment of type 1 diabetes comprises efforts to control blood glucose levels (Krentz et al. 2005). Control in this context means preventing blood glucose levels that are too low (hypoglycaemia) or too high (hyperglycaemia). Haemoglobin A1c (HbA1c) levels are used to assess average glycaemia over a period of two to three months (National Institute for Health and Care Excellence 2009b). Evidence for the effectiveness of controlling HbA1c to prevent long term complications comes from the Diabetes and Complications Trial Research Group (DCCT Research Group 1989). In the long-term, consistently high levels of blood glucose leads to macrovascular and microvascular complications. These include retinopathy, neuropathy, nephropathy, myocardial infarction and stroke. Short-term problems arising from

² It should be noted that whilst this latest guidance is referred to, the study was undertaken when the previous guidance prevailed.

low blood glucose levels include hypoglycaemia and diabetic ketoacidosis. Diabetic ketoacidosis is a result of insufficient insulin and may be life threatening (Cummins et al. 2010). Symptoms of hypoglycaemia include sweating and a feeling of hunger which if uncorrected can lead to behavioural disturbances, unconsciousness or ultimately death (Cummins et al. 2010). Repeated hypoglycaemic events can result in cognitive impairment in young children due to brain cell damage through lack of glucose (Cummins et al. 2010).

Treatment of type 1 diabetes is therefore a complex mix of measures to prevent short- and long-term complications and includes attention to blood pressure and lipid levels as well as measures to control blood glucose. This is a challenge for both health care professionals and patients. It is increasingly understood that diabetes self-management is crucial to mitigating the long-term disease complications and that this relies upon knowledgeable, autonomous and self-sufficient patients working in partnership with health care professionals (Department of Health et al. 2002).

It has been recognised that enabling individuals to self-manage diabetes over their life time requires high quality structured education (Dinneen 2008). The Dose Adjustment for Normal Eating (DAFNE) programme (DAFNE Study Group 2002), endorsed by NICE (National Institute for Health and Care Excellence 2003), is now an integral part of the National Service Framework for Diabetes and has been widely adopted in the UK (Lawton et al. 2010) .

2.4 The Delivery of Care for Individuals with Type 1 Diabetes

In 2001 the Department of Health set standards for the care of individuals with all types of diabetes. The National Framework for Diabetes was reinforced by NICE in 2011 with the publication of a quality standard for adults with diabetes (National Institute for Health and Care Excellence 2011). A key aspect of these standards are the nine care processes to be delivered annually in order to monitor the progression of the disease (National Institute for Health and Care Excellence 2011). These care processes are shown in Table 2.2 and form a key part of the National Diabetes Audit³.

In 2004 the Quality and Outcomes Framework (QOF) was introduced, as part of the new General Medical Services contract, as a voluntary scheme with the aim of rewarding the

³ <http://www.hscic.gov.uk/nda>

delivery of quality care and to 'help standardise improvements in the delivery of clinical care'(NHS Employers 2012, p. 3). The QOF provides an opportunity for GP practices to increase their income through the achievement of points in relation to various indicators in four main areas: clinical standards; organisational standards; patient experience and additional services. The clinical indicators included in the set for diabetes are those that would be expected to be included in an annual review and QOF guidance states that although GP practices are not required to undertake all the indicators (for example, retinal screening) practices are responsible for ensuring that they have been carried out (NHS Employers 2012). It should be noted, however, that care processes are 'a means to an end and not an end in themselves' (Health and Social Care Information Centre 2013, p. 7) and an emphasis has been placed on the importance of using the care processes as an agenda for discussion with patients in which partnerships between individuals with diabetes and health care professionals are developed and decisions on forward plans are jointly agreed (Health and Social Care Information Centre 2013). The promotion of self-care amongst individual with long term conditions is viewed as a way to empower patients to take a more active role in decision-making dialogue with health care professionals (Department of Health 2009) and in relation to diabetes these partnerships are viewed as critically important in relation to continued improvements in health care outcomes (Health and Social Care Information Centre 2013).

There is variation in diabetes services provision within England. Some may be led by GP practices, some by specialist hospital departments and some by intermediate community services (National Audit Office 2012). Whereas individuals with type 2 diabetes tend to receive all their care within the GP surgery, individuals with type 1 diabetes may attend appointments at specialist services, the GP surgery, a mixture of both or none at all. Hence patients who only attend specialist services may not receive all the care processes carried out at annual review, since this is part of the GP surgery remit covered under the Quality and Outcomes Framework (Sharp et al. 2012). It is estimated that up to 20% of individuals with type 1 diabetes may not be receiving care at a specialist centre (Sharp et al. 2012).

NICE guidance does not specify that individuals should attend any particular centre for their diabetes care but that they should receive care from 'a range of professionals with skills in diabetes care working together in a coordinated approach' (National Institute for Health and Care Excellence 2015, p. 14). The guidance states that a 'common environment (diabetes centre) is an important resource in allowing a diabetes multi-disciplinary team to work and communicate effectively while providing consistent advice' (p. 14).

A recent audit of diabetes services found that less than half of patients had received eight care processes (eye screening was not included (Health and Social Care Information Centre 2013)). Only 12% of adults with type 1 diabetes achieved their goals in terms of HbA1c levels, blood pressure and cholesterol (Health and Social Care Information Centre 2013).

Table 2.2 The annual nine care processes (National Audit Office 2012)

Care Process	Purpose to detect/ manage/monitor:
Urine test	Problems in the kidney
Blood pressure	Problems in the cardiovascular system
Body mass index	Obesity
Cholesterol	High levels of fat in the blood
Creatinine	Problems with the kidneys
Eye screening	Changes at the back of the eye
Foot examination	Damage to the feet caused by complications
HbA1c	Blood glucose levels
Smoking advice	Smoking risk

2.5 Use of Technology to Manage Type 1 Diabetes

The use of technology to assist in the self-management of diabetes has grown enormously since the 1980's. Two broad categories may be identified: equipment for self-monitoring of glucose levels and insulin delivery systems.

2.5.1 Self-Monitoring of Blood Glucose Levels (SMBG)

The widespread use of blood glucose monitoring was triggered by the results of trials showing the benefits of strict glycaemic control. The first meters came into use in the 1980's. Initially meters were mains powered and larger than the compact battery operated meters currently available. Blood glucose monitoring largely superseded urine testing in type 1 patients (NHS diabetes 2010). Testing blood glucose levels involves pricking a finger with a lancet, placing the blood on a strip, inserting the strip in a meter and reading the results from the meter. The results are an estimate of blood glucose levels and are within 10-20% of the value achieved with laboratory equipment (Belsey et al. 2009). By comparison, urine glucose testing involves dipping a test strip in a small amount of collected urine and checking the strip against a reference colour chart.

In the UK, manufacturers do not charge for meters. Test strips, however, require a prescription. Individually, test strips are not expensive, however over time the cumulative effect of testing frequency, coupled with large numbers of patients, involves a considerable cost to the NHS (Coster et al. 2000). In 2009-10, prescriptions for items associated with blood glucose monitoring agents and devices represented 22.5% of the total cost of prescribing for the treatment of both type 1 and type 2 diabetes (Yorkshire and Humber Public Health Observatory 2009).

The early evidence on effectiveness of SMBG in type 1 diabetes was inconclusive (Coster et al. 2000). The authors found that studies carried out in the 80's and 90's lacked the requisite statistical power to confirm either benefits or adverse effects of SMBG for this group of patients. Nevertheless, the consensus is that SMBG in type 1 diabetes is effective (Bergenstal et al. 2005). This is due in part to the inclusion of SMBG in several influential studies showing the benefits of intensive glycaemic control. In the Stockholm Diabetes Control Study and the Diabetes and Control Complications Trial, SMBG was used as an integral part of the intervention (Kolb et al. 2010). Although it is not possible to isolate the effects of SMBG in these studies, the results of the studies show an overall positive effect of SMBG in conjunction with the study interventions (Kolb et al. 2010). Hence SMBG is recognised as an essential part of the self-care regimen in type 1 diabetes (Bergenstal et al. 2005) and is recommended by NICE, although frequency is not specified (National Institute for Health and Care Excellence 2004).

2.5.2 Continuous Glucose Monitoring System (CGMS)

Continuous blood glucose monitors represent a further advance in the development of a 'closed loop' system whereby real time monitoring of blood glucose is linked to an insulin delivery system (Bilous et al. 2010). Currently these monitors measure glucose in interstitial fluid (via a sensor inserted on the abdominal wall) and hence there is a time lag in measuring blood glucose (Bilous et al. 2010). This procedure is more complex, costly and invasive than SMBG (St John et al. 2010). In the UK, until recently, these monitors were more frequently found in research but are now beginning to be adopted more widely in clinical practice (Cummins et al. 2010). NICE recommends the use of CGMS for adults with type 1 diabetes who have persistent problems with hypoglycaemia unawareness, or repeated hypoglycaemia or hyperglycaemia (National Institute for Health and Care Excellence 2015). In adults this guidance applies to those who are unresponsive to conventional insulin dose adjustment and conventional blood glucose monitoring. At the time of the study there were three models of

the device available in the UK, all manufactured by Medtronic (Diabetes UK 2011b). Two of the models are 'real time' devices (Guardian REAL-Time and Minimed Paradigm REAL-Time) where measurements of interstitial fluid are taken every five minutes, twenty four hours a day and results are displayed onto the monitor (Diabetes UK 2011b). The Minimed integrated pump and CGMS is not however a 'closed loop' system (Diabetes UK 2011b). Consumables associated with the CGMS include sensors which cost around £50 and last for approximately six days.

2.5.3 Insulin Regimens

Individuals with type 1 diabetes require insulin for survival. Insulin is provided in different treatment regimens ranging from single long lasting injections, through to multiple daily injections (MDI) aiming to mimic normal pancreatic function. MDI provides a low level of insulin throughout the day as would a normal pancreas. In addition a short acting bolus is administered at meal times to counteract the effects of higher blood glucose levels.

2.5.4 Insulin Pumps

CSII are portable pumps designed to infuse insulin via an implanted cannula in such a way as to mimic insulin delivery in non-diabetic patients (Bilous et al. 2010) (see Figure 2.1). Modern pumps are small, lightweight battery operated devices. NICE recommends restricted use of CSII for type 1 diabetes patients (National Institute for Health and Care Excellence 2008). Despite pioneering CSII in the 1970's (Pickup et al. 1978) this technology is much less used in the UK than in the United States and other equivalent European countries (Colquitt et al. 2004). Although prescribing costs and current usage are not routinely collected (Yorkshire and Humber Public Health Observatory 2009) a recent UK service level audit of insulin pump therapy in adults (White et al. 2014) found that usage of the technology is well below the estimated levels (15-20%) of individuals who are likely to benefit from the therapy (Pickup 2006). In addition, although reporting higher usage (6% of adults in the UK) than previous estimates (Yorkshire and Humber Public Health Observatory 2010), the prevalence of use is well below other European countries and the USA (White et al. 2014). Barriers to accessing insulin pump therapy are reported to be related to lack of health care professional funded time to initiate the therapy and to provide both education and follow up care (White et al. 2014).

Figure 2.1 Insulin pump



(Reproduced with permission from Medtronic, Inc.)

The extra annual cost (per patient) of CSII compared with multiple daily injections averages £1700 (Cummins et al. 2010). A recent Health Technology Assessment, when looking at the totality of evidence, found advantages of insulin pumps over multiple daily injections which included: better control of glucose levels as measured by HbA1c; fewer problems with hypoglycaemia; and better quality of life through greater lifestyle flexibility (Cummins et al. 2010).

2.6 Summary

This chapter has provided an overview of the characteristics of type 1 diabetes and its management. Treatment for type 1 diabetes ranges from simple to more complicated regimens. The more intensive regimens are associated with better long-term outcomes but are more demanding for patients.

Chapter 3. Literature Review

3.1 Introduction

This chapter presents the literature review that relates to three main areas of research relevant to my thesis. First, it was important to establish evidence of an association between socioeconomic factors and health outcomes for adults with type 1 diabetes; since the underlying premise of investigating inequitable access rests on an assumption that inequalities in health care outcomes persist. Hence the chapter begins with a systematic review of this evidence in relation to mortality and morbidity (section 3.2). The evidence of the socioeconomic impact on access to health care and diabetes management is reviewed in section 3.2.4. Second, in section 3.3 the wider literature on access to health care and issues of inequitable access is reviewed to ensure that this thesis about type 1 diabetes is shaped by the evidence base on access to health care for other conditions. Third, in section 3.4 the literature on influences relating to patient-provider communication that may affect equity of access is presented including patient involvement in medical decision-making. Finally, the chapter concludes with the thesis aims and objectives in section 3.5.

3.1.1 Inequalities in Health and the Role of Equitable Health Services

There is considerable evidence that socioeconomic inequalities in health persist, with the least well off in society having reduced life expectancy (Marmot et al. 2005) and increased morbidity compared with the affluent. Socioeconomic status refers to an individual's type of employment and this in turn determines both income and working conditions. Low income, material deprivation and inequalities in one area very often lead to other forms of disadvantage. Hence there are associations between inequalities in social class, income and education. Previously the Registrar General's classification based on occupation was the most widely used in medical research in the UK.

There has been a widening of social inequalities since the 1970s (Whitehead et al. 1997). The social gradient observed in the first Whitehall study of British civil servants showed higher risks of mortality in relation to decreasing employment grade (Marmot et al. 1978). This gradient has become steeper and there are large differentials in both mortality and morbidity between the professional classes compared with unskilled manual workers (Whitehead et al. 1997). However, the social gradient is applicable not just to the less well off. The phenomenon provides evidence of a social hierarchy of health (Marmot et al. 2005).

The determinants of health are complex and although mortality and morbidity are associated with social class, correlation does not imply causality. A number of explanations for health inequality have been proposed; these encompass behavioural, material, psychosocial and life-course models (Bartley 2003). It is important when investigating inequalities in health that the pathways involved in these models are the subject of research (Marmot et al. 2005).

What part is played by equitable access to health care?

There is evidence that access to essential health care plays only a small part in differences in mortality (Fox et al. 1989). However, health services may have an important role in lessening the impact of growing inequalities (Whitehead et al. 1997) and universal access to health care is now viewed as one of the social determinants of health (Wilkinson et al. 2003). It is therefore of utmost importance to ensure that access to health care is equitable, particularly for those who are most vulnerable in society (Whitehead et al. 1994). Equity of access is particularly important in terms of diabetes care since it is known that the complications associated with poor diabetes management may be prevented through the adoption of effective regimens (DCCT Research Group 1989).

3.1.2 Socioeconomic Status and the Health of Individuals with Diabetes

In their review of socioeconomic position and health amongst individuals with diabetes (type 1 and 2), Brown et al. (2004) depict a conceptual framework, involving a complex web of interrelated influences, in order to explain the potential mechanisms whereby socioeconomic position may affect health outcomes amongst individuals with diabetes.

Three ways in which socioeconomic position may influence health outcomes are posited and comprise: access to care; process of care; and individual behaviour (Brown et al. 2004). In this framework access to care includes visits to both primary and specialist services. Process of care comprises aspects of diabetes care monitoring including: HbA1c levels; eye checks; cholesterol levels; and foot checks. Individual behaviour relates to the work that people with diabetes must accomplish in order to manage the condition. Brown et al. (2004) discuss the respective roles played by providers of health care, health care system characteristics and the community in which individuals reside. It is suggested that poor health outcomes are a combination of lack of access to high quality health care resulting in inadequate and inferior treatment (resulting in increased morbidity) and deficits in self-care behaviour (Brown et al. 2004).

3.2 Socioeconomic Inequalities in Adults with Type 1 Diabetes

The framework proposed by Brown et al. (2004) was useful in helping to frame the content of the current literature review. Brown et al. (2004) included studies addressing both type 1 and type 2 diabetes in their review whereas the current review focuses on adults with type 1 diabetes. It was important for the purposes of this study, therefore, to commence with a review of the impact of socioeconomic factors in relation to adults with type 1 diabetes before exploring some of the other factors identified in the review by Brown et al. (2004).

A systematic approach to reviewing the literature was adopted (Booth et al. 2012) both in terms of the search strategy and the application of selection criteria. However, the review does not fulfil some of the criteria for a systematic review since dual selection of papers and data extraction was not undertaken because this was a PhD thesis.

3.2.1 Search Strategy

The search, limited to papers published in the English Language, was carried out in six databases including: Medline (accessed via OVIDSP); PsycINFO (accessed via OVIDSP); EMBASE (accessed via OVIDSP); Web of Science; CINHAL (accessed via EBSCOhost); and the Cochrane Database of Systematic Reviews. Databases were selected for their specialist coverage of literature on: medicine (Medline and EMBASE); nursing and allied health (CINHAL); systematic reviews (Cochrane Database); psychology and related fields (PsycINFO); and both social sciences literature and conference citations (Web of Science). This broad coverage was required in order to capture both quantitative and qualitative literature relating to inequalities in type 1 diabetes.

The search, completed in March 2014, included MeSH headings and text terms for both adults with type 1 diabetes and socioeconomic factors (including social class, poverty, access, inequity and health care disparity). The search strategy applied to Medline is in Appendix 1. No date limits were specified for inclusion of studies. The references of papers found were checked for further studies. Additionally, citation searches were carried out and a 'snowballing' technique was adopted (Booth et al. 2012 p. 78) in order to ensure that all key studies were identified. This was carried out using the selected databases and Google Scholar. Hand searching of a group of journals focused on diabetes research was also carried out. These included Diabetic Medicine, Diabetes Care, Diabetologia, Diabetes and Practical Diabetes for

the most recent period (2013-2014) to capture citations and conference material not yet added to the databases.

One researcher (AS) read the titles and the abstracts. Studies were included if they reported socioeconomic findings in adults (defined as 16 years and above) with type 1 diabetes in the following:

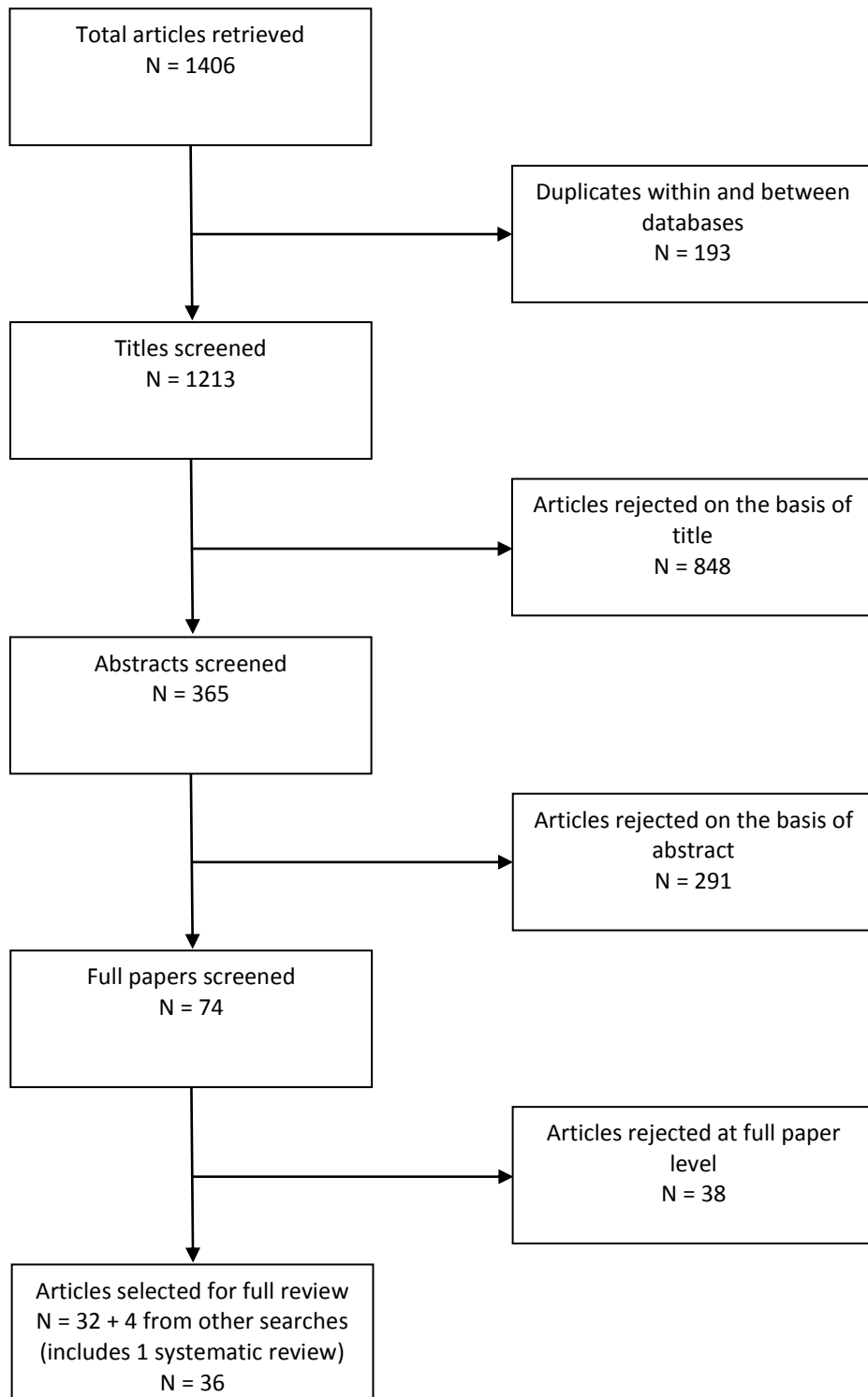
- Mortality
- Morbidity arising from diabetes (short and long term complications)
- Glycaemic control
- Insulin regimens
- Access to care

Studies were excluded if they:

- Focused on pregnant women only.
- Involved only children and adolescents.
- Focused on the transition of children from paediatric to adult services.
- Focused on type 1 and type 2 diabetes but did not report on the former separately.
- Included both adults and children but did not report on the former separately.

Following the database search 1406 references excluding duplicates were retrieved. 848 were excluded on the basis of title and 291 were excluded following a review of abstracts. Citations were rejected on the basis of title if they were studies of children, for type 2 diabetes or did not meet the inclusion criteria. If there was any doubt about the title, the appraisal proceeded to the next stage which was a reading of the abstract. 74 full papers were requested and screened and a final 36 were included in the review (this included one systematic review). Reasons for exclusions included: not found to be relevant; did not report type 1 diabetes separately; or did not report adults separately. An additional four studies were found in reference searches. Data was extracted from the studies using the checklist in Appendix 2. The results of the systematic literature search are summarised in the PRISMA flow diagram (Booth et al. 2012) (Figure 3.1).

Figure 3.1 PRISMA Flow Diagram showing included/excluded studies



Assessment of study quality was undertaken on full papers based on the Critical Appraisal Skills Programme (CASP) (Critical Appraisal Skills Program (CASP) 2006) using the author's own form in Appendix 3. Since weaknesses are likely to be present in each study and quality assessment must not become a pursuit of unattainable perfection (Booth et al. 2012 p 104) studies were only excluded that did not meet the inclusion criteria. Also some studies albeit of lesser quality may contain highly relevant data. The primary aim in carrying out each assessment was to determine the strengths and weaknesses of each study so that this could be taken into consideration when presenting the findings.

Two reviews relevant to the thesis were found. First, a systematic review investigating social inequalities in diabetes by Ricci-Cabello et al. (2010). This study included ethnic and gender inequalities as well as socioeconomic disparities. Second, a literature review of socioeconomic position and health among individuals with diabetes by Brown et al. (2004).

However, there was a need to undertake a new review of the literature for this thesis because the existing systematic review and literature review did not distinguish between type of diabetes or between adults and children. In addition a new review would identify more up to date studies. However, the contents of both reviews were incorporated into the current review to ensure that no important studies were omitted.

The following section presents the review findings, exploring inequalities in the following for adults with type 1 diabetes:

- Mortality
- Morbidity (short and long term complications)
- Glycaemic control
- Insulin regimens
- Access to care

Study characteristics are presented in Appendix 4 for all studies included in the review.

3.2.2 Mortality

Socioeconomic differences in mortality generally have been well documented (Marmot et al. 1997). It is known that disadvantaged individuals have less favourable outcomes than those in higher socioeconomic groups (Townsend et al. 1988a; Whitehead 1988) and that these disparities are becoming more pronounced over time (Feldman et al. 1989). Compared with

the population, individuals with diabetes have an increased risk of mortality (Dorman et al. 1985; Laing et al. 1999). Although a social gradient for individuals with diabetes has been reported (Chaturvedi et al. 1998), relatively few studies have reported the association between socioeconomic factors and mortality in type 1 diabetes relating to adults specifically. This review found nine papers that reported socioeconomic factors in relation to mortality in type 1 diabetes.

Characteristics of studies reporting mortality

As the focus of the thesis is access to health care, tables relating to the review of mortality (all causes) in adults with type 1 diabetes have been placed in Appendix 4 (summarising study characteristics) and Appendix 5 (study findings). Five studies were population based and four studies recruited patients at specialist diabetes clinics in secondary care (centre based). Studies were carried out in the UK, Finland, Italy, Germany and the USA (summarised in Appendix 4). All of these countries except the USA have a form of universal health care system. Although the studies included in the review reported on socioeconomic factors in relation to diabetes, the aims of the research were diverse (summarised in Appendix 5). For two studies the aim was to identify key mortality predictors (Mühlhauser et al. 2000; Rossing et al. 1996). The former study explored factors in individuals who were intensively treated with insulin. The remaining studies focused on the influence of socioeconomic factors on mortality in diabetes. Five studies related to both type 1 and type 2 diabetes and four related to type 1 diabetes specifically.

In terms of socioeconomic measures, the most commonly used were social group (based on occupation) and education (see Table 3.1 for measures used). Due to the variation in defining variables across studies it was not possible to carry out a meta-analysis. Instead, study findings have been presented as a narrative synthesis.

Table 3.1 Socioeconomic associations with mortality in type 1 diabetes

Study	Socioeconomic variable							
	Social class	Education	Income	Employment	Housing	Municipality	Living alone	Marital status
Matsushima et al. (1996)		✓	✓				x	x
Rossing et al. (1996)	✓							
Robinson et al. (1998)	x	✓		✓	✓			
Mühlhauser et al. (2000)	✓*							
Forssas et al. (2003)	✓							
Gnavi et al. (2004)		✓						
Forssas et al. (2012)	✓							
Secrest et al. (2011a)	x	✓	✓					
Forssas et al. (2010)	✓	✓†	✓	✓		x	✓	

✓ Indicates that an association was found between a socioeconomic variable and mortality in either univariate or multivariate analyses

x Indicates that no association was found on an investigated socioeconomic variable

*An aggregate score based on a mix of highest education level and last employed position

† Women only

In the nine papers selected for this review of mortality in adults with type 1 diabetes, each paper reported an association between at least one socioeconomic variable and mortality for adults with type 1 diabetes in either univariate or multivariate analyses (Table 3.1). Strength of association is reported in Appendix 5. This consistency of association for type 1 diabetes is in contrast with previous inconsistencies amongst studies reporting on the influence of socioeconomic factors on mortality in diabetes (Forssas et al. 2003) in which both type 1 and type 2 were included in the analysis.

Comparing mortality (the general population and/or adults with type 1 diabetes)

Since there is a known social gradient in relation to mortality in the general population it is important to establish whether or not this is mirrored in adults with type 1 diabetes. Alternatively the social gradient might be exacerbated due to the complications arising from diabetes or perhaps mitigated owing to the presumed additional care received by adults with type 1 diabetes. Some studies focused on comparisons involving the general population and others more narrowly focused on differences within the adult type 1 diabetes sample.

Comparisons with the general population

Mortality in type 1 diabetes is higher than in the general population (Dorman et al. 1985). In comparison with the general population the risk of death was estimated to be double (for men) and triple (for women) (Gnavi et al. 2004) and four times higher in another study (Secrest et al. 2011a). Whereas individuals in the highest income groups had similar mortality rates to the general population, those without a college degree and those on the lowest income had approximately five times the mortality rates of their counterparts in the general population (Secrest et al. 2011a). Among individuals having only primary school education or no formal education, risk of death during follow up was three (men) to four (women) times higher than for those with at least high school education or above (Gnavi et al. 2004). This social gradient in mortality appeared to have particularly affected those in the younger age and less educated category (20-49). In Finland increasing disparities over time between type 1 diabetes mortality and the general population were attributed to a reduction in mortality in the higher socioeconomic groups compared with little progress on improvements in the lower socioeconomic groups (Forssas et al. 2003).

Comparing disparities amongst adults with type 1 diabetes

It would appear that not only are disparities in mortality present in adults with type 1 diabetes compared with the general population; there are also differences in mortality amongst adults with type 1 diabetes when data is stratified by socioeconomic group. It appears that the socioeconomic gradient in mortality in the general population is steeper for adults with type 1 diabetes. Disparities in mortality amongst individuals with type 1 diabetes were associated with unemployment and education. Utilising duration adjusted odds ratios, mortality rates of unemployed individuals were approximately three times higher than those who were employed (Robinson et al. 1998). Those who reported that they had been unemployed for more than one year had 6.8 times the mortality of those who reported they had been

unemployed for less than one year (Robinson et al. 1998). However, in multivariate analysis, employment no longer remained an independent predictor of mortality in type 1 diabetes; whereas leaving school under the age of 16 persisted as a predictor (Robinson et al. 1998).

Mortality and confounding factors

Whilst associations with socioeconomic status were found in univariate analyses for a number of studies, modelling other known risk factors in multivariate analysis revealed a more complex picture. For example, Secrest et al. (2011a) found that the strong association between education and all cause mortality was lessened when other risk factors (HbA1c, cholesterol, hypertension and microalbuminuria) were taken into account. This demonstrates the difficulty in identifying independent predictors of mortality, since variables may be associated with one another (Secrest et al. 2011a). Cardiovascular mortality was consistently found to be a major cause of death and not all studies explored lifestyle factors such as smoking and alcohol that may act as confounding factors (Robinson et al. 1998). However, a relationship between social status and mortality persisted in one study even when traditional risk factors for cardiovascular disease were taken into account (Mühlhauser et al. 2000).

Summary for mortality

In summary, there were few studies focusing on socioeconomic factors in relation to mortality in type 1 diabetes. The review was limited by the variability in both methods used (cohort and case control studies), different samples (centre based versus population based), different age ranges and in particular variety in definitions of socioeconomic variables. The review results also point to the complexity of issues surrounding the outcomes for diabetes. Although the evidence is far from consistent across all variables used, it appears that social status, education and deprivation measured by unemployment are all to some extent associated with mortality.

3.2.3 Morbidity in Adults with Type 1 Diabetes

Characteristics of studies reporting on morbidity in adults with type 1 diabetes

Nineteen studies met the inclusion criteria for investigations relating to morbidity and socioeconomic status in adults with type 1 diabetes. Fifteen studies were conducted in Europe (including EURODIAB, the largest European study of diabetes complications within the review), one in Canada and two in the USA. Methods included cohort and cross sectional studies. A variety of measures were used to determine socioeconomic status. The majority of authors chose an individual measure of socioeconomic status such as education, income or occupation.

Some used an aggregate score of a combination of either two or three individual measures. Five studies used a group level measure based on indices of deprivation (Carstairs index (Carstairs et al. 1991) or Townsend score (Townsend et al. 1988b)).

The findings are summarised in two tables. The first table (Table 3.2) includes long-term complications associated with diabetes (microvascular and macrovascular). The second table (Table 3.3) presents a summary of findings for hypoglycaemia and ketoacidosis. In contrast to the complications presented in Table 3.2, ketoacidosis and hypoglycaemia are short-term in nature; however, both may be life threatening. In ketoacidosis, a build up of acids and ketones arises due to lack of insulin leading to the body using body fat as fuel. Hypoglycaemia on the other hand is often as a result of too much insulin or glucose deprivation.

In both Table 3.2 and 3.3 some studies appear more than once if they investigated multiple conditions. In Table 3.2, 11 out of 14 studies found a significant association with socioeconomic status for complications associated with diabetes. An association with prevalence of risk factors for cardiovascular disease and low socioeconomic status was reported in 8 out of 9 studies (Table 3.2). For example, an association between smoking and low socioeconomic status was reported in eight studies. Strength of association together with study aims and findings are reported in Appendix 6.

Table 3.2 Socioeconomic associations with microvascular and macrovascular complications

Morbidity/Study	Socioeconomic variable			
	Social class	Education	Income	Deprivation score
General[#]				
Chaturvedi et al. (1996)	✓	✓		
Mühlhauser et al. (1998b)	✓‡ x¶			
Mühlhauser et al. (2000)	✓‡			
Lievre et al. (2005)	✓			
Secrest et al. (2011b)	✓	✓	✓	
Swaminathan et al. (2004)				x
Nephropathy				
Mühlhauser et al. (1998b)	✓			
Rossing et al. (2002)	x†			
Wolf et al. (2011)	x‡			
Painful neuropathy				
Anderson et al. (2014)				✓
Cardiovascular disease/ risks of CVD				
Robinson et al. (1984)	✓*			
Chaturvedi et al. (1996)	✓*			
Connolly et al. (1996)				✓
Unwin et al. (1996)				✓
Mühlhauser et al. (1998b)	✓‡			
Swaminathan et al. (2004)				x
Nadas et al. (2009)		✓		
Secrest et al. (2011b)		✓		
Sastre et al. (2012)		✓		

✓ Indicates that an association was found between a socioeconomic variable and at least one complication/risk factor in either univariate or multivariate analyses

x Indicates that no association was found on an investigated socioeconomic variable

¶ No association found for retinopathy

Includes complications associated with retinal, renal, and lower extremity arterial disease

† Social class was an aggregate score based on education and occupation

‡ Social class was an aggregate score based on education, occupation and income

* Association in women only

At least one association between a socioeconomic measure and either hypoglycaemia or ketoacidosis or both was found in five out of six primary studies and one systematic review (Sawka et al. 2007) (Table 3.3). Butalia et al. (2013) was the only study that did not find an association between ketoacidosis in either income or education. The authors suggested that this may have been as a result of using group level data rather than individual measures of income and education. A more likely explanation was their acknowledgment that Calgary is a relatively affluent city and that their study lacked socioeconomic diversity.

Table 3.3 Socioeconomic associations with ketoacidosis and hypoglycaemia

Morbidity/Study	Socioeconomic variable			
	Social class	Education	Income	Deprivation score
Ketoacidosis				
Lievre et al. (2005)	✓			
Butalia et al. (2013)		x*	x*	
Weinstock et al. (2013)		✓	✓	
Hypoglycaemia				
Mühlhauser et al. (1998a)	✓†			
Leese et al. (2003)				✓
Pederson-Bjergaard et al. (2004)		✓		
Lievre et al. (2005)	x†			
Sawka et al. (2007) ¶	✓	✓		✓
Weinstock et al. (2013)		✓	✓	

✓ Indicates that an association was found between a socioeconomic variable and at least one complication in either univariate or multivariate analyses
 x Indicates that no association was found on an investigated socioeconomic variable
 *Education and household income were group level variables
 †Social class was an aggregate score based on education, occupation and income
 ¶ Systematic review included papers by Mühlhauser et al. (2000), Leese et al. (2003) and Pederson-Bjergaard et al. (2004)

Sawka et al. (2007) in a systematic review of socioeconomic status and hypoglycaemia concluded that low socioeconomic status was associated with increased incidence of severe hypoglycaemia (included in Table 3.3). Although the study by Lievre et al. (2005) found no association between hypoglycaemia and socioeconomic status the authors acknowledged that the least well off patients were under-represented in their study.

Summary for morbidity

Low socioeconomic status was associated with a number of macrovascular and microvascular complications arising from diabetes. Low socioeconomic status was found to be a predictor for both hypoglycaemia and ketoacidosis.

3.2.4 Diabetes Management

Diabetes management includes glycaemic control, self-monitoring of blood glucose levels, insulin regimens and access to diabetes care. The rationale for reviewing these aspects of diabetes management is that despite the evidence that controlling risk factors can prevent long term complications (DCCT Research Group 1989) many individuals with type 1 diabetes have poor metabolic control. Issues relating to diabetes care may account for the poor metabolic control observed amongst many individuals with diabetes.

Characteristics of studies reporting on diabetes management

Fourteen studies were found that investigated socioeconomic status with at least one aspect of diabetes management (glycaemic control, self-monitoring of blood glucose levels, insulin regimens or access to diabetes care). Appendix 4 contains detailed study characteristics of all the studies included in the review. The studies were carried out in the USA (5), UK (3), Australia (1) and other European countries (5). The study aims and principle findings in relation to this review are described in Table 3.4.

Five of these studies were previously also included in the morbidity review (Chaturvedi et al. 1996; Mühlhauser et al. 1998b; Nadas et al. 2009; Secrest et al. 2011b; Unwin et al. 1996). All of the studies were quantitative in design. Ten studies investigated glycaemic control. Few studies were found that investigated socioeconomic status in relation to either self-monitoring of blood glucose levels, insulin regimens or access to specialist health care in relation to adults with type 1 diabetes.

Table 3.4 Associations between diabetes management and socioeconomic status

Author/ Date	Study aims	Study findings reported for adults with type 1 diabetes
Johansen (1983)	To examine social status in relation to diabetes control and knowledge of diabetes management.	Glycaemic control: Significantly more patients with HbA1c <8.5% belonged to social class 1-3 compared to social class 4-5 (p=0.0015). HbA1c was lower in social class 1-2 than social class 5 (median HbA1c 8.1% versus 10.3% p=0.02). Diabetes Knowledge: Knowledge was significantly better in social class 1-2 than social class 5 (p=0.007).
Lloyd et al. (1993)	To examine glycaemic control in adults with type 1 diabetes in relation to psychosocial factors.	Glycaemic control: Low income and a lower level of education was significantly associated with poorer glycaemic control (income p < 0.05 and education p > 0.001).
Harris et al. (1993)	To examine the frequency and determinants of blood glucose monitoring in adults with diabetes.	Self-monitoring of blood glucose levels: Education, income and health insurance were not associated with self-monitoring of blood glucose levels in adults with type 1 diabetes.
Hepburn et al. (1994)	To investigate psychological and demographic associations with glycaemic control in adults with type 1 diabetes.	Glycaemic control: No association with socioeconomic status or education.
Chaturvedi et al. (1996)	To explore the relationship between socioeconomic factors and diabetes control and complications in adults with type 1 diabetes.	Glycaemic control: Mean percentage HbA1c was worse in primary versus college educated men and women (6.6 v 6.1 respectively for men) p = 0.007 value for trend and 6.5 v 6.0 p = 0.0007 (for trend) for women. Access: For men and women attendance at clinic was associated with educational level (p = 0.003 and p < 0.0001 for trend respectively).
Unwin (1996)	To examine the relationship of socioeconomic status and risk factors for cardiovascular disease in individuals with diabetes.	Glycaemic control: No significant association between HbA1c and socioeconomic status.

Table 3.4 Associations between diabetes management and socioeconomic status

Author/ Date	Study aims	Study findings reported for adults with type 1 diabetes
Mühlhauser et al. (1998b)	To investigate social status and diabetes care in adults with type 1 diabetes.	<p>Glycaemic control: Lower social status was associated with higher HbA1c values ($p < 0.0001$).</p> <p>Self-monitoring of blood glucose levels: Lower class was associated with carrying out blood glucose less often than higher class (OR = 1.38, CI: 1.18-1.61 $p = 0.0001$).</p> <p>Insulin regimen: There was a strong association between lower social class and the intensity of insulin regimen ($p < 0.0001$). Insulin adjustment was associated social class. Insulin adjustments in relation to both blood glucose monitoring and carbohydrate intake was carried out more by high SES than low SES participants ($p < 0.0001$ for both).</p> <p>Access: A higher percentage of higher SES attended specialist diabetes clinic services (OR = 1.36, CI: 1.17 – 1.56 $p < 0.0001$).</p> <p>Structured Education: Higher social status was associated with a higher percentage attendance.</p>
Perros 1998	To investigate factors associated with different insulin regimens.	<p>Insulin regimen: Basal bolus regimens were associated with higher levels of education ($P = 0.03$) and higher socioeconomic groups ($P = 0.002$).</p>
Karter et al. (2000)	To examine practices and barriers to self-monitoring of blood glucose in diabetes care.	<p>Self-monitoring of blood glucose levels: In multivariate analysis predictors of monitoring less frequently than recommended by the American Diabetic Association was associated with deprivation (neighbourhood area $< \\$13,959$ average annual income).</p>
Zgibor et al. (2000)	To investigate the association between attendance at specialist diabetes services and glycaemic control and self-care practices in adults with type 1 diabetes.	<p>Access: Individuals accessing specialist care were more likely to have higher education levels, to have income above $> \\$20,000$) and to have health insurance.</p> <p>Glycaemic control: Differences in glycaemic control noted for education and income (10.4 ± 1.8 v 9.8 ± 1.7 $p \leq 0.01$)(High school or less v more than high school), 10.5 ± 1.8 v 9.9 ± 1.7 $p \leq 0.01$) Income $\leq \\$20,000$/year v $> \\$20,000$/year.</p>
Nadas et al. (2009)	To investigate the association between cardiometabolic risk factors.	<p>Glycaemic control: Worse in low education patients versus high (HbA1c: 8.8 ± 1.6 versus $7.9 \pm 1.4\%$; $p = 0.0006$).</p>

Table 3.4 Associations between diabetes management and socioeconomic status

Author/ Date	Study aims	Study findings reported for adults with type 1 diabetes
Secrest et al. (2011b)	To explore the relationship between socioeconomic status and risk of complications.	Glycaemic control: HbA1c decreased with increased income level ($p = 0.01$). Insulin regimen: College graduates compared with individuals with less education were more likely to be on an intensive insulin regimen (23.7% v 12.8% $p \leq 0.05$). Individuals in professional occupation versus non-professional occupation were more likely to be on an intensive insulin regimen (27.2% v 8.7% $p \leq 0.01$).
Sastre et al. (2012)	To assess glycaemic control, cardiovascular risk factors and treatment regimens in type 1 diabetes.	Glycaemic control: Univariate analysis showed glycaemic control ($HbA1c \leq 7\%$) was associated with educational level (middle plus higher education versus primary or no education). Multivariate analysis found that better glycaemic control ($<7\%$ HbA1c) was associated with secondary or higher education, intensified regimen coupled with regular self-monitoring of glucose monitoring.
Kibbey 2013	To investigate the barriers and enablers to accessing specialist care in an area of social disadvantage.	Access: Greater satisfaction with services was found to be associated with higher levels of income and education. Although cost and time taken to travel were reported as barriers they were not associated with levels of income. A previous unsatisfactory experience was found to be a barrier to attendance with a number of participants reporting (in open ended responses) a feeling of being judged by overly critical staff. These responses were not reported by socioeconomic group. Facilitators of engagement included continuity of care, time of day for appointment and distance from home to the clinic.

Glycaemic control

Maintaining control of blood glucose levels has been demonstrated to minimise the risks of long-term and short-term complications (DCCT Research Group 1989). Despite the evidence for benefits of tight glycaemic control on the prevention of long term complications, around 25% of the adult diabetes population is in persistent poor control (Devries et al. 2004).

Ten studies explored associations between HbA1c levels and socioeconomic status (Table 3.5). An association between low socioeconomic status (as measured by education, social class or

income) and glycaemic control was found in eight of the ten studies (Chaturvedi et al. 1996; Johansen 1986; Lloyd et al. 1993; Mühlhauser et al. 1998b; Nadas et al. 2009; Sastre et al. 2012; Secrest et al. 2011b; Zgibor et al. 2000).

Table 3.5 Socioeconomic associations with glycaemic control measured by HbA1c

Study	Socioeconomic variable			
	Social class	Education	Income	Deprivation score
HbA1c levels				
Johansen (1986)	✓			
Lloyd et al. (1993)		✓	✓	
Hepburn et al. (1994)	x	x		
Chaturvedi et al. (1996)		✓		
Unwin et al. (1996)				x
Mühlhauser et al. (1998b)	✓†			
Zgibor et al. (2000)		✓	✓	
Nadas et al. (2009)		✓		
Secrest et al. (2011b)			✓	
Sastre et al. (2012)		✓		

✓ Indicates that an association was found between a socioeconomic variable and at least one complication in either univariate or multivariate analyses
x Indicates that no association was found on an investigated socioeconomic variable
†Social class was an aggregate score based on education, occupation and income

Self-monitoring of blood glucose levels

Self-monitoring of blood glucose is not widely practised (Evans et al. 1999; Hansen et al. 2009; Scorpiglione et al. 1996). In section 2.5.1 it was noted that the evidence on effectiveness of self-monitoring of blood glucose is inconclusive. Nevertheless self-monitoring of blood glucose is recognised as an essential part of the regimen for individuals with type 1 diabetes and has a number of advantages for patients. These include: alerting patients to hyperglycaemia which is associated with long term complications; helping to recognise the onset of hypoglycaemia or ketoacidosis; and providing an aid to decision-making with regard to insulin adjustment (Harris et al. 1993).

The evidence for socioeconomic association with self-monitoring of blood glucose levels for adults with type 1 diabetes was weak. Although a number of studies identified an association between self-monitoring of blood glucose levels and socioeconomic status in type 1 diabetes, for example Evans et al. (1999), studies were excluded if the sample included both children and adults. Only three studies were found that met the inclusion criteria. All three of these studies were based on self-reporting which may be an unreliable measure (Adams et al. 2003). Harris et al. (1993) found no association between socioeconomic status and self-monitoring of blood glucose levels whereas a German study and a study conducted in the USA found an association between low socioeconomic status and lower rates of self-monitoring of blood glucose levels (Karter et al. 2000; Mühlhauser et al. 1998b).

Access to specialist diabetes care

All four studies included in the review of access to diabetes care found an association between attendance at specialist diabetes centres and socioeconomic status for adults with type 1 diabetes (Chaturvedi et al. 1996; Kibbey et al. 2013; Mühlhauser et al. 1998b; Zgibor et al. 2000). In the EURODIAB study, Chaturvedi et al. (1996) postulated that access to care may be a possible explanation for poorer outcomes for low socioeconomic groups. The authors assessed attendance at clinic using the proxy of last available HbA1c result (over two years). A social gradient for attendance at clinic according to educational level was found. For men and women with primary education 67% had at least one reported HbA1c result in the previous two years compared with 79% (men) and 82% (women) with college education.

Mühlhauser et al. (1998b) found that more of the individuals in the higher socioeconomic group compared with the lower socioeconomic group consulted specialist diabetes clinics. However, more patients of low socioeconomic status compared with high socioeconomic status reported visiting a primary care physician during the previous year. Individuals with low socioeconomic status had poorer outcomes in term of higher rates of complications (reviewed in section 3.2.3).

In a study conducted in the USA, Zgibor et al. (2000) found that attending specialist adult type 1 diabetes services was associated with education and income. Additionally, those individuals attending specialist services were more likely to have received diabetes education recently, to be knowledgeable about HbA1c, to carry out self-monitoring of blood glucose levels and to be injecting insulin more than twice daily. Those individuals with a lower HbA1c were more likely to have attended specialist services.

There was a paucity of research explaining the poor outcomes or potential pathways resulting in lack of access. One quantitative survey conducted in Australia, targeting an area of deprivation, explored barriers and enablers for young adults with type 1 diabetes (Kibbey et al. 2013). Greater satisfaction with services was found to be associated with higher levels of income and education. Satisfaction with services was also associated with having recently had contact with specialist services, having a lower HbA1c, awareness of HbA1c result, lower depression score and lower anxiety score. Smoking was associated with individuals who were least satisfied with their care. Although cost and time taken to travel were reported as barriers to access they were not associated with levels of income. A previous unsatisfactory experience was found to be a barrier to further attendance with a number of participants reporting (in open ended responses) a feeling of being judged by overly critical staff. These responses were not reported by socioeconomic group. Facilitators of engagement with services included continuity of care, time of day for appointment and distance from home to the clinic. Although the target population was individuals from a deprived area, the study response rate was low (24%) and hence may not be representative of this group.

Adoption of an intensive insulin regimen and associations with socioeconomic status

Associations between intensity of insulin regimens and socioeconomic status were found in all three studies included in the review (Mühlhauser et al. 1998b; Perros et al. 1998; Secrest et al. 2011b). For example individuals in higher socioeconomic groups injected insulin more frequently on a daily basis, carried out more insulin adjustments, were more likely to be using insulin pumps, were better informed and a higher percentage had attended structured education than individuals in lower socioeconomic groups (Mühlhauser et al. 1998b). A strong association was found between social class and daily injections, with fewer of the lower class patients on intensified regimens. The authors concluded that since the same opportunities had been provided for all socioeconomic groups, equality of access was demonstrated in their study and inequalities in uptake of services were viewed as stemming from a deficit in health motivation amongst people from lower socioeconomic groups (Mühlhauser et al. 1998b).

Intensity of insulin regimen was associated with socioeconomic status in two further studies. A study conducted in Scotland found that individuals on a basal bolus regimen compared with twice daily regimens tended to be younger, adjusted their regimens more frequently, were more highly educated and were of a higher socioeconomic class (Perros et al. 1998). Additionally these individuals were less likely to smoke. In a study conducted in the USA those

adults with more education or better employment were significantly more likely to be on intensive regimens by age 28 (Secrest et al. 2011b).

Access to insulin pumps

Insulin pumps represent the most intensive of all regimens in type 1 diabetes since insulin is continuously administered subcutaneously via the equipment. Insulin pump therapy was mentioned in only one of the three studies investigating intensity of regimen and associations with socioeconomic status (Mühlhauser et al. 1998b). However this form of therapy was not reported separately.

It was noted in Chapter 2 that insulin pumps are not widely used in the UK although uptake has increased in recent years. Access to insulin pumps has been described as another national lottery (Walker et al. 2011) and a postcode lottery (Diabetes UK 2011a). Although some studies in the USA have found an association between low socioeconomic status and the use of insulin pumps, these studies did not include adults (Cortina et al. 2010; Wood et al. 2013). Additionally differences in the ways health care is financed through insurance in the USA may account for these socioeconomic differences whereas in the UK health care is universally provided. There is a paucity of research in the UK examining the uptake of this technology amongst individuals of low socioeconomic status.

Summary for diabetes management

Evidence suggests that attending specialist diabetes services appeared to be associated with better outcomes and these individuals were of higher socioeconomic status. Caution is needed, however, since two of these studies were cross sectional and hence causality cannot be inferred. Nevertheless, a profile appears to be emerging of individuals in lower social classes that: are less likely to attend regular specialist services; are less likely to be on intensive regimens; are less likely to monitor blood glucose levels; are more likely to have higher HbA1c levels; are more likely to suffer complications arising from diabetes; may not have attended structured education; and are less knowledgeable about their diabetes care.

3.2.5 Summary of Socioeconomic Inequalities Review for Adults with Type 1 Diabetes

Low socioeconomic status in adults with type 1 diabetes was found to be associated with poorer outcomes in terms of mortality and morbidity. Low socioeconomic status was also found to be associated with aspects of diabetes care. Although research has identified these disparities there is little research explaining the causes of these inequalities. Mühlhauser et al.

(1998b) concluded in their study that as patients had been invited to take up offers of diabetes care, lack of motivation was the root cause for lack of access. Although an Australian study offered some explanations for lack of uptake of services by exploring barriers and facilitators for engagement with services (Kibbey et al. 2013), the authors acknowledged that the study was limited by a low response rate and may therefore not represent the most disadvantaged groups. In order to seek explanations for lack of access to care for adults with type 1 diabetes and low socioeconomic status, a further literature review was undertaken relating to access to health services more generally.

3.3 Equity of Access to Health Care

Equity of access was established as a central tenet of the newly formed NHS in 1948 where the emphasis was on equality of access based on medical need (Gulliford et al. 2003). The NHS continues to aspire to fair and equitable delivery of health care services (Department of Health 2010). Whereas inequalities in health indicate that variation persist, inequity implies unfairness or injustice (Gulliford et al. 2001). As noted in section 3.1.1 low socioeconomic status is associated with increased mortality and morbidity and it is important when considering equity of access that these inequalities in health are taken into consideration (Gulliford 2003 p. 39).

Three excellent reviews of access to health care in England have been undertaken by Goddard and Smith (1998), Gulliford et al. (2001), and Dixon-Woods et al. (2005). Hence in the following section these reviews and referenced papers within these reviews relevant for my thesis are summarised rather than undertaking a new review. Two of these reviews were commissioned by the NHS Research and Development Service Delivery and Organisation Programme (Dixon-Woods et al. 2005; Gulliford et al. 2001). The review carried out by Gulliford et al. (2001) provided a broad overview of issues of access including equitable access. The review by Dixon-Woods et al. (2005) focused on access to health for vulnerable groups. The third review, carried out by Goddard and Smith (1998), focused on equitable access to health care in the NHS in England. Due to the pressure of timescales involved in all three reviews the authors were unable to carry out a systematic review.

Despite its stated importance and although extensively researched, equity of access has proved difficult to measure (Goddard et al. 2001 p. 66). In part this is because of the complexity and elusiveness of the concept of access (Goddard et al. 2001) as well as much of the evidence on utilisation of health care by vulnerable groups being 'highly complex,

contradictory and difficult to interpret', due in part to the ways in which access has been defined (Dixon-Woods et al. 2005, p. 97). Before discussing issues involved in equitable access there needs to be an understanding that access is a complex and multifaceted concept (Gulliford et al. 2003) and definitions are required.

3.3.1 Defining Aspects of Access to Health Care

Access to health care is defined as comprising four dimensions: service availability; service utilisation; service effectiveness; and equitable access (Gulliford et al. 2003). It is important to distinguish between availability of services and utilisation of services since there is a difference between having the potential to use services and actually gaining access to services (Gulliford et al. 2002).

Availability of services

Availability of services refers to the opportunity for individuals to gain access to services they require (Gulliford et al. 2002). In order that access to health care can be achieved there needs to be an adequacy in the available health care provision for a given population (Gulliford et al. 2002). It is known that geographical variation in health care supply persists in many countries including the UK (Gulliford et al. 2003).

Utilisation of services

Utilisation of services is influenced by factors including personal, organisational and financial that may restrict consumption of health care (Gulliford et al. 2002). For example, barriers to access may include difficulties with transport to and from health care appointments or an inability to take time off work.

Service effectiveness and access

Gulliford et al. (2002) assert the importance of measuring service effectiveness since accessing and utilising services represents only one aspect of the health care interaction. The authors emphasise the importance of measuring health outcomes in order to determine the success or otherwise of making services accessible to individuals (Gulliford et al. 2002).

Equity of access

Equity of access relates to the ability of health care services to enable all individuals to access the services they need. For example an individual may have the potential to access services but

for a variety of reasons may be unable to make effective use of the service on offer. These factors influencing access may relate to the individual or to services or alternatively the interaction between both.

3.3.2 Categorisation of Equitable Access

Equity of access may be categorised as horizontal or vertical. Horizontal equity relates to those with equal need having equal access whereas vertical equity relates to the notion of those with greater need having greater access (Gulliford 2003 p. 37). Most of the research relating to equitable access has investigated horizontal access whereas it is apparent from research into socioeconomic health inequalities that certain groups have greater need (Gulliford 2003). The notion that the most deprived individuals with the greatest need for health care services seemingly have impaired access was termed the 'inverse care law' (Tudor Hart 1971). To some extent empirical evidence substantiates the claims for an 'inverse care law' particularly with regard to preventive care and the use of specialist services (Goddard et al. 1998). However some research finds higher utilisation by individuals of low socioeconomic status in general practice and emergency care services and inconsistencies in the evidence on utilisation of health care services by different socioeconomic groups (Gulliford et al. 2001 p. 68). Nevertheless there are suggestions that different groups may require different approaches (Goddard 2008). For example smoking cessation interventions may need to be adapted according to socioeconomic group since some individuals experience greater obstacles relating to their socioeconomic status (Goddard 2008).

3.3.3 Evidence on Access Varies according to Measures Used and Type of Service

Evidence of inequity appears to depend on the types of measures used (Gulliford 2003 p 55). For example, in terms of equitable access to health care there is an important distinction to be made between utilisation of services versus availability of services. In terms of utilisation of primary care services, studies show that lower socioeconomic groups have equitable access, whereas when other measures are chosen such as availability of services, inequities are detected (Gulliford 2003). In their review of equity of access to health care, Goddard and Smith (1998) found that although inequity of access did not seem to be observed at the 'aggregate level' for primary care and secondary care attendances, there appeared to be some evidence of inequity at the specialty level, particularly with regard to elective surgery and coronary artery disease, with lower referral rates for the latter in lower socioeconomic groups.

Higher rates of GP consultations were observed in areas of deprivation and amongst lower socioeconomic groups, however, individuals in manual occupations were 10% less likely to attend the GP for preventive care (Goddard et al. 1998 p. 21). Emergency services were utilised more and specialist services less by individuals of low socioeconomic status (Goddard et al. 1998). The evidence that individuals from lower socioeconomic groups tend not to make use of specialist services generally, resonates with research in diabetes which suggests that less advantaged patients with diabetes, in terms of income and education, appear to make greater use of primary care and less use of specialist diabetes services (Bachmann et al. 2003).

3.3.4 Factors Influencing Equitable Access

The factors influencing whether individuals will attend hospital services are known to be complex and multi-faceted involving the characteristics of individuals, health care professionals and the service they provide (Goyder et al. 2000). It is postulated that financial costs act as a barrier for individuals attending 'optional' services although these barriers are not a sufficient deterrent when individuals are ill (Goddard 2008). Whereas individuals in lower socioeconomic groups make much greater use of emergency services, they have a tendency not to keep specialist appointments because those in lower paid jobs find it more difficult to get time off work and may experience problems with arranging child care (Dixon-Woods et al. 2005).

Access may be conceptualised as a continuum with opportunities to interact with services at a number of stages (Gulliford et al. 2001 p. 20). At each stage individuals may choose whether or not to engage with services on offer. It is important to recognise that supply and demand factors affect the uptake of services (Goddard et al. 1998). Equality of treatment also arises out of and is affected by an interaction between supply side (health care provider) and demand side (patient) factors. Equality of access does not equate to equality in treatment (Goddard et al. 1998 p. 14) and availability of service does not equate to utilisation of services (Gulliford et al. 2003).

In principle although individuals may have access to services, as a consequence of barriers this potential access may not be realised (Gulliford et al. 2003 p. 5). Access needs to be viewed more widely than simply service availability and utilisation and these two should be considered separately (Gulliford et al. 2003).

3.3.5 Methodological Problems with the Evidence on Access to Health Care

In their review Goddard and Smith (1998) concluded that many of the studies included in their report exhibited methodological inadequacies. This included possible biases in studies involving the identification of need for services disguising the fact that individuals from low socioeconomic groups were in poorer health and hence had greater need for services. The other drawback with studies reviewed was that despite the evidence of inequities in certain services, simply observing disparities in utilisation did not assist in elucidating the complex intricacies of supply and demand factors influencing these patterns of consumption (Goddard et al. 1998). For example on the supply side, some health care professionals may have a propensity to treat some groups in preference to others. On the demand side some patients may be less inclined to present for treatment in a timely fashion (Goddard et al. 2001). Focusing on the utilisation of services (realised access) does not provide insights into inequities in potential access since it is difficult to determine from these studies how to disentangle the complexities of interaction involved and without a more nuanced insight into access inequity, recommendations for policy prescription are somewhat limited (Goddard et al. 1998). Quantitative research has been able to identify inequities but is less able to explain the findings and disentangle demand and supply side factors (Goddard et al. 2001). The evidence from the current review was largely quantitative and it has been suggested that qualitative research may be better able to extricate demand side and supply side factors influencing equity of access (Goddard et al. 2001).

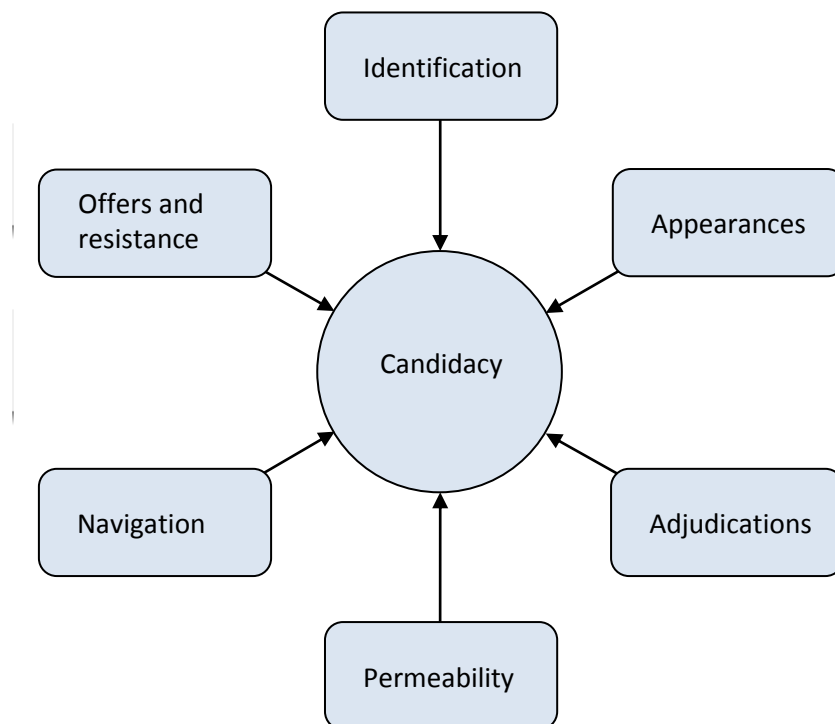
3.3.6 Providing a Theory of Access to Health Care by Vulnerable Groups

Starting from a position that acknowledges the limitations of research focusing on utilisation of services, Dixon-Woods et al. (2005) suggest that this attention to the amount of services 'consumed' by individuals takes no account of other factors that have considerable influence over access. For example, focusing on utilisation takes no account of the complexity involved in the receipt of health care by individuals. In contrast to the reviews conducted by Goddard and Smith (1998) and Gulliford et al. (2001), Dixon-Woods et al. (2005) proposed a theory to explain access. Rather than providing a systematic review, Dixon-Woods et al. (2005) provide a 'critical interpretive synthesis' of access to health care by vulnerable groups, using an approach grounded in meta-ethnography (p. 6). In common with Goddard and Smith (1998) and Gulliford et al. (2001), Dixon-Woods et al. (2005) concluded that the evidence on access to health care by vulnerable groups was inconclusive and difficult to interpret.

Candidacy theory

Dixon-Woods et al. (2005) proposed a dynamic model in which ‘candidacy’ was identified as the most useful way to comprehend the way individuals interact with health care systems and could explain the particular issues faced by vulnerable groups in terms of barriers to health care. The term candidacy encompasses the complex interactions involved when an individual presents for health care and includes the notion of acceptance by health care professionals or the individual themselves for potential services. Candidacy theory captures the concept that eligibility for access to health care services is a jointly negotiated undertaking and involves a dynamic component in which interactions between individuals and health care providers are in a constant state of change. Six core categories are used to explain how ‘candidacy’ for services is ‘jointly accomplished by people and health services’ (Dixon-Woods et al. 2005, p 97): Identification, permeability, navigation, appearances at health services, adjudications, offers and resistance. The six key concepts and the central core category are depicted in Figure 3.2.

Figure 3.2 The key concepts of Candidacy theory (Dixon-Woods et al. 2005)



Permeability

Permeability is a term used to describe how easily patients may access services (Dixon-Woods et al. 2005). Dixon-Woods et al. (2005) describe how ‘services can be conceptualised as being surrounded by membranes that are more or less porous’. A membrane is described as permeable if it is easy for a patient to cross it; either navigating from one service to another, or

entering the system (Dixon-Woods et al. 2005, p. 86). For example, gaining access to specialist services in a hospital outpatients' department is described as less permeable than visiting the local general practice or emergency department because a greater effort and more resources are required from the patient in order to access the former (Dixon-Woods et al. 2005).

Navigation

Navigation refers to the set of routes a patient may take in order to access services. Some individuals seem better able to negotiate health care services than others. It appears that this ability may be unequally distributed and that lower socioeconomic groups may be disadvantaged. Influences on ability to navigate services include lack of knowledge about what is available, beliefs about the usefulness of seeking help and the problems associated with stigmatising conditions leading to a reluctance to engage with services (Dixon-Woods et al. 2005).

Appearances

The concept of appearances proposes that individuals either present themselves at health care services through their own actions or appear in response to health care initiated invitations. In presenting at health care services individuals assert their candidacy for a particular treatment or service. However, presentation requires effort by patients and it seems that ability to present as an eligible candidate is subject to variation in the population leading to potential disadvantage amongst individuals in lower socioeconomic groups.

Relevant research contests that individuals from lower socioeconomic groups are less able to articulate their needs and present credibly than middle class individuals, possibly due to the social distance between themselves and health care providers (Dixon-Woods et al. 2006). It appears that middle class individuals are better able to articulate their demands whereas individuals from lower socioeconomic groups are less verbally active (Dixon-Woods et al. 2006). Issues of communication were a recurrent theme in a number of studies reviewed by Dixon-Woods et al. (2005) and were an important influence on whether potential access to treatment was converted to realised access or 'in service' access (p. 44).

Adjudications

Adjudications refers to the ways in which individuals are judged, by health care professionals, to be suitable candidates for treatment and services. Adjudications may be adversely

influenced by aspects of patient characteristics more prevalent amongst vulnerable groups, for example co-morbidities or presenting late. Dixon-Woods et al. (2005) identify the study conducted by Hughes and Griffiths (1997) as key to understanding how individuals are judged by doctors to merit various interventions. Hughes and Griffiths (1997), investigating decision-making relating to cardiac surgery and specialist neurological rehabilitation, found that doctors' decisions, based on lifestyle factors such as smoking or obesity, identified some patients as less suitable candidates for surgery or other interventions. Dixon-Woods et al. (2005) suggest that patients who are judged to be less likely to do well following interventions and hence may not be identified as suitable candidates are also more likely to be from disadvantaged groups.

Offers and resistance

Health care professionals may or may not make offers of treatment and services to patients. Patients may choose to accept or decline the offers. There has been an assumption in studies investigating utilisation of services that non-utilisation is indicative of non-offers (Dixon-Woods et al. 2006). However, patients can choose to resist offers made following adjudication, either delaying or refusing treatment (Dixon-Woods et al. 2006).

Use of Candidacy theory in empirical research

Candidacy theory has been used to investigate or elucidate aspects of access in mental health services, (Bristow et al. 2011; Kovandzic et al. 2011), emergency and urgent care (Hunter et al. 2013; O'Cathain et al. 2008), diabetes, coronary heart disease or mental health problems in British South Asian patients (Garrett et al. 2012), and systems of care for Aboriginal and Torres Strait Islander people (Peiris et al. 2012). Candidacy theory has also been used to develop a model to improve access to psychosocial interventions (Gask et al. 2012).

3.3.7 Reflections on Equitable Access to Diabetes Care

Following this outline of the concepts involved in access to health care, it appears that a more complicated picture emerges for access to care for adults with type 1 diabetes than the one proposed by Mühlhauser et al. (1998b). To recap, Mühlhauser et al. (1998b) showed in their study that although socioeconomic disparities in access to diabetes care were found, study participants in low socioeconomic groups had had opportunities to access all the aspects of diabetes care under investigation. The authors concluded that lack of motivation was the root

cause of poor uptake of services. However, as noted in the previous section, having access to services or being offered services does not necessarily equate to equity of opportunity.

3.3.8 Summary for Equity of Access to Health Care

Research into equity of access for individuals of low socioeconomic status has identified that the area is fraught with complexities. There appears to be greater utilisation of primary care and less of some secondary care services amongst individuals in low socioeconomic groups (Dixon-Woods et al. 2005; Goddard et al. 1998; Gulliford et al. 2001). In addition, preventive health care is less utilised by lower socioeconomic groups. Candidacy theory appears to provide a way to understand how vulnerable groups experience inequity of access (Dixon-Woods et al. 2005) and qualitative research may offer a way to extricate demand and supply side factors involved in inequities in access to health care (Goddard et al. 2001). A key aspect of asserting candidacy for services and treatment involves patients making appearances at health care services and interacting with health care professionals. Patient-provider communication is therefore likely to be an important area of investigation when examining issues of access to intensive regimens in type 1 diabetes.

3.4 Patient-Provider Communication

Patient-provider communication is a crucial element of the therapeutic process (Zolnierek et al. 2009) with the quality of patient-provider interaction playing an important role in both the effectiveness of health care delivery (Drew et al. 2001) and the accessibility of health care for individuals (Willems et al. 2005). The interaction between health care providers and adults with type 1 diabetes is of central importance to the current study since decisions about adopting a given insulin regimen will be conducted in health care settings and involve both patients and their health care providers. In relation to access to health care, therefore, a number of areas of research relating to patient-provider communication appeared to be pertinent. These were: patient involvement in decision-making; socioeconomic influences on patient-provider communication; health literacy: issues related to access and patient-provider communication; the impact of co-morbid depression on patient-provider communication; and patient-provider communication in diabetes care. Section 3.4 focuses on a review of the literature on patient-provider communication relating to these areas. Since the body of literature is large, another systematic review was not considered appropriate. Instead a number of key papers and two books were identified as relevant to the current study and were used as the starting point for the review. These papers were supplemented through further

citation and reference searches using Google Scholar and Medline (accessed via Ovid). The following summarises the key literature relevant to the three main areas described above:

- An overview of patient involvement in decision-making (Collins et al. 2007a; Say et al. 2006)
- Patient-provider communication in diabetes care (Brown et al. 2004; Montori et al. 2006)
- Patient-provider communication and the influence of socioeconomic status (Brown et al. 2004; Roter et al. 2006; Verlinde et al. 2012; Willems et al. 2005)

3.4.1 Patient-Centred Care and Involvement in Decision-Making

In recent decades there has been a shift away from paternalistic health care and an impetus to engage patients in an active way in their own health care decisions (Edwards et al. 2009a). Efforts to involve patients in decision-making have resulted in a growth in research focused on how this goal may be accomplished (Elwyn et al. 2009). Various terms have been used to describe approaches to patient-provider communication (Elwyn et al. 2014). These include: patient-centred care; patient involvement; patient engagement; informed patient choice; and shared decision-making (Elwyn et al. 2014). Other researchers have focused on the terms patient participation and partnership (Collins et al. 2007b). The genesis of these approaches, though, all appear to have arisen from an interest and debate about ‘patient-centred’ care originating in the work of Balint (Enid and Michael) and of Byrne and Long (1976). The latter described the different approaches taken by doctors within the consultation and observed that some were ‘doctor-centred’ and others ‘patient-centred’.

Although there has been some variation in the use of the term ‘patient-centred’ within studies (Dwamena et al. 2012) nevertheless proponents of the approach appear to share a desire to understand illness from the patient’s perspective (Dwamena et al. 2012). Shared decision-making has been seen as ‘the crux of patient-centred care’ (Godolphin 2009, p. 186). Shared decision-making, viewed as a way to promote a patient-centred approach to care, is particularly relevant given the increasing number of health care choices available (Stacey et al. 2010). The widespread interest in shared decision-making amongst research communities is evidenced by the exponential growth in the publication of related papers in high impact journals in the period 1996 to 2011 (Blanc et al. 2014).

The impetus behind encouraging greater patient involvement in decision-making processes is seen as an ‘ethical imperative’ by some (Edwards et al. 2009a; Elwyn et al. 2010). Others point

to the growing evidence of benefits of the approach (Légaré et al. 2010; Stacey et al. 2014). For example patients who are more active in decisions about their health have better health outcomes and health care experiences (Hibbard et al. 2013). Shared decision-making is also promoted because of the important part the process may play in three key respects relating to patient safety (Godolphin 2009). First, responses to enquiries into patient safety, for example, the Bristol Enquiry, highlighted the ‘failure to put patients at the centre of care’ and emphasised the need to ‘deliver a high quality, patient-centred service for the twenty first century’ where ‘patients and staff work in genuine partnership’ (Department of Health 2002, p. 1). Second, patient involvement may play a part in avoidable errors that arise as a consequence of poor communication around the use of medication (Godolphin 2009). Third, shared decision-making is viewed as a way to address variation in health care (Coulter et al. 2011; Godolphin 2009).

One of the key imperatives for the drive to involve patients in decision-making, however, has been the growing prevalence of chronic disease and with it an emphasis on self-management (Charles et al. 1997). It is increasingly recognised that the patient needs to have involvement and ownership of their treatment regimen (Charles et al. 1997). Hence, the move to involve patients in decisions about their health care has been reinforced through policy (Department of Health 2010; Department of Health 2013) and through guidance issued by the General Medical Council (2013) and other professional regulatory bodies (the Nursing and Midwifery Council (2015) and the Health and Care Professions Council (2008)).

Defining shared decision-making

Shared decision-making may be defined as a process in which one or more health care professionals together with a patient (or significant other or both) choose a treatment together (Charles et al. 1997; Légaré et al. 2014; Towle et al. 1999). The basis of the process rests on a requirement for health care professionals to present evidence based treatment options and to encourage patients to share in the decision-making process through informed choice and the patient’s own expressed preferences (Elwyn et al. 2012).

The concept of shared decision-making is predicated on the notion that both the patient and the health care professional have expertise and as such both parties should be involved in the decision-making process (Coulter et al. 2011). Hence a mutually agreed decision takes account of both the patient’s experience of illness and their views on the options presented, together with the information presented by the health care professional formulated through their knowledge and expertise of the possible range of options (Coulter et al. 2011).

The shared decision-making model

According to Edwards et al. (2009a) and Makoul et al. (2006) one of the most commonly cited models of shared decision-making was developed by Charles et al. (1997). This model offers an alternative to two 'polar extremes'. The first of these positions is the paternalistic model depicted as the health care professional making the decision on behalf of the patient. The alternative position identifies the patient as an informed autonomous decision maker (the informed model of decision-making). The shared decision-making model proposed by Charles et al. (1997) offers a mid-way between these two positions. Their approach allows for the patient to be fully informed about the pros and cons of treatment alternatives but also proposes that the health care professional does not abandon the patient to making their decision but rather that they remain involved in the decision-making process without dominating the outcome of the treatment decision (Charles et al. 1997). This model takes account of the empirical evidence which suggests that although not all patients want the same level of involvement, very few patients want none at all (Charles et al. 1997). The key features proposed for this model are:

- At least two participants are involved in the process (patient and physician)
- There is a sharing of information by both parties
- Participants in the process are involved in building a consensus regarding the preferred treatment option
- Both parties reach an agreement on the treatment decision

This model was further summarised comprising three key phases: information exchange, deliberation and treatment decision (Elwyn et al. 2001). Although the essential elements of shared decision-making have been identified and summarised (Makoul et al. 2006), Elwyn et al. (2012) argue that relatively little attention has been paid to providing pragmatic advice regarding the implementation of the shared decision-making process in routine clinical settings. In order to address this need for advice Elwyn et al. (2012) propose a model for 'how to do shared decision-making in routine settings'. The authors recommend the use of a three step model that comprises: 'choice talk', 'option talk' and 'decision talk' (Elwyn et al. 2012). First, 'choice talk' relates to the task of letting patients know that options exist. Second, 'option talk' is about laying out possible courses of action whilst eliciting patient knowledge, describing the pros and cons of the various options decision talk and providing decision support tools where applicable. Third, 'decision talk' involves encouraging the patient to

identify their preferences whilst eliciting if the patient is ready and willing to make a decision and if not recommending that the decision may be deferred (Elwyn et al. 2012).

Elwyn et al. (2012) contend that the objective of shared decision-making should be to enable individuals to 'act independently and to make their own free choices' and that this is best accomplished in two key ways. First, the primary objective of shared decision-making should be to ensure that patients have the necessary high quality information to provide a sound basis from which to engage in the process of decision-making. Second, a key aspect of the model is the need to allow individuals time to think about the options discussed. This process is termed 'deliberation' and it is understood that this may in part be conducted outside the clinical environment. It would seem that 'deliberation' is the key to shared decision-making and there is an important distinction to be made between 'deliberation' and 'determination' (Politi et al. 2013). Although not all patients want to make a choice ('determination') many want to be involved in the decision-making process ('deliberation') (Politi et al. 2013).

Has shared decision-making been adopted?

Although promoted as the ideal, shared decision-making is not widely experienced by patients or practised by health care professionals (Entwistle et al. 2008; Stevenson et al. 2000; Stevenson et al. 2004; Stringer et al. 2008) and in particular appeared not to be experienced by adults with type 1 diabetes around 10 years ago (Paterson 2001). According to Elwyn et al. (2010) shared decision-making 'implementation has proved difficult and slow' (p. 971). It appears that patients are not always fully informed prior to decisions (Coulter 2010; Fagerlin et al. 2010) despite many patients having a preference for shared decision-making (Hibbard 2008). Although patients who are involved in decision-making have better outcomes, very often patients are not involved in decisions (Légaré et al. 2014).

Influences on shared decision-making

The reasons why shared decision-making has not been widely adopted appear to relate to both patient and health care professional factors. For example it has been observed that although advocated as the optimum model of patient-provider communication, shared decision-making should not be assumed to be the ideal in all circumstances (Edwards et al. 2009a). Some patients may be reticent to take on a participative role (Stevenson 2007) and prefer a paternalist approach to decision-making or the informed model of decision-making (Murray et al. 2006). Hence it has been argued that the term shared decision-making should be used to indicate the degree of involvement preferred by the patient and the ways in which

health care professionals can strive to meet and realise these preferences (Edwards et al. 2009a).

From the health care professional perspective a systematic review of barriers and facilitators found that the three most commonly reported hindrances to shared decision-making were time constraints, the influence of patient characteristics and the clinical situation. Légaré et al. (2008) suggest that health care professionals make judgements about which patients may benefit the most from the shared decision-making approach and that this in turn leaves open the possibility that health care professionals may incorrectly perceive that some patients are not interested in the process. In contrast the most commonly reported factors facilitating shared decision-making were health care professional motivation and perceived positive impact on both patient outcomes and on the clinical process (Légaré et al. 2008).

Patient preferences for shared decision-making

There is evidence that various factors are influential in patients becoming involved in the decision-making process. In their narrative review, Say et al. (2006) found certain demographic variables were influential in determining patient preference for involvement in decision-making. Younger, better educated and female patients had a preference for playing a more active role in making decisions. In contrast individuals of low socioeconomic status, as measured by occupation and income, had a preference for a more passive role. Health status was found to influence patient preferences for involvement. Individuals with more serious conditions for example, severe diabetes, heart disease and recently diagnosed breast cancer patients have shown a preference for less involvement. This finding was not consistent across all serious conditions however, for example women with ovarian cancer had a preference to share decisions (Say et al. 2006).

All the quantitative studies in the review by Say et al. (2006) were of observational design and hence causality cannot be assumed. Additionally there were problems of sample size (too small and in some cases too homogeneous) and therefore studies may have been prone to bias. The authors acknowledged that some of the limitations of the studies in their review involved the measurement of variables. For example the complexity of decision-making preferences may not be fully reflected in quantitative studies because the possible response options for participants are limited. Qualitative research was therefore also reviewed in order to offer a more nuanced explanation for the results of the quantitative studies. This aspect of the review found that some patients, whilst wishing to participate, may have felt that they did not have the knowledge and expertise to involve themselves in decision-making (Charles et al.

1998). Another study of patients with type 1 diabetes found that stage of illness had a bearing on the level of support patients required from health care professionals (Thorne et al. 2001). This study was, however, limited to individuals who had either selected themselves or who had been nominated as experts. In another study (involving patients with cancer), having a good relationship with health care professionals, actively seeking information and being encouraged to participate was found to promote involvement whereas poor relationships tended to restrict involvement (Sainio et al. 2001). Whereas the review by Say et al. (2006) focused on patient preferences there is evidence that patient involvement in consultations is influenced by both patient and provider characteristics.

3.4.2 Patient-Provider Communication and Socioeconomic Status

The previous section identified shared decision-making as an ideal goal for patient-provider communication but acknowledged that the process has not been widely adopted. This section discusses research findings that focus on some of the barriers to effective communication between patients and providers relating to socioeconomic factors that are also likely to adversely affect attempts to implement shared decision-making. This is particularly pertinent to the current thesis since socioeconomic disparities in communication have been postulated as a hindrance to the ability of individuals to benefit from diabetes health care (Brown et al. 2004).

The influence of socioeconomic factors on the relationship between patients and health care providers has been the focus of much research (Verlinde et al. 2012). In this section the ways in which communication may affect the ability of health care providers to deliver equitable health care are discussed. Drawing on a number of systematic reviews as a starting point, and using a 'snowballing' technique (Booth et al. 2012 p. 78) in conjunction with citation and reference searches, this section identifies the prominent influences on socioeconomic disparities in communication. These include: the style of communication adopted by both patients and providers; the role of information provision; and the ways in which patients experience disparities in relation to this key factor.

Style of communication

It would appear that socioeconomic disparities influence patient participation in health care communication. This is of particular concern given the prominence of shared decision-making as a goal in health care communication. In their systematic review of the social gradient in doctor-patient communication Verlinde et al. (2012) discussed the influences on patient-

centred approaches. For example, in a cross sectional study conducted in the USA Kaplan et al. (1995) found that a participatory decision-making style was associated with levels of education. Adults without education above the level of high school experienced consultations with less patient participation than those with a college education (Kaplan et al. 1995).

It also appears that shared decision-making can be affected by the style of communication adopted by health care professionals with those of low socioeconomic status. In a review of the effects of socioeconomic status on communication, patients from lower socioeconomic groups received a more directive approach, less participatory discussion, had less control over the direction of the conversation and received less information from doctors (Willems et al. 2005). In one study, patients of low educational attainment received a more directive style of communication and patient expectations were less likely to have been met (Fiscella et al. 2002).

Hence it would appear that style of communication is implicated in socioeconomic disparities. Roter et al. (1997), exploring patterns of communication in primary care doctors, found a spectrum that ranged from the 'narrowly biomedical' (closed questions and talk relating to biomedical matters) to a 'consumerist' pattern that involved patients asking questions and doctors giving information. Patients that experienced communication in the narrowly biomedical pattern were more likely to be of low socioeconomic status. There was less scope for these patients to have discussions involving psychosocial issues and less communicative control for these individuals.

These findings need to be viewed with caution. As noted in section 3.4.1 patient preferences also play a part in socioeconomic disparities. In research conducted in the UK, McKinstry (2000) found that lower socioeconomic status (educational level) was associated with a preference for a more directive rather than shared approach to decision-making. Hence there are complex factors involved in patient-provider communication. There also appears to be evidence of bi-directional influences on patient involvement. Willems et al. (2005) provides evidence of this in a review of the socioeconomic factors on patient involvement since it appears that patients with higher levels of education engender a more participatory approach from physicians and that in turn patient communication style is further influenced by partnership building utterances (Street 1992; Street 1991).

Disparities in information sharing

It appears that information sharing may be a key influence on some of the socioeconomic disparities noted in patient-provider communication research. In chronic disease management, the exchange of information is essential to the process of shared decision-making (Montori et al. 2006). However, although information sharing is an important component of patient-provider communication, it remains an area of difficulty in health care interactions (Street 1991). A number of early studies showed a positive relationship between information giving by health care professionals and socioeconomic status of patients (Pendleton et al. 1980; Street 1991; Waitzkin 1985). In an early study of patient doctor communication both education and social class predicted how much information was received by patients (Waitzkin 1985). Both college educated and individuals of corporate and upper middle class backgrounds received more information than those who were not college educated or were from lower middle and working class backgrounds. Waitzkin (1985) also found that the higher socioeconomic groups had lengthier consultations and more explanations from doctors. Education rather than social class was found to be more important in explaining the transmission of communication (Waitzkin 1985).

'Passive' and 'active' patients

Some reasons for socioeconomic disparities in information sharing were suggested by Street (1991). In this study patients who were the recipients of more information tended to have higher educational levels, were more anxious and were younger than other participants. The author proposed that information giving was related to patients' communication behaviour (asking questions) and differences in anxiety and education levels amongst patients. This suggested that greater information giving by the doctors was in response to a more verbally active and assertive patient. Hence some patients received less information both because of their communication style as well as their social characteristics.

These findings relating socioeconomic status to patient-provider communication were strengthened in a follow up study in which Street (1992) found that patients of higher educational level were more verbally active in interaction with doctors and asked more questions than other participants. It appeared that some patients were more involved in the consultation with doctors than others. Social and personal characteristics were found to have played a part in patient communication (Street 1992). Older more educated patients generally offered more opinions and provided more information. Patients from lower socioeconomic

groups tended to be more reticent than their counterparts in the higher socioeconomic groups (Street 1992).

The results of these studies suggest that communication was influenced by both health care professional and patient characteristics and the interplay between both. For example Street (1992) observed that physician communication may well be influenced by patients asking questions because normatively, answers follow questions and hence physicians provide more information to patients who are verbally assertive. Street (1992) draws on the work of conversation analysts in making this point and in particular the work of Sacks, Schlegoff and Jefferson in their landmark study 'A simplest systematics for the organization of turn-taking for conversation' (Sacks et al. 1974). Amongst those individuals with high educational attainment and social status there appears to be a tendency to seek clarification through questioning and to be more involved in the decision-making process (Scambler 2003). In a study conducted in the UK only 25% of individuals from lower socioeconomic groups sought clarification in a consultation with their GP compared with 45% in the higher socioeconomic groups. This clarification process precipitated a lengthier discussion and consultation (Tuckett et al. 1985).

Cultural distance and influences on patient-provider communication

It has been suggested that there is less cultural distance between higher socioeconomic groups and health care professionals compared with their counterparts in lower socioeconomic groups and that this contributes to a greater ease in communication between the former and their health care providers (Willems et al. 2005). The tendency for individuals in low socioeconomic groups to be more diffident in consultations than individuals of higher socioeconomic status was noted by Waizkin (1985). This was explained by sociolinguistic differences associated with education and social class. Whereas the desire for information did not differ amongst socioeconomic groups, the diffidence amongst individuals from lower socioeconomic group led doctors to assume, incorrectly, a lack of interest about information (Waitzkin 1985).

Willems et al. (2005) discussed the disadvantages to patients of low socioeconomic status in both having a more passive style of communication and of being perceived by health care professionals as less interested in information relating to their health. Waitzkin (1985) found that differences in the way socioeconomic groups communicate with health care professionals are likely to amount to significant barriers to interaction.

Communication is influenced by both patient and provider characteristics

Verlinde et al. (2012) conclude that the social gradient in patient provider communication is a complex mix of patient and health care professional characteristics. Patients and health care professionals are influenced by each other in the ways that they communicate. Although patients have the ability to influence health care professional communicative behaviour it seems that patients of lower socioeconomic status tend not to be as able to exert as much control in the health care interaction as patients from higher socioeconomic groups (Verlinde et al. 2012).

The impact of socioeconomic status on shared decision-making

The influence of socioeconomic status has been suggested as a barrier to shared decision-making and there have been calls for further research to investigate these factors (Durand et al. 2014). It seems likely that there will be a propensity for the articulate and well educated patient to be attracted to shared decision-making leaving less advantaged individuals possibly disengaged with the process (Coulter et al. 2011). These disparities may lead to an increase in health inequalities (Durand et al. 2014). A recent review suggested that shared decision-making interventions resulted in improved outcomes for lower socioeconomic status participants including increased knowledge and participation in decision-making (Durand et al. 2014). Disparities between disadvantaged and higher literacy/higher socioeconomic status participants post-intervention were eliminated in a number of areas relating to: knowledge; decisional conflict; and preferences for treatment, thus highlighting the potential of these interventions to reduce health inequalities (Durand et al. 2014). Health literacy is postulated as one of the key influences on ability to influence the health care interaction and lower health literacy is often found in individuals of lower socioeconomic status (Verlinde et al. 2012; Paasche-Orlow et al. 2007). The following section discusses disparities in health literacy and the ways in which this factor may affect patient-provider communication.

3.4.3 Health literacy: Issues Relating to Access and Health Care Communication

Defining health literacy

It is acknowledged that low levels of literacy pose a problem in the developed world (Easton et al. 2013). In England functional literacy has been defined as ‘the ability to read, write and speak in English, and to use mathematics at a level necessary to function at work and in society in general’ (Moser 1999). In England five levels are used to measure literacy and numeracy (see Box 3.1).

Box 3.1 Measures of literacy and numeracy

Entry Level 1: the national school curriculum equivalent for attainment at age 5-7

Entry Level 2: the national school curriculum equivalent for attainment at age 7-9

Entry Level 3: the national school curriculum equivalent for attainment at age 9-11

Level 1: equivalent to GCSE grades D-G

Level 2: equivalent to GCSE grades A*-C

Level 1 (for literacy) and Entry Level 3 (for numeracy) have been identified as the minimum standards required for individuals to be able to function adequately at both work and in society (Moser 1999). In England the Skills for Life survey of literacy levels amongst English adults found that 15% of respondents (the equivalent of 5.1 million working age adults) were at or below the level of attainment of an 11 year old (i.e. below the equivalent of the General Certificate of Secondary Education Grades D-G). In relation to numeracy, 24% of respondents (the equivalent of 8.1 million working age adults) fell below Entry Level 3 (that is, below the equivalent attainment of a 9 year old) (Department for Business Innovation and Skills 2012).

It is postulated that low literacy and numeracy levels are correlated with poor health outcomes; the preferred concept is that of health literacy (Easton et al. 2010). Health literacy is 'a set of skills that people need to function effectively in the health care environment' (Berkman et al. 2011a, p.97) and relates to the acquisition, processing, and understanding of health care information required for effective decision-making (Berkman et al. 2011b). The World Health Organisation (1998) define health literacy as 'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' (p. 20).

There has been much debate about definitions, conceptualisation and measurement of health literacy (Smith et al. 2013). Some definitions are restricted to the concept of skills in literacy. Others use the term more expansively to encompass the ways in which individuals are able to interact socially. A widely cited model of health literacy, proposed by Nutbeam (2000), utilises a broader definition comprising three levels. First, functional literacy encompasses the minimum elementary skills required for reading and writing. Second, communicative literacy involves a level of social skills that enables individuals to elicit information and meaning from a

variety of communication scenarios and to be able to apply this information to dynamic situations. Third, critical literacy is the cognitive skill involved in being able to analyse information in a way that enables individuals to exert greater power over their circumstances and events in their lives (Nutbeam 2000).

The relationship between functional literacy and health literacy is not straightforward (Easton et al. 2010). Although some factors would appear to be common to both concepts it has been difficult to distinguish between the impacts of each. For example high functional literacy does not guarantee high health literacy although having low functional literacy is likely to inhibit high levels of health literacy (Easton et al. 2010).

Health literacy and health outcomes

Regardless of the ways in which health literacy is defined, a growing literature has acknowledged that health literacy skills are strongly associated with health related outcomes (Berkman et al. 2011a; Easton et al. 2010). For example, poor health literacy was associated with higher emergency department utilisation (Baker et al. 2004) and a greater likelihood of hospitalisation (Baker et al. 2002). Those with poor health literacy were less knowledgeable about health (Gazmararian et al. 2003; Williams et al. 1998), used less preventive care (Scott et al. 2002) and had worse chronic illness control (Schillinger et al. 2002). In adult patients with diabetes, sub-optimal glycaemic control was associated with inadequate health literacy (Schillinger et al. 2002). Patients with inadequate health literacy were also more likely than those with adequate health literacy to report retinopathy (Schillinger et al. 2002).

In a systematic review a relationship was found between functional or health literacy and ability to manage long term conditions (Easton et al. 2010). Low health literacy was associated with poorer adherence to treatment regimens in studies involving both HIV/AIDS and asthma patients (Easton et al. 2010). In a recent review, literacy and numeracy were associated with knowledge relating to diabetes (Bailey et al. 2014).

Although research has identified associations between health literacy and various health related factors there has been less success in establishing the causal pathways involved in these relationships (Dewalt et al. 2004; Paasche-Orlow et al. 2007). Paasche-Orlow et al. (2007) acknowledge that given the associations between health literacy and socioeconomic factors such as age, ethnicity and educational attainment it is difficult to extricate the independent effect of the health literacy component. Due to the complexity of relationships and the interrelatedness of the factors the authors' model of causal pathways connecting

health literacy to health outcomes focuses on direct linkages between health literacy and health outcomes whilst also acknowledging that there are other less direct factors involved.

Three domains are included in their conceptual model of proposed causal pathways: access and utilisation of health care; provider-patient interaction and self-care. Each of the three domains is further subdivided into patient level factors and system level factors in order to acknowledge the importance of both the patient and factors external to the patient in the model. Paasche-Orlow et al. 2007 considered the potential influence of poor health literacy on access and utilisation of services, including the notion that poor health literacy may lead to delays in help seeking, feelings of inadequacy and shame at the prospect of health encounters deterring primary prevention access and difficulties navigating health care services due to the complexity of directions and instructions.

In a systematic review investigating the relationship between low functional or health literacy and health, Easton et al. (2010) found that difficulties were associated less with gaining initial access than with patients making the most appropriate use of services and being able to attain suitable treatment. The authors suggested that being able to access appropriate services and good quality treatment may mediate some of the associations between low functional and health literacy and poorer outcomes. This suggests that what happens when patients interact with health care services is of particular importance and that patient-provider communication is likely to be a key influencing factor.

The impact of health literacy on patient-provider communication

Health literacy and the impact of information on shared decision-making

In section 3.4.1 the role of information exchange was described as an essential element in shared decision-making and socioeconomic disparities in information exchange were discussed in section 3.4.2. For effective shared decision-making, patients need to be informed about the treatment options and possess an understanding of the risks and benefits of treatment. Studies have shown that poorly informed patients may affect the shared decision-making process. For example, in a study conducted in the US, patient knowledge about the facts surrounding decisions that patients had recently made was poor (Fagerlin et al. 2010). Patient characteristics and the type of decision had a bearing on the patient's knowledge (Fagerlin et al. 2010). Part of the problem appeared to be the lack of awareness patients have in relation to their knowledge deficits (King et al. 2011).

It also appears that poor health literacy is an important influence on information exchange (Edwards et al. 2009a). In their review, Ishikawa et al. (2008) found associations between health literacy and the ability to elicit information from health care professionals as well as difficulties in understanding information imparted from health care professionals. Poor reading ability amongst low income elderly patients was associated with the use of television as the main source of health related information. Ishikawa et al. (2008) suggest that the evidence on the impact of health literacy largely focuses on the functional aspects of the concept and it appears that there is a gap in the research relating to communicative and critical health literacy (Ishikawa et al. (2008).

Edwards' et al. (2009) meta-synthesis provides a conceptualisation of external influences on information exchange in shared decision-making where health literacy mediates patient related influences and is also an influence on empowerment. Health literacy appears to act as a facilitator or inhibitor in relation to whether or not patients are motivated to seek information and having acquired information, determines whether or not this knowledge is used in their health care interactions. What appears to be a key influence is the ability to assess critically the acquired information. These critical health literacy skills go beyond functional health literacy and require patients to be able to communicate effectively their understanding of the acquired information. Edwards et al. (2009b) concluded that more equitable health care encounters could be facilitated by addressing the improvement of information exchange.

The impact of health literacy on the quality of communication and patient involvement

In their review Paasche-Orlow et al. 2007 consider the ways in which health literacy may impact on patient-provider communication. They asserted that having less knowledge about a disease has a number of implications in terms of communicating with health care providers, including feelings of shame if patients are aware of their knowledge gaps and an avoidance of asking questions of their health care professionals. The authors observed that links have also been made between low literacy and mental health problems. They proposed that this may lead patients to adopt a passive stance within consultations and in some cases may lead to problems with 'miscommunication' (Paasche-Orlow et al. 2007 p. S22).

In a review of the 'hidden population' of people with low literacy, Easton et al. (2010) observed that factors external to the patient may moderate the impact of low functional or health literacy including the ability of health care professionals to recognise these difficulties amongst

their patients and hence to accommodate them. In their review, Easton et al. 2010 focused on individuals with literacy difficulties that may not be readily apparent to health care professionals.

The concept of health literacy and its influence has been proposed as a potential barrier to effective participation in health care (Ishikawa et al. 2009; Protheroe et al. 2009). There has been increasing interest in the important influence of health literacy for effective communication (Lambert 2014) and interventions for individuals with low health literacy (Sheridan 2011, Berkman 2011)). The model of health literacy proposed by Nutbeam (2000) (defined above) appears to be pertinent in relation to shared decision-making since it highlights the health literacy skill levels (functional, interactive and critical) that are necessary to achieve an increasing level of decision-making involvement (Smith et al. 2013). Although there is an expectation that patients will be more involved in decision-making, there are concerns that some do not have the ability to do so (Hibbard et al. 2007) and it appears that low health literacy and low numeracy pose a challenge to shared decision-making (Elwyn et al. 2012; Smith et al. 2013). For example a recent study found that low health literacy was implicated in perceived barriers to care and attitudes towards shared decision-making amongst low socioeconomic status parents (Yin et al. 2012). Those with low health literacy reported a feeling that they were not partners in decision-making and that they were more likely to leave the decision-making to doctors (Yin et al. 2012).

The impact of health literacy on patient involvement and communication more generally has been investigated in a recent review conducted by McCaffery et al. (2013). The review found that individuals with lower health literacy were less inclined to want to participate than those with higher literacy. Additionally lower health literacy was associated with asking fewer questions and also less involvement in the medical encounter. Lower patient-centred consultations were reported for individuals of lower health literacy. One study found no difference between the experience of higher and lower health literacy patients in terms of their perceptions of involvement in the consultation and one study reported that lower health literacy patients had a greater satisfaction with their health care encounter. In contrast a study of patients with breast cancer found that lower health literacy patients were less satisfied with decisions in relation to treatment. One study investigating the three forms of health literacy outlined above (functional, communicative and critical) found that individuals with lower communicative health literacy were more satisfied with the doctor's explanations as the amount of information they received increased. This relationship did not appear to be so clear for individuals with higher communicative literacy (McCaffery et al. 2013).

In a review of health literacy and health outcomes in diabetes, Al Sayah et al. (2013) also investigated patient-provider communication. On the basis of their more limited number of papers they found that higher health literacy was associated with better patient-provider communication and better information exchange. The evidence from all studies was however, rated as low (Al Sayah et al. 2013).

Low health literacy appears to be associated with low socioeconomic status, the elderly and those with chronic conditions (Protheroe et al. 2009). It appears that whilst shared decision-making is the ideal, promoting this approach without considering health literacy amongst the population may lead to an exacerbation of health inequalities (Protheroe et al. 2009). These inequities will arise if there are disparities between those well able to engage with health care services and those who are 'least able to navigate their way into the health care system, interact successfully with health care professionals and understand disease prevention and management options' (Protheroe et al. 2009, p. 722).

Health literacy and interventions to promote patient engagement in decision-making

It is known that people with low health literacy tend to defer to health care professionals to make decisions for them (Shalowitz et al. 2004) and also tend to have less good health outcomes than people who are more actively involved in their health (Coulter et al. 2011). The term 'patient activation' has been used to describe the 'characteristics that enable a patient to take a more active part in the health care consultation and management of their illness' (McCaffery et al. 2010, p. 41). The core components that facilitate active engagement are patient knowledge, skills and confidence (Hibbard et al. 2005). A systematic review of studies attempting to develop patient activation amongst the general population found improvements in health outcomes and adherence (Michie 2003). A Cochrane review reporting on interventions designed to enhance patient participation through a range of strategies for helping patients to elicit the information they need in health care consultations found a small increase in levels of questions asked and patient satisfaction (Kinnersley et al. 2007). Both reviews were of studies conducted in the general population. As noted previously health literacy levels affect health outcomes, information exchange and engagement in the decision-making process and there is growing interest in decision support interventions that take account of different levels of health literacy (Frosch et al. 2014). Although it seems pertinent that health literacy levels should be taken into consideration in the development of patient decision aids it appears that this is rarely the case (McCaffery et al. 2013). Additionally, the authors identified a lack of papers investigating health literacy interventions to support

patient-provider communication. In their review of health literacy and patient decision aids, McCaffery et al. (2013) concluded that individuals with lower health literacy should be a priority for improvements in supporting the decision-making process.

3.4.4 The Impact of Depressive Symptoms on Patient-Provider Communication

In their review of socioeconomic factors in relation to diabetes, Brown et al. (2004) identified mental health issues as an important influence in relation to access to health care. According to Brown et al. (2004) depression is more likely in individuals with diabetes than in the general population and mental health issues are more common amongst individuals of low socioeconomic status (Brown et al. 2004). In a systematic review, rates of clinical depression in adults with type 1 diabetes were 12.0% compared with 3.2% for control subjects (Barnard et al. 2006). Depression in diabetes has been associated with hyperglycaemia and increased risk of complications (Barnard et al. 2006).

In the previous section it was noted that Paasche-Orlow et al. (2007) had postulated the ways in which mental health problems, which are more common amongst individuals with lower health literacy, may adversely impact on patient-provider communication. In their review of the influence of socioeconomic factors in individuals with diabetes, Brown et al. (2004) also made reference to the potentially adverse influence that depression may have on communication with health care providers.

A small body of relatively recent research investigating patient-provider communication in relation to depression and/or depressive symptoms in co-morbid chronic disease was identified for this review using Medline and PsycINFO with search terms including: depression; depressive symptoms; communication; and diabetes. This was further supplemented through a combination of citation and reference searches using Google Scholar. Five papers were identified which investigated communication and depressive symptoms in relation to: coronary heart disease (Schenker et al. 2009); HIV (Jonassaint et al. 2013); and diabetes (Beverly et al. 2012; Green et al. 2012; Swenson et al. 2008). All five were conducted in the USA.

In one study, investigating adults with type 1 and type 2 diabetes, no discernible difference in patient-centred communication was found in relation to levels of depressive symptoms (Green et al. 2012). Communication overall, however, was not patient-centred in most cases (Green et al. (2012). In another paper, adult patients with severe depressive symptoms and type 2 diabetes were more likely than those patients without depressive symptoms to report 'sub-

optimal' communication across four patient-centred domains including the elicitation of patient problems, empowerment, explanations of condition and decision-making (Swenson et al. 2008). A study that included adult individuals with type 1 and type 2 diabetes found that the majority of participants had confidence in their doctor, liked their doctor and described a good working relationship with their doctor (Beverly et al. 2012). Nevertheless approximately a third of participants were reluctant to discuss their self-care with the doctor and this reluctance to communicate was associated with depressive symptoms (Beverly et al. 2012). In relation to coronary heart disease, co-morbid depressive symptoms were associated with adult patient dissatisfaction with doctor-patient communication including patients reporting poor explanations from providers of health care and lack of responsiveness to patient preferences (Schenker et al. 2009). One study investigating the impact of depressive symptoms on patient-provider communication in adult individuals with HIV found that provider ratings were more negative for individuals with more depressive symptoms than other patients (Jonassaint et al. 2013). In this study patients with more depressive symptoms felt that their health care professionals lacked respect for them as people (Jonassaint et al. 2013). A framework for contextualising the findings of these studies in relation to patient-provider communication in adults with depressive symptoms includes three possible pathways: visit recall; visit content; and visit process (Swenson et al. 2008).

Visit recall refers to the proposal that the condition itself leads patients to view their interactions negatively and that their recollection is skewed (Swenson et al. 2008). Whereas Schenker et al. (2009) propose that patient perception and reports of communication with their health care providers are influenced by the patient's psychological condition, Swenson et al. (2008) view this as less plausible. The authors argue that if misinterpretation due to psychological factors were a plausible explanation, the other communication domains, for example patient trust and information sharing, would also have been implicated in feelings of dissatisfaction. That this is not the case suggests that other explanations should be sought (Swenson et al. 2008).

Visit content refers to the potential impact that having multiple conditions may lead to different patient-provider communication between those with and those without depressive symptoms (Swenson et al. 2008). This includes the difficulties experienced by health care professionals in relation to having the time to deal with multiple issues in a single consultation. Time pressures may mean that health care professionals may not diagnose and hence treat depression amongst people with diabetes (Swenson et al. 2008).

Visit process refers to factors involved in the way that patient and providers interact with each other. It may be that doctors communicate differently with patients with depressive symptoms. For example, Swenson et al. (2008) discuss the potential problem that patients with depressive symptoms may not be liked by their health care providers and consequently the latter may become frustrated and disengaged with patients. Evidence that process factors may be a plausible explanation was found in a qualitative study of GP perceptions of patients with depression (Chew-Graham et al. 2000). This study found evidence of reported 'interactional difficulties' between GPs and patients with depression (Chew-Graham et al. 2000). GPs reported that they often felt frustrated and drained when interacting with depressed patients and overall there was a feeling that this work was 'an unrewarding domain of clinical practice' (Chew-Graham et al. 2000, p.140).

Patients who are depressed may also behave differently to patients without depressive symptoms, for example they may exhibit a passive stance in the health care interaction (Swenson et al. 2008). There is a tendency for 'active' patients to be more involved in decision-making and for 'passive' patients to receive a more directive style of communication from health care professionals (Swenson et al. 2008). Patients with depression may also have difficulty discussing their problems with health care professionals. In a study conducted in a primary care setting patients' perceptions of the quality of care for depression revealed that depression itself appeared to have a disruptive effect on patient-provider communication (Gask et al. 2003). Half of the patients in this study reported a reluctance to talk to doctors about their problems with depression citing reasons that it was not acceptable 'to take up the doctor's time' reflecting feelings of low self-worth. This is also evident for individuals with diabetes and depressive symptoms who did not want 'to disappoint their doctor or to be judged by their doctor' (Beverly et al. 2012, p.1470). Most patients with depression have a preference for a partnership style of communication; hence there is likely to be a clash between their preferences and what is achievable given that an inability to engage with health care professionals is likely to result in conflicting styles of communication (Swenson et al. 2008). This appears to explain why patients with depressive symptoms reported substandard communication in relation to empowerment and decision-making (Swenson et al. 2008).

This review has identified a number of factors that add to the complexity of patient-provider communication. These include potential barriers associated with socioeconomic status, low health literacy and co-morbid depressive symptoms. The final part of the review focuses on patient-provider communication in relation to diabetes care.

3.4.5 Patient-Provider Communication in Diabetes⁴ Care

The importance of patient involvement in the health care process is particularly relevant in chronic disease management and of great importance in a disease such as diabetes that requires an enormous commitment to self-care by patients (Ishikawa et al. 2009). The impact of patient-provider communication has been documented in a number of studies involving patients with diabetes. For example, effective physician communication has been found to be correlated positively with patient adherence to treatment (Zolnierek et al. 2009). Additionally, in a randomised trial increasing patient involvement in diabetes decision-making was found to improve blood glucose control (Greenfield et al. 1988). In diabetes research, systematic reviews have found evidence that interventional studies promoting patient involvement in the decision-making process have led to improvements in both quality of life and HbA1c levels (Montori et al. 2006). In a study of patients with type 2 diabetes, involving patients of low socioeconomic group in decision-making led to greater patient satisfaction (Golin et al. 2002). The most satisfied group were those who had expressed little interest in being involved in decision-making (Golin et al. 2002) hence indicating the importance of involving patients who might initially express a reluctance to be involved in decision-making. It also suggests that the supposition that some patients 'are not able or do not want to participate in decision-making is inconsistent with both the evidence and contemporary models of care' (Politi et al. 2013, p.2).

Success in managing diabetes comprises a partnership between health care professionals and patients so that agreed optimum treatment strategies may facilitate the patient in managing the disease (Heisler et al. 2003). In relation to health care professional influences on patient outcomes in diabetes, Heisler et al. (2002) strengthened the findings of earlier studies indicating the importance of a participatory style for decision-making. Satisfaction with health care professional communication and a participatory decision-making style predicted diabetes self-care behaviour. This indicated that improved self-management as a result of patient-provider communication offered an explanation for the improvements in health outcomes observed in previous studies (Heisler et al. 2003). In a study involving adults with type 2 diabetes, Heisler et al. (2003) found that the characteristics of patients more likely to agree on goals and strategies with their health care providers were individuals with more education, those with a greater confidence in the efficacy of the treatment regimen and those who had

⁴ Much of the research on diabetes in this review does not specify type of diabetes. Type of diabetes will be specified where it is given in the paper.

shared in the decision-making. In general however, agreement on treatment decision-making was low in this primary care setting.

The influence of provider communication as a barrier to improved outcomes was found in a study of patients with type 2 diabetes (Street, Jr. et al. 1993). Patients who interacted with nurses who exhibited more directive communication had poorer metabolic control. In contrast patient involvement in decision-making was associated with nurses' use of patient-centred communication (Street, Jr. et al. 1993).

In a recent systematic review of factors influencing adult patient ability to self-manage diabetes, communication with health care providers was found to be a key issue (Wilkinson et al. 2014). The authors identified aspects of communication that impacted both positively and negatively on ability to self-care. Negative aspects involved patients who struggled to communicate their requirements, questions and concerns and hence these needs were not addressed by their health care providers. In contrast 'respectful' communication involved patients experiencing dialogue that acknowledged that 'their opinions had value' (Wilkinson et al. 2014). The authors concluded that partnership building with patients was likely to be impeded by some of the barriers to communication identified in their review.

Qualitative findings on decision-making in diabetes

Adopting a qualitative approach to investigating patient involvement allows researchers the ability to explore some of the complexities of decision-making not readily apparent in studies limited to quantitative methods (Smith et al. 2009). Two papers, utilising a qualitative approach, were found that provided a more nuanced understanding of aspects of communication in relation to decision-making in diabetes. Treatment decision-making in diabetes was explored from the perspective of patient involvement in a study by Entwistle et al. (2008) and from the perspective of the manner in which doctors talked with patients about their treatments in a study by Collins et al. (2005). The former study (Entwistle et al. 2008) involved interviewing twenty patients (a mix of type 1 and type 2 patients). This study found that patients' views on whether or not they were involved in their treatment decisions were dependent on feeling that health care professionals appreciated their subjective experience. The 'ethos and feel' of the consultation and whether or not they were encouraged or enabled influenced their opinion on whether or not they felt that they had been involved in decisions (Entwistle et al. 2008, p. 372). The authors asserted that their study highlighted some inadequacies in focusing more narrowly on some of the actions involved in consultations, for

example, information exchange. They argued that more emphasis should be placed on the patient's subjective experience and for example the importance of feeling respected.

Using conversation analytic techniques, Collins et al. (2005) approached an investigation of patient participation in decision-making by observing the respective parts played by patients and professionals in videotaped consultations in primary care (diabetes related) and a specialist centre for oncology. Patterns of communication adopted by doctors were categorised as ranging on a continuum from 'bilateral' approaches that encouraged more patient involvement to 'unilateral' approaches that tended to diminish the options for patient participation (Collins et al. 2005, p. 2625). This more nuanced investigation of patient participation suggested that involvement of patients in treatment decision-making was influenced by the approach taken, either 'unilateral' or 'bilateral'. However, Collins et al. (2005) also observed that patient involvement in the consultations was, in general, low and that 'bilateral' approaches did not guarantee patient participation in the final decision. Collins et al. (2005) recommended that further analysis of these styles of communication was warranted since their occurrence might differ according to clinical setting. No further qualitative studies were found relating to decision-making in specialist centres for adults with type 1 diabetes.

3.4.6 Summary of Patient-Provider Communication Review

This section has reviewed the literature on patient-provider communication and shared decision-making. The findings concur with Verlinde et al. (2012) that patient-provider communication is 'a complex interactional system' (p. 11). Communication was influenced by both patients and health care professionals (Verlinde et al. 2012). Low socioeconomic status was associated with less involvement in treatment decision-making, less partnership building talk, more directive communication, and less information about treatment and diagnosis (Verlinde et al. 2012). In contrast individuals of higher socioeconomic group were more involved in treatment decisions and received more information. It appears that shared decision-making may increase health inequalities since patients who have a natural propensity to seek information and to engage in consultations will benefit whereas those patients who are already marginalised are likely to be further disadvantaged since they have a tendency to passivity in health care interactions (Durand et al. 2014).

Individuals of low socioeconomic status who have achieved access to health care may well experience communication barriers that lead to less satisfaction with the process and less

agreement with health care professionals. Some of the barriers associated with literacy, health literacy and numeracy may offer potential explanations for health inequalities since they indicate the potential for individuals to experience difficulties in accessing health care services and functioning effectively in the health care environment (Protheroe et al. 2009). In addition depression and psychological factors, which affect individuals of lower socioeconomic status more than individuals of higher socioeconomic status, may also have an impact on communication. Some of these findings resonate with the earlier discussion of barriers identified by Dixon-Woods et al. (2005) in their interpretive synthesis of access to health care by vulnerable groups.

Decision-making research in diabetes has explored some of the aspects of communication important to patients in terms of the 'ethos and feel' of consultations. Conversation analysis has been used to identify the different styles of communication adopted by doctors. These studies have provided a more nuanced exploration of patient involvement in decision-making in type 2 diabetes suggesting that a qualitative approach to treatment decision-making in type 1 diabetes might be warranted since no studies were found exploring decision-making in this group of patients.

3.5 The Research Gap

Three main areas of research relevant to the current thesis were reviewed in this chapter: evidence of inequalities in outcome and access for adults with type 1 diabetes; the wider literature on access to health care; and communication between patient and providers. The review of socioeconomic inequalities identified disparities in health outcomes for adults with type 1 diabetes. Further exploration of the literature found socioeconomic disparities in access to specialist diabetes care, the use of intensive regimens, glycaemic control and blood glucose monitoring.

However, whilst the socioeconomic review identified disparities in access for adults with type 1 diabetes little research was found that explored the pathways involved in this lack of access. In particular it appeared that decision-making processes involved in gaining access to an IIR from the perspective of equity had not been investigated for adults with type 1 diabetes.

The literature on communication in diabetes and on socioeconomic disparities in communication more generally suggested that this was an important area of investigation for the current study. It was evident in section 3.4 that socioeconomic factors were an important

influence in terms of communication between patient and providers. This body of literature on variation in patient-provider communication identified some important insights into the ways in which individuals of low socioeconomic group may be disadvantaged since it is through health care interactions that decisions are reached regarding treatment regimens.

Having established that socioeconomic inequity persists in terms of usage of intensive insulin regimens and that quantitative research, although identifying this disparity, has so far not elucidated the possible pathways involved in this inequity, it seemed that qualitative research could be used to elicit some of the key influencing factors involved.

In summary the literature review identified a need to explain the pathways resulting in poorer outcomes for individuals with type 1 diabetes of low socioeconomic status and whereas quantitative research identified the persistence of health care disparities it was less useful in describing the causes. A qualitative approach was adopted in order to answer these questions.

3.5.1 Thesis Aims and Objectives

A need was identified to:

- Explore the treatment decision-making processes in type 1 diabetes (preferably in the clinical setting), focusing on the range of insulin regimens available and to
- Elucidate the influencing factors involved in patients accessing an IIR with a particular focus on how decision-making processes may lead to variation in access to regimens by socioeconomic status.

The aims and objectives of the primary research were initially developed to explore the decision-making processes involved in *gaining* access to an intensive insulin regimen. During the course of the primary research it became apparent that whilst the interview data could do this by exploring the patient's perspective on the processes involved in changing insulin regimen, the consultation data could not examine this process because all of the consultations involved patients who had already commenced an intensive insulin regimen. Instead the consultation data could be used to explore *maintaining* access to intensive regimens.

The aim of this thesis was to:

- Explore equity of access to an IIR for adults with type 1 diabetes.

The objectives were to:

- Explore patients' perspectives on opportunities to change insulin regimens with particular reference to the role and influences of health care encounters in relation to these decisions.
- Explore health care professionals' perspectives on the factors involved in patients accessing an IIR.
- Observe the routine interactions between patients and health care professionals in a specialist diabetes clinic in order to analyse the processes which may have a bearing on maintaining access to an IIR for adults with type 1 diabetes.

Chapter 4. Methods

4.1 Introduction

This chapter presents the study design (section 4.3), the rationale for the design (section 4.4), research quality (section 4.5), other study considerations including ethics and patient involvement (section 4.6), data collection (sections 4.7-4.10) and data analysis (section 4.11). Section 4.2 provides a recap of the aims and objectives of the study.

4.2 Aims and Objectives

The aim of this thesis was to explore equity of access to an IIR for adults with type 1 diabetes. The objective was to carry out an in-depth investigation of both patient and health care professional perspectives on the factors involved in accessing an IIR with particular reference to the influence of health care encounters.

4.3 Design

The study design used a qualitative multi-methods (Tashakkori et al. 2003, p. 712) approach with a mix of observation and interviews.⁵ As described earlier in Chapter 2, care for type 1 diabetes may occur in specialist services in secondary care and/or in general practice. In the setting selected for the study (described later in section 4.7) health care was provided predominantly within secondary care and in this sample access to an IIR was only possible in secondary care. Therefore recruitment was focused on specialist diabetes services in a secondary care setting. Three components of the study were started in sequence. First, observations were made of patients and health care professionals during consultations in secondary care. Second, follow up interviews were carried out involving these same participants. Third, interviews were carried out with patients who did not attend the specialist services and health care professionals involved in their care. This was so that a more complete picture of accessibility to an IIR in secondary care could be obtained, rather than carrying out a detailed exploration of access to an IIR in primary care. Although started in sequence, the data

⁵ Tashakkori and Teddlie (2003) define qualitative multi-methods studies as those in which either two qualitative data methods or two qualitative data collection procedures are used to answer the research question. They point out that multi-methods is synonymous with the term 'multiple methods' (p. 712).

collection of all three parts occurred concurrently. The three parts of the study are referred to as follows:

- Part one: non-participant observation of consultations in specialist diabetes services.
- Part two: interviews in secondary care.
- Part three: interviews in primary care.

4.3.1 Parts One and Two - Observations and Interviews (Specialist Diabetes Services)

Parts one and two of the study were linked so closely that they are described together. The aim in combining qualitative methods was to carry out an exploratory study of the pathways involved in patients gaining access to their current regimen and the potential influence of health care interactions in this process. Whereas the observations provided access to 'naturally occurring' data (Silverman 2006, p 201), the interviews provided an opportunity to explore with patients and health care professionals an in-depth understanding of personal perspectives related to the research phenomena (Lewis 2003).

4.3.2 Part Three - Interviews (Primary Care)

Some individuals do not attend appointments when they are referred to specialist care or prefer their care to be undertaken at their GP practice. These patterns of service utilisation are known to be associated with deprivation in relation to specialist diabetes care (Bachmann et al. 2003) and in health care more generally (Goddard et al. 2001). Since the aim was to gain an understanding of the factors involved in accessing an IIR including issues of inequity it was important to understand why some people do not use secondary care. A decision was reached to incorporate a small number of participants attending a GP practice in an area of deprivation for two reasons: first, research shows that these areas will be more likely to encounter individuals not attending specialist centres (Bachmann et al. 2003) and second, access to secondary care was through primary care and hence it was important to consider this pathway as part of the study.

It would have been preferable to have given equal weight to both primary care and specialist services. Unfortunately the resources of the PhD did not permit this. Rather than focus solely on specialist services with the possibility that this might lead to misleading interpretations it was decided that the primary care perspective should be included. The addition of this small sample helped to maintain an awareness of this important aspect of the story during the process of analysing and interpreting the specialist services data.

4.4 Rationale for Design

The following section provides a rationale for the research design and my research stance in terms of what I believe it is possible to know about the world (ontological position). I leave until section 4.11 the rationale for the chosen analytic methods (conversation analysis and thematic analysis).

4.4.1 Rationale for Qualitative Research

In Chapter 3, I identified that whilst much research had adopted a quantitative approach in exploring inequalities in outcome in adults with type 1 diabetes, there was a paucity of research explaining these phenomena. The aim of this study was to investigate the processes and pathways involved in gaining access to an IIR in an attempt to explain these inequalities. In keeping with other researchers whose aim is to investigate processes rather than outcomes I chose a qualitative approach (Murphy et al. 2001). This decision was reinforced by Goddard and Smith's (2001) view that qualitative research might offer a better approach to addressing the complexity of supply and demand features involved in accessing health care.

Qualitative research is particularly appropriate for the investigation of processes (Patton 2002) for the following reasons: first, in describing processes a detailed account of the ways individuals interact with one another is required; second, it is important to document variation in the ways that individuals experience the processes from their own perspective; and third, qualitative enquiry is well suited to investigating the dynamic nature of processes. A qualitative approach was therefore chosen to address the aims and objectives of the study since the focus was on asking 'how' and 'why' questions through an in-depth investigation of the processes involved in decision-making, access to and allocation of an IIR.

4.4.2 Theoretical Stance

There is much debate in the social sciences about approaches to research and strategies of investigation (Bowling 2002). Whereas quantitative researchers often adopt a positivist or post-positivist approach using the scientific method, qualitative research is associated with interpretivism (Snape et al. 2003). Each branch of scientific enquiry has a set of theoretical assumptions underpinning its approach (Bowling 2002). However, defining qualitative research is challenging (Snape et al. 2003). This is in part because the practices of qualitative research encompass a wide range of approaches informed by diverse ontological and epistemological positions (Barbour 1998; Snape et al. 2003).

It is important when discussing research strategy to be transparent about one's theoretical assumptions since 'what we see depends on what we look at' (Bowling 2002) citing (Kuhn 1970, p. 119). Beliefs about the nature of the social world and what can be known about it (ontology) together with the nature of knowledge and how it can be acquired (epistemology) are amongst the key factors determining how qualitative research is carried out (Snape et al. 2003).

My own experiences have no doubt determined the approach I have taken with the research design. If I had designed the study with a sociological, philosophical or psychological background, my design may well have been very different since diverse groups of investigators focus on different aspects within their chosen field of enquiry (Bowling 2002). My own influences have been shaped by taking a master of public health (Health Services Research). As a health care researcher my ontological position has been influenced by 'subtle realism' (Hammersley 1992). Subtle realism was proposed by Hammersley (1992) as an alternative ontological stance to either realism or idealism.

Realism is an ontological position that asserts that there is a reality independent of people's perceptions of it (Murphy et al. 2001). In relation to research, Hammersley (1992) describes realism as 'the idea that there is a reality independent of the researcher whose nature can be known and that the aim of research is to produce accounts that correspond to that reality' (p. 43).

Proponents of idealism claim that the nature of the social world is not rigidly fixed since what constitutes the correct or standard way of doing something in society may change over time and hence 'reality is only knowable through the human mind and through socially constructed meanings' (Snape et al. 2003, p. 11).

Hammersley (1992) found difficulties in adopting either of these two 'stark' positions, arguing that neither the adoption of realism nor idealism offered 'a sound philosophical basis for social research' (Murphy et al. 2001, p.69). As Murphy et al. (2001) suggest, naive idealism, with its assumptions of multiple realities taken to its logical conclusion, 'renders social research pointless' (p. 69), since 'if the findings of any research cannot be taken to represent even an approximation of truth, then one has to ask why commissioners should invest public money in funding such research' (p. 178). In contrast, naive realism fails to acknowledge the impact of the researcher on the research and the inappropriateness of viewing observations as entirely objective (p. 69). This led Hammersley (1992) to advocate that 'there are more subtle forms of

realism that avoid the problems of these two positions' (p. 54). Hammersley's approach (1992) to subtle realism has been viewed as a credible ontological stance in health care research (Murphy et al 2001).

Subtle realism

Subtle realism is influenced by the philosophical underpinnings of idealism which means that although there is an acknowledgement that social reality can be studied, this is only possible via the interpretations of individuals and in addition the further construal of these interpretations by the researcher (Snape et al. 2003). As Murphy et al. (2001) suggest, this adoption of a 'mid way' approach that avoids the extremes of either naive realism or naive idealism 'allows us to accommodate some elements of social constructivism without abandoning a commitment to independent truth as a regulative ideal' (p. 69).

This emphasis on the interpretations of the participants in the research means that the aim is to provide representations of reality rather than a single 'truth' (Mays et al. 2006). The importance of this for the current study is that reality may be represented via multiple perspectives (Murphy et al. 2001). The aim, therefore, is to 'apprehend and convey as full a picture as possible of that multifaceted reality' (Snape et al. 2003, pp. 19-20) since these diverse representations enable a rich understanding of the phenomena under investigation (Snape et al. 2003). A key issue with subtle realism is that although diverse representations are possible and this 'opens up the possibility of multiple *non-competing* valid descriptions and explanations of the same phenomenon' nevertheless these diverse representations must not contradict one another (Murphy et al. 2001, p. 69). Hence quality in qualitative research is of paramount importance in order to demonstrate the validity of the research. This rigour or quality in qualitative research must be demonstrated through detailed reporting of data collection and analysis in order that others may be able to judge the legitimacy of findings (Mays et al. 2006). Issues addressing research quality including fair dealing, triangulation, and transparency in reporting methods and findings, together with reflexivity are discussed in section 4.5. In summary, my own stance in conducting the research was influenced by a need to produce qualitative evidence that was 'neutral... unbiased and clearly defensible in terms of how interpretations have been reached' (Snape et al. 2003, p. 19) with the intent of providing accessible research findings that have the potential to inform policy making and practice.

4.4.3 Rationale for Combining Qualitative Methods

A combination of 'qualitative observation' (Mays et al. 1995a, p. 185) and interviews was chosen to address the research objectives. A key aspect of the study design was the use of methods triangulation to construct a more thorough understanding of the phenomena under investigation (Mays et al. 2006). This approach seeks multiple perspectives (Patton 2002) and involves different methods of data collection (Mays et al. 2006) and has been used in the current study to provide a more holistic understanding of the interactions of patients and health care professionals related to equity of access. The rationale behind using a mix of observation and interviews was an understanding that each method has its limitations and that using a design that includes multiple approaches would enable a more comprehensive investigation of the research objectives (Patton 2002).

Combining observation and interviews had a number of advantages for this study. As Bryman suggests there are many 'issues resistant to observation' (Bryman 2008). Observations of clinics could provide a snapshot in the patient's history of living with diabetes and illuminate the decision-making processes. Part of the purpose of the study, however, was to explore patient pathways over time and the observations part of the study was unable to accomplish this objective. As Bryman points out, sometimes the only way to find out about a particular issue is to ask participants to give their accounts about the matter (Bryman 2008). Interviewing participants allowed access to data that would have been hard to acquire otherwise (Hammersley et al. 1995). Interviews revealed the treatment pathways the patient had followed and their perspectives on the influences on decisions to change regimens. The purpose, therefore, of the qualitative interview was to explore past events, something that could not be accomplished through non-participant observation. The advantage of combining observations with interviews was that the data collected from one was used to elucidate or shed light on the findings of the other (Hammersley et al. 1995). Observations also had the advantage of informing the later interviews with both clinic attendees and health care professionals. The decision to interview after the observation was influenced by other studies using this approach in order to elicit views on the consultation (Goberman-Hill et al. 2010; Stevenson et al. 2003).

Using a mix of qualitative methods has been promoted in health care research where observation and conversation analysis in particular have been used in conjunction with a number of other methods including interviews and think aloud techniques (Bugge et al. 2007). Mixing qualitative methods within studies is not uncontroversial (Bugge et al. 2007). Caution

has been expressed in relation to the use of multiple qualitative methods in order to obtain a fuller picture. The disadvantages are that a researcher has to learn more methods of analysis and there is a temptation to flit from one data set to another when progress is difficult (Silverman 2010). In addition to practical considerations involved in using a mix of qualitative methods, there are also concerns that using methodological approaches informed by differing philosophical approaches may lead to inconsistencies and therefore undermine the quality of the research (Snape et al. 2003).

Whilst I recognise that there are concerns about mixing methods from different qualitative traditions (Barbour 1998), the two methods selected have been deliberately adopted to address particular parts of the research question; each method in isolation provides an incomplete picture. In adopting a multi-methods approach I have taken a pragmatic stance that these approaches are increasingly being used in health care research (Bugge et al. 2007; Pope et al. 2006a). The subtle realist stance adopted in this study allows for both parts of the study to be accorded an equal status since 'different vantage points will yield different types of understanding' (Snape et al. 2003).

4.4.4 Rationale for Observational Methods

Qualitative observation is frequently associated with ethnography (Bowling 2002; Pope et al. 2006a). The approach is derived from the work of anthropologists who lived alongside people in societies and cultures different to their own in an attempt to learn about how these groups functioned (Pope et al. 2006a). It is usual in ethnographic studies to make observations in only one or a small number of settings (Hammersley et al. 2007a).

Observation in qualitative studies and ethnography have a long history of use in health care research (Bowling 2002) where the focus of interest is processes and interactions relating to patients and health care professionals (Pope et al. 2006a). Observational methods allow systematic and rigorous investigations of how individuals interact in natural settings with little interference from researchers (Pope et al. 2006a).

Observation of clinical decision-making

Observational approaches have been used in a number of studies where the aim has been to explore and explain clinical decision-making. Bloor's observational study of childhood tonsillectomy revealed differences amongst doctors with regard to decisions to carry out tonsillectomies (Bloor 1976). Silverman observed clinic interactions in a study of paediatric

cardiology identifying different approaches to the decision to carry out cardiac surgery for children with and without Down's syndrome (Silverman 1989).

Types of observation

The options for qualitative observational methods include participant observation, non-participant observation and concealed observation. Participant observation and concealed observation were not applicable for this study since my purpose was not to participate in the activity or carry out the research in a covert manner. Non-participant observation was chosen for the study because the aim was to observe the routine interactions that occurred in clinic consultations without being a part of the activity itself. The aim in using this approach was that observing and recording clinic sessions might reveal taken for granted phenomena that would not come to light in other methods such as interviewing (Pope et al. 2006a). The rationale for observing clinic encounters was similar to that stated in Silverman's study, that is, the clinic provided a timetabled event with a particular focus (Silverman 2010). There was an assurance, therefore, that a reasonable body of data could be collected (Silverman 2010) in this study about interactions and decision-making between health care professionals and individuals with diabetes.

Rationale for approaches to data collection

Different approaches to data collection can be undertaken in non-participant observation. I selected three approaches:

- Recording the consultation
- Field notes Form
- Diary

Recording the consultation

Audio and video recordings are playing an increasingly important part in qualitative research because, in comparison to field notes, recordings provide a dependable and trustworthy record of observations (Silverman 2006). Two approaches have been used in observational studies: audio recordings and video recordings. Each of these methods has their advantages and disadvantages (Flick 2006). Audio recordings are straightforward to set up and relatively discrete which is an important consideration for health care consultations. Video recordings allow facial expressions and body language to be recorded and the additional visual material may help when transcribing the recording subsequently. However, positioning the camera in

the room may be difficult in order to capture all of the participants in a consultation particularly if there are several members of a multi-disciplinary team present. With video recordings there may be a trade-off between quality of detail with for instance facial detail as compared to having a more panoramic overview of the social interaction (Flick 2006). There is also the issue of confidentiality: participants are less easily identifiable in audio recordings than in video recordings.

The decision to choose audio recording rather than video recording was influenced by a number of factors. In attempting to record a naturalistic interaction the aim should be to make the recorder as unobtrusive as possible (Flick 2006). It was felt that the audio recording would be less intrusive and would be easier to set up than a camera, particularly in a busy clinic. It also appears that patients find audio recordings less daunting than video recordings when asked for their opinion prior to observation (Themessl-Huber et al. 2008).

In making the decision to adopt audio recordings I was also swayed by the practical considerations that this mode of research had been used in a number of studies looking at interactions in consultations (Barry et al. 2001; Byrne et al. 1976; Coulthard et al. 1975; Silverman 1989). I was also conscious of the pragmatic considerations that ethical approval for video recordings may prove to be a more difficult and lengthy process than audio recordings. It should be noted that video recordings are seen as the 'gold standard' (Toerien 2014) in terms of conversation analysis (the method chosen to analyse the consultations) since amongst other advantages it allows what happens in silences to be observed. Drew (2005, p. 78), however, argues that 'none of the practices, devices or patterns identified in conversation analysis research are shaped or altered in any significant way accompanying nonverbal conduct'. Indeed much of the early research carried out by Sacks involved analysing telephone calls to a 'suicide prevention centre' (Hutchby et al. 2008, p. 16) .

Audio recording of clinic encounters played a crucial role in the study. By recording conversations, I was free to make other observations pertinent to the interaction such as who was present, where individuals were located in the room, and non-verbal communication. Without recordings, I would not have had as complete an account of the proceedings since it would have been impossible to note down entire conversations and key items may have been forgotten.

Field notes Form

Field notes are an essential part of observational studies (Patton 2002). Therefore, audio recordings were supplemented by written records for each consultation. A Field Notes Form was used so that data could be collected in a systematic way in order to enhance the reliability of the study (Silverman 2006). This was developed in the initial weeks of observation and was based on the types of activity and information to be gained from clinics. It was used in conjunction with recordings of clinics to analyse activity (see section 4.11.2 (Analysis of Clinic Observations)). The Field Notes Form (adapted from Silverman (2006)), is provided in Appendix 7 and was used in two ways. First, information was collected from each participant after the consent process and prior to the consultation. This included patient characteristics (for example age and ethnicity), a brief record of onset of diabetes and treatment received since diagnosis. Second, the form was used to describe the consultation including who was present, the key actions by participants including decisions discussed and a brief record of the content of the consultation.

Research diary

In addition to data collected at clinics using the audio digital recorder and Field Notes Form I also kept a research diary. Keeping a diary is a way of collecting information in a systematic way about experiences in the field (Flick 2006). My objective in keeping a diary was to provide a means of documenting and reflecting on the outcome of observations and interviews as well as providing a record of how recruitment was progressing.

4.4.5 Rationale for Interview Methods

Amongst the three forms of data collection in health care research, qualitative interviews are the most common (Britten 2006). Qualitative interviews are chosen in order to elicit from individuals their thoughts, feelings, experiences and meanings they attach to their world (Patton 2002). In this study qualitative interviews were chosen in order to explore the influences on accessing intensive insulin regimens via the reported experiences of both patients and health care professionals.

There are a number of approaches to qualitative interviews. Within the literature writers have identified the main types of approaches to qualitative interviewing ranging from the very structured to the unstructured (Britten 2006; Legard et al. 2003; Patton 2002). Unstructured interviews are at one end of the spectrum and offer the most informal approach to

interviewing since they are conversational in nature and content is determined in the course of interaction depending on the topics that emerge (Patton 2002). This approach is flexible but offers less scope for comparing participant responses since each interview will be unique (Patton 2002). In contrast semi-structured interviews are controlled much more by the researcher since the same questions are asked in each interview, in the same order and there is less scope for probing (Legard et al. 2003). I adopted a mid way approach that most closely approximates to in-depth interviewing described by Legard, Keegan and Ward (2003). Although I used a comprehensive topic guide, the phrasing and ordering of questions was left flexible to enable exploration of emerging issues.

The topic guide was designed with flexibility in mind and was used as an 'aide memoire' rather than as a prescription for how to conduct the interview (Arthur et al. 2003). Topic guides for in-depth interviews can vary in detail and length, however it is often preferable to keep the length to no more than two or three pages (Arthur et al. 2003). My own topic guide for both patients and health care professionals was limited to two sides of an A4 sheet.

As the study was exploratory the approach taken with interviews was to keep the topic guide as broad as practicable. This contrasts with an approach known as tape-assisted recall (TAR) in which participants are asked to reflect on sequences within a recorded consultation. TAR has been used to elicit the perspectives of patients in relation to communication in primary care consultations (Buszewicz et al. 2006) and secondary care (Salmon et al. 2011). TAR has the advantage that the interview is prompted by what has actually taken place in the consultation and the insights of both patients and health care professionals on the consultation may be obtained (Cape et al. 2010). In the current study, however, the research objectives were to explore, from the patient's perspective, the pathways taken that had led to their current regimen in order to identify key influences. The aim of the interviews with health care professionals was to provide insights into the influences on access to intensive regimens rather than to focus on specific patient consultations. Hence the methods were chosen to reflect the broader range of the study, namely consideration of the wider factors influencing access to health care.

The aim with in-depth interviewing is to gain a thorough and detailed understanding of the individual's subjective viewpoint. Researchers approach in-depth interviewing from a variety of perspectives (Legard et al. 2003). Silverman describes the realist perspective which views the results of interviews as gaining access to experiences and feelings of interviewees (Silverman 2010). Another perspective views the interview as an active process in which

meanings are co-produced by interviewer and interviewee (Byrne 2004, p. 181). In these interview studies, it is not what is said but how it is communicated that is of interest (Byrne 2004). Whilst acknowledging that data from interviews does not provide a 'mirror image' of social reality, the perspective adopted in this study was a pragmatic mix of viewing the interview as requiring both an analysis of what and how individuals communicate in response to questions (Byrne 2004).

This approach is not without difficulty in terms of participants being partial in what they choose to relate (Miller et al. 2004). Nevertheless acknowledging the fact that individuals do not want to reveal their entire selves in an interview can result in a fuller appreciation of subjects' lives and the aspects under scrutiny (Miller et al. 2004). Whilst acknowledging the subjective nature of individuals' accounts, the aim of the research was to faithfully portray a fair representation of subjects' meanings (Miller et al. 2004).

Face to face interviews were chosen rather than telephone interviews. Although there are some advantages in terms of cost and personal safety, there are some disadvantages to using the telephone for qualitative interviewing (Bryman 2008). The main disadvantage referred to by Bryman (2008) of relevance to the current study is the inability to observe body language reactions and hence be in a position to pre-empt communication difficulties by rephrasing questions. Other practical considerations include the difficulties of conducting telephone interviews with people with hearing impairment. Overall any benefits of telephone interviewing were felt to be outweighed in terms of potential problems of building a rapport and interpreting participants' responses without body language cues (Bryman 2008).

4.5 Research Quality

There is considerable debate surrounding what constitutes quality in qualitative research (Mays et al. 2006). This includes discussion about the applicability of terms such as 'validity' and 'reliability' to qualitative research and has received considerable attention (Lewis et al. 2003). Terms such as 'confirmability', 'trustworthiness', 'consistency' and 'dependability' have been used in place of reliability (Lewis et al. 2003). Although replication of studies is viewed by some as 'somewhat unrealistic', given the nature of qualitative research (Seale 1999, p. 157), the aim should be to provide sufficient detail in methods and analysis to allow the reader to judge the adequacy of research claims (Seale 1999, p. 552). Research findings need to be considered robust in order for findings to be viewed as useful and having applicability outside the original settings of the research (Lewis et al. 2003). Credibility of research encompasses an

interweaving of 'rigorous methods', 'credibility of the researcher' and a 'philosophical belief' in the value of qualitative inquiry (Patton 2002, pp 552-553). Quality is an integral part of design, sample selection, data collection, analysis and reporting (Mays et al. 1995b). The aim was therefore to carry out research that was transparent in methods and provided a credible account of research findings. The Critical Appraisal Skills Programme (CASP) tool for qualitative research was also used to inform the approach to ensuring quality (Critical Appraisal Skills Program (CASP) 2006).

Mays and Pope (2006) discuss six possible ways of ensuring the quality of qualitative research:

- Use of triangulation
- Respondent validation
- Transparency of methods and analysis
- Researcher reflexivity
- Searching for alternative explanations and negative cases
- Fair dealing

4.5.1 Triangulation

Triangulation in this study involves the use of multiple methods and multiple perspectives. The use of triangulation aimed to provide a more thorough and comprehensive insight with respect to findings rather than aiming for a single truth (Mays et al. 2006; Patton 2002; Ritchie 2003). This was achieved through using a mix of methods (observations and interviews) and seeking multiple perspectives by recruiting individuals with diabetes and health care professionals involved in their care.

4.5.2 Respondent Validation

Although respondent validation has been suggested as one of the strongest forms of checking on the validity of research projects, other researchers, however, question this approach to ensuring credibility of findings (Mays et al. 2006). Whilst member checking can generate interesting research material the approach is not recommended as a test of validity (Bloor cited in Silverman (1985)) and was not utilised in this study.

4.5.3 Reflexivity

In qualitative research the researcher is the main 'instrument' (Mays et al. 1995b, p. 111) Whilst aiming to adopt a stance of 'empathetic neutrality' (Patton 2002, p. 40), there was an acknowledgement that my own personal perspectives would play a part in the interpretation of research findings (Snape et al. 2003). It is important, therefore, that researchers are explicit about the part they have played in shaping the study and its findings (Mays et al. 2006). As a subtle realist it was important to adopt a reflexive approach to data analysis and reporting. Hence, a diary was kept to record impressions of encounters with participants following interviews and observations.

During the course of interviews my aim has been to adopt 'empathetic neutrality' to counter any potential bias. This meant that respect for what individuals divulged was of paramount importance (Patton 2002). My objective was to build rapport whilst maintaining neutrality and a non-judgmental approach (Patton 2002). Following interviews with participants I reflected on what had gone well or badly and aimed to improve my technique for the next interview.

4.5.4 Transparency of Methods and Analysis

The main way to ensure credibility is to keep detailed records throughout the research process, including data collection and analysis (Mays et al. 1995b). Accurate data was collected by recording interviews and observations. NVivo™ 9 was used to record key material in the research process, including transcripts of interviews, and coding analysis. A clear description has been given of the process of analysis, leading from early codification of data, through to explanations of findings (Mays et al. 2006).

4.5.5 Alternative Explanations and Negative Cases

It is important to be open minded during the process of analysis and one of the ways that this can be accomplished is to 'take seriously the possibility of having got it wrong' (Denscombe 2010, p. 303). In order to enhance credibility in findings it is important that researchers demonstrate they have carried out rigorous searches in their analyses for both alternative explanations and negative or disconfirming cases ((Lewis et al. 2003; Patton 2002; Seale 1999). During the course of analysis, searches were made for alternative explanations supported in the data (Patton 2002). The aim was to search for the 'best fit' for the majority of data (Patton 2002, p. 553).

4.5.6 Fair Dealing

One of the ways to reduce bias in qualitative research is to ensure that a diverse range of perspectives are included so that no one group is represented as providing the 'sole truth' about the issues (Mays et al. 2006, p. 90). This has been termed 'fair dealing' (Mays et al. 2006, p. 90) citing (Dingwall 1992). Throughout this study the aim was to ensure that many diverse groups were incorporated. Both health care professionals and patients were represented and every effort was made to recruit individuals from different backgrounds, economic circumstances, gender and age groups. This was accomplished by keeping a log of participants' characteristics and using a sampling structure as a check on participants recruited to each type of regimen, numbers of males and females and their ages. As the study progressed and more participants were recruited via the insulin pump clinic I met regularly with the diabetes specialist nurse, assigned to this clinic, in order to target under-represented groups.

4.6 Other Study Considerations

4.6.1 Ethics

Ethical approval was granted from Nottingham Local Research Ethics Committee 2 in November 2011 (REC reference 11/EM/0381) (Study documents are in Appendix 7). NHS research governance approval was obtained from the relevant NHS trusts in parallel to ethics approval.

The study was conducted in accordance with the principles of the Declaration of Helsinki (World Medical Association 2008). In considering the ethics of recruiting individuals to the study the need for potential participants to be 'adequately informed' (World Medical Association 2008) was addressed by ensuring that individuals were given written and verbal information about the study prior to consent.

Good ethical practice dictates that individuals must have sufficient time to consider involvement in health care research and must not experience coercion. The main ethical objective in this study was to ensure that individuals had sufficient time to consider whether or not to participate. This was addressed in the study by ensuring that participants had a minimum of twenty four hours to consider involvement in the study. This requirement included both staff and patient participants. All initial approaches to patients were made by health care professionals either in person or by letter. Initial contact with a potential

participating health care professional was by e-mail followed up with a meeting to discuss the study.

Consent Process

As part of the process of consent the purpose of the research was explained to participants as well as the type of data collection involved, the part they would play in participating and that their involvement was voluntary. For both patients and health care professionals it was very important to ensure that they understood the implications of participating in a qualitative study. For example it was stressed that verbatim extracts of conversations would be used in written output from the study and may include some of their conversations within the consultation.

It was made clear that at any time during the data collection process participants could withdraw from the study and that they could change their minds about allowing their recordings (observations or interviews) to be part of the study. This latter point is very important when considering consultations since it has been noted that patients very often change their minds after the recording has taken place (Themessl-Huber et al. 2008). I was therefore conscious of the need to be very clear to participants that their withdrawal from the study would not pose a problem. Participants were provided with my mobile phone number in case of questions or in the event that they wished to withdraw consent.

Prior to consent for both staff and patients my aim was to:

- Ensure that individuals had received the information pack.
- Ensure that the study was fully explained (including confidentiality, anonymity, and use of research data).
- Explain that participation was voluntary.
- Establish if participants were willing to be recorded.
- Obtain informed consent to the recordings.

Data collection did not proceed without the appropriately signed and dated consent form. Participants were given a copy and the researcher retained a copy for the study records. A copy of the consent form was filed in the patient's record for individuals participating in recorded consultations.

All participants were informed that their recordings would be erased and field notes destroyed if they withdrew consent. It was also explained to participants that once anonymisation of data and analysis had commenced it would be more difficult to remove their data from the study. No participants withdrew from the study.

Eligibility

Individuals were eligible for the study if they were able to give informed consent. The lower age limit was set at eighteen since below this age limit individuals are deemed to be children for the purposes of consent. There was no upper age limit. Special ethical considerations apply in terms of consent for individuals with severe mental health and learning difficulties so these individuals were excluded. For practical considerations individuals were excluded if they were unable to converse in English. Pregnant women were excluded since diabetes management is different in this group as compared with other individuals with diabetes and includes attendance at joint diabetic-pregnancy clinics (Holt et al. 2010). It was also felt that in order to be able to give a reasonable account of changes from one regimen to another, individuals should have had diabetes for at least one year.

Confidentiality

All personal data collected during the course of the study was treated as confidential. A log of individuals participating in the research was recorded electronically on my password protected space on the university central drive. Signed consent forms were held within a locked cabinet at my home. Digital recordings were stored on my password protected space on the university central drive and backed up on an encrypted flash drive. Anonymised transcriptions were held on a password protected computer.

Confidentiality of participants was facilitated by holding personal details of participants separately from recordings and field notes. During the course of transcribing recordings, personal details were removed from transcription. Transcriptions were anonymised and only anonymised transcripts were shared with academic supervisors. Direct quotes from the research findings used codes assigned to participants in order to preserve anonymity.

Interview recordings were sent by post on a password protected flash drive to the professional transcriber rather than being e-mailed. All recordings were deleted from the audio digital recorder after being uploaded to the shared university drive and copied onto an encrypted flash drive.

4.6.2 Patient and Public Involvement

The need for patient and public involvement in applied health research is an area of growing interest (Staley 2009). It is generally recognised that individuals should have a say in research that may affect them and hence increasingly public involvement is a requirement stipulated by research funders (Staley 2009). In a recent review, the impact of public involvement was found to be of particular value in qualitative research (Staley 2009). Prior to submitting the study for ethics and NHS organisational approval several meetings were arranged with representatives of the local branch of Diabetes UK to obtain their views about the planned research. Discussions included the potential focus of the study, the local service configuration and how best to recruit patients. For example in August 2011 a meeting was arranged with eight committee members of Diabetes UK to discuss the recruitment strategy and participant information sheets. This was to ensure that these elements were both understandable and acceptable to individuals with diabetes. Members suggested that the information sheet should be available in a large font since one of the complications of diabetes is problems with eyesight. There was discussion on what constituted a reasonable length for an interview. It was agreed that ninety minutes was too long and that patients would prefer a shorter interview time of an hour. This was incorporated into the patient information sheet. There was a strong feeling amongst the members that patients should not receive payment for involvement in the study. It was agreed that payment would only be made for car parking or travel expenses incurred as part of the study.

4.7 Data Collection: Part One – Observations (Specialist Diabetes Services)

Having discussed the rationale for the study design I now turn to a detailed description of the data collection. In this section I discuss the study setting, the sample, recruitment and the data collection process for part one of the study (involving observations in specialist diabetes services). Data collection for parts two and three of the study are reported in sections 4.8 and 4.9 respectively. Data analysis for all three parts of the study is discussed in section 4.11. Given that parts one and two were linked together, some aspects of the study were the same for both. In addition, parts two and three utilised the same approach for interviews. However, for ease of presenting the methods I have kept each part separate. Table 4.1 provides a summary of the complete data set (Interviews and recorded consultations).

The plan for this first part of the study was to observe the interactions of individuals attending diabetes clinics and health care professionals involved in their care. Initially the aim was

primarily to explore decision-making processes involved in *gaining* access to an IIR. However, as the study progressed it was apparent that very few consultations involved this type of interaction. The majority of data collected was related to patients *maintaining* access to an IIR. The focus of this part of the study, therefore, became the analysis of interactions from the perspective of equity in maintaining access to an IIR.

Table 4.1 Interviews and consultations

Data Collected	Numbers
<i>Patient Interviews:</i>	
Specialist diabetes services	25
Primary Care	3
Total	28
<i>Health Care Professional Interviews:</i>	
Specialist diabetes services	4
Primary Care	2
Total	6
<i>Consultations attended by the researcher at specialist diabetes services:</i>	
Insulin pump clinic	21
Specialist diabetes nurse led clinic	1
General diabetes clinic	3
Total	25

4.7.1 Study Setting

The hospital and its catchment area

Given that type 1 diabetes care is often provided in secondary care, a single hospital offering this care in England was selected. The aim in selecting a single hospital was not to achieve generalisability to the whole population but rather to establish the relevance of the single case to other similar settings through potentially shared features and characteristics (Mays et al. 1995a). Therefore it is important to describe the hospital and its catchment area in detail.

A single hospital in the middle of England was chosen where individuals attended a range of specialist diabetes clinics. The hospital has over 500 beds and covers the full range of services associated with a District General Hospital including a full Emergency Department. The hospital is situated in an urban area comprising a population of approximately 142,000 people. Additionally it serves a large rural area populated with villages and small towns comprising a further 160,000 individuals. The hospital is situated within an area that includes a district ranked amongst one of the top ten percent most deprived in England (Office for National Statistics 2010a).

Diabetes services within the hospital

Within the hospital, at the time of the research, diabetes care was arranged around a number of diabetes clinics. Some of these were consultant led, some nurse led and some were multi-disciplinary involving medical, nursing and dietetic staff. These covered specialist clinics for individuals with diabetes who were pregnant, children with diabetes, a diabetic foot clinic and clinics for individuals with cardiovascular or renal problems. In addition there was a general diabetes clinic and an insulin pump clinic. The latter two clinics were selected together with their respective nurse led clinics because the aim was to focus on patients managing diabetes rather than patients requiring complex management owing to multiple co-morbidities. Decisions about movement to or between intensive regimens would occur at the general diabetes clinic and decisions about movement to, or maintenance of, pumps would occur in the insulin pump clinic.

The clinics involved in the study were attended by individuals with type 1 diabetes, although the general diabetes clinic was also attended by individuals with type 2 diabetes. The general diabetes clinic was typically accessed by patients on the more simple regimens whereas the insulin pump clinic (which had been an insulin intensification clinic prior to study commencement) focused on more complex treatment. These two clinics differed also with regard to health care professional involvement. At the start of the study the general diabetes clinic was run by a general physician. Part way through the data collection period this doctor was replaced with a locum specialist consultant in diabetes. Towards the end of the study the latter consultant introduced a nurse into some of the consultations. At the end of the data collection period this consultant had secured a position at another hospital.

By comparison the insulin pump clinic was multi-disciplinary and the same health care professionals remained at the clinic throughout the study period. In this clinic the aim was that a specialist diabetes nurse, specialist diabetes dietitian and consultant would attend all

consultations. Occasionally a junior doctor deputised for the consultant. The consultant involved in the clinic held a senior position within the department.

4.7.2 Sample for Observations

The sample strategy was the same for parts one and two of the study. Sampling in qualitative research does not aim to be statistically representative (Ritchie et al. 2003). The aim is to sample according to those aspects that are of primary interest to the researcher and that will enable a detailed exploration and understanding of the research question (Ritchie et al. 2003). The approach to sampling of consultations within clinics was maximum variation sampling (Patton 2002), aiming for maximum variation of the health care professionals running the clinics and patients attending the clinics since, as Patton (2002, p. 235) explains, any common themes identified during analysis from 'great variation are of particular interest and value in capturing the core experience and central, shared dimensions of a setting or phenomenon'.

Health care professionals

Health care professionals included in the study were those involved in the clinics under observation. They included specialist medical and nursing staff. It was envisaged prior to the study that between 5-10 health care professionals would be involved in the diabetes clinics and that all of them would be approached for recruitment.

Patients

The aim in sampling patients for the study was to ensure diversity across gender, age and the range of regimens used. This ensured that as full a range as possible of experiences could be included. The primary sampling strategy was based on type of regimen. The expectation was that patients attending the general diabetes clinic would be on less technologically advanced regimens than those in the insulin pump clinic. A secondary consideration was to include patients of both gender and of different ages. A sampling structure was utilised and updated as the study progressed in order to keep a check on the number of participants in each category. This was monitored periodically and where possible health care professionals were requested to target under-represented groups for recruitment.

4.7.3 Recruitment for Observations

Recruitment was carried out at the insulin pump clinic and the general diabetes clinic. Recruitment for observations involved recruiting both patients and health care professionals.

Health care professionals willing to consider participation in the study were given an information sheet and a minimum of 24 hours to consider their involvement. Some health care professionals were recruited at the beginning of the study for the duration of the data collection period whereas others were recruited as the study progressed. This was predominantly due to the six monthly changeover of junior doctors. Consent was required for both patients and health care professionals involved in the observed clinics. Patients tended to be recruited several weeks before their appointment and in some cases this stretched to a period of months.

Health care professionals (insulin pump clinic, general diabetes clinic and nurse led clinics)

In April 2010 a meeting was arranged with a key gatekeeper, the diabetologist running the insulin pump clinic. The aim in approaching this health care professional was to gain access to the team running the clinic and patients attending for appointments. This doctor explained how clinics ran in the hospital and that the majority of type 1 patients were seen in the general diabetes clinic. A second doctor was contacted in July, therefore, to arrange access to a general diabetes clinic.

An initial meeting was also arranged in June 2010 with the diabetes specialist nurse for the pump clinic. Recruitment processes were developed based on conversations with these gatekeepers. It was suggested that patients could be invited to participate by letter using the departmental database containing details of insulin pump users. All relevant staff members were approached following contact with the initial gatekeeper and through his permission.

In October 2011 the study was submitted for both ethics and research governance approval. Just before approval the chief collaborator left his post, handing the study over to one of his colleagues. Hammersley and Atkinson (2007b) discuss the need to be aware that initial access through a key gatekeeper does not guarantee access with other key members of the organisation and that problems of access are often a recurring feature throughout studies involving observation. This was the case in the present study and some of the difficulties with recruitment are outlined in section 4.10.

Patients

All potential participants were approached initially in person or in writing by clinical staff. The recruitment strategy captured patients attending clinic in one of two ways: prior to clinic appointment or at clinic.

Prior to clinic appointment

Patients were identified from clinic lists and sent information by NHS staff at least two weeks in advance of the appointment. If willing to participate, patients confirmed their interest by returning a reply form in a stamped addressed envelope or by contacting staff by telephone. I was then able to contact patients by telephone to ask if they had any questions about the study and to confirm their interest. I made arrangements to meet them at their next appointment to answer questions, confirm continuing interest in participating in the study and to obtain their consent.

At clinic

Staff agreed to approach patients attending clinic appointments to ascertain if they would be willing to meet with me to hear more about the study. When I was in clinic I was able to meet potential participants, outline the study, give an information sheet and explain that consent would be taken at their next appointment when the research involvement would commence. This gave patients the necessary time to consider involvement prior to consent.

When I was not able to meet the patient in person, health care professionals provided the study information sheet and a letter with a reply form. Patients who were interested in the study returned the form to the hospital for collection by me. I contacted these participants in order to give further information about participating in the study, to check their eligibility for the study and to ensure that they wished to proceed. Arrangements were made to meet them at their next appointments at the hospital. Letters of invitation, information sheet, consent form and reply form are in Appendix 7. Individuals accompanying patients to appointments were given separate information sheets and consent forms (Appendix 7).

4.7.4 Data Collection for Observations

Recruitment commenced in the secondary care setting in February 2012 and recruitment ceased in December 2012. This section describes the procedure I followed in collecting the observational data.

Before the recorded consultation

I met with patients approximately fifteen minutes prior to their appointments. Prior to the consultation and following consent I had a brief discussion with patients in which I obtained their age, ethnic origin, occupation, diagnosis date for type 1 diabetes and brief details about

their treatment regimens since diagnosis. This information was recorded on the Field Notes Form. Following consent, patients were taken by an outpatients' nurse for weight and blood pressure readings to be taken. From here patients were asked to sit in another smaller waiting area until they were called for their appointment. I followed the patient around to this area and waited for an opportunity to enter the consulting room to set up the recorder. The consulting rooms were positioned off a long corridor located near the waiting area. The clinic was shared with other consultants of different specialties and the outpatients' nurses on some days were looking after clinics comprising up to fifty doctors. The consulting rooms were of moderate size and different ones were used from week to week. On one side of the corridor the rooms were smaller and had no windows.

During the consultation

I attended each consultation. When the recorder was set up the patient was invited to sit in the consulting room. Occasionally, depending on how many individuals were attending the consultation, the space proved to be somewhat limited. I positioned myself in the least intrusive way towards the back of the room. Initially the recorder was placed on the desk in front of the doctor in attempt to be less intrusive. After a few consultations where the voices of some of the team were found to be indistinct, the recorder was placed centrally in order to overcome this problem. During the consultation I was free to observe the interaction and made brief notes to supplement the audio recording. For example, I noted that some patients brought paperwork or equipment to the consultations. Additionally I recorded when members of staff entered or left the room since this information would not have been available from the audio recording. This data was recorded on the Field Notes Form and used in conjunction with the audio recording for analysis purposes (see section 4.11.2).

At an opportune moment either at the beginning or end of the consultation I requested the patient's most recent HbA1c results from the doctor. At the end of the consultation and after all conversation with the patient had ceased, I turned off the recorder, thanked the staff and followed the patient to the waiting area. I then arranged an interview with the patient and obtained contact details from those willing to participate further in the study.

Numbers of observations

Data was collected for 25 recordings of consultations. Three of these were recorded in the general diabetes clinic, 21 were recorded in the insulin pump clinic and one recording was made of a nurse led insulin pump clinic.

The composition of the three clinics in terms of participating health care professionals is shown in Table 4.2. The primary doctor involved in the pump clinic and the primary diabetes specialist nurse attended 18 consultations. The specialist diabetes dietitian attended 17 consultations. This sample also included two doctors working on a six monthly rotation in the hospital (doctors 2 and 3). Three consultations were recorded at the general diabetes clinic with doctor 4. One of these consultations also involved another diabetes specialist nurse.

Table 4.2 Health care professionals involved in each consultation

Health care professionals	Consultations
<i>Insulin Pump Clinic</i>	
Doctor 1, diabetes specialist nurse 1, dietitian 1 (primary team)	9
Doctor 1, diabetes specialist nurse 1	5
Doctor 1, dietitian 1	2
Doctor 1, diabetes specialist nurse 2, dietitian 1 (stand in nurse)	2
Doctor 2, diabetes specialist nurse 1, dietitian 1 (stand in doctor)	1
Doctor 3, diabetes specialist nurse 1, dietitian 1 (stand in doctor)	2
<i>General Diabetes Clinic</i>	
Doctor 4	2
Doctor 4 diabetes specialist nurse 3	1
<i>Diabetes Specialist Nurse and Diabetes Specialist Dietitian Led Clinic</i>	
Diabetes specialist nurse 1, dietitian 1	1
Total number of consultations	25

Quality of data

The majority of recordings were of reasonable quality, although there were occasional difficulties in transcribing the recordings of some patients and staff whose voices were particularly quiet. In order to pre-empt some of these problems I made notes during the consultation on sections of conversation and terminology that I felt would be difficult to transcribe.

All consultations except one were successfully recorded. For this consultation I wrote detailed notes on the actions within the consultation and recorded them on a Field Notes Form. A diary was kept to record reflections on the observation of clinics. An extract from 28 March 2012 is shown in Box 1 below and highlights some of the day to day issues encountered whilst collecting the data. For example there were difficulties in identifying the patients who had

agreed to participate in the study. This problem was exacerbated because the waiting room served three different clinics. There was a need to go through the consent process in a timely way since there was the potential to hold up clinic appointments. These issues were lessened by ensuring that there was always a gap of at least one appointment in between patients recruited to the study. The diary extract also illustrates the ethical issues involved in a study of this type.

Box 4.1 Diary Extract 1

28/3/2012 Patient 1 (MDI) and Patient 2 (Pump)

Both patients attended pump clinic. Small hitch in that I had assumed patients would report to the desk but the hospital has an electronic booking system in place. I agreed with the outpatients' nurse that she would let me know when a patient had arrived in clinic. As it turned out I stood in reception and because the booking system wasn't working I was able to deduce who the patient was. As the system wasn't working properly reception staff let me know when the second patient arrived.

The patient arrived very early and therefore I thought we had plenty of time to run through the study and consent. However the patient was called early for their appointment just as I was consenting them. Fortunately we had covered most things as the nurses were eager to get the patient weighed etc. This takes time as the clinic nurses are looking after several clinics. As there was a gap between consenting the patient and their consultation I was able to go into the room and set up the recorder.

During the consenting process for the second patient the pump clinic nurse came in. The patient started explaining about some personal difficulties and began crying. I was very concerned and asked if she wanted to go ahead. She said she was definitely ok to proceed with the recording. After the consultation we agreed that because of these personal difficulties we would delay the interview in the short term to allow these problems to unfold. With regard to the recordings, both were acceptable – I had agreed with the doctor that the recorder would be on before the patient came in. I placed the recorder on the desk between patient and doctor. This meant that the nurse's voice was a little less clear and this may be an issue when the dietitian joins in. I sat in the middle away from the desk towards the back of the room.

4.8 Data Collection: Part Two - Interviews (Specialist Diabetes Services)

In this section I discuss the sample, recruitment and data collection process for part two of the study (follow up interviews with participants in the observation part of the study). The study setting was the same as for part one (see section 4.7.1).

4.8.1 Sample for Interviews

The sample for the interviews of patients and health care professionals was drawn from participants recruited in part one of the study (see section 4.7.2).

4.8.2 Recruitment for Interviews

Health care professionals

Health care professionals involved in the consultations were contacted towards the end of the observation data collection period and arrangements were made, if they were willing, to meet with the researcher for an interview. Health care professionals were consented immediately before their interview, since study details had been given at the same time as those given for the observation part of the study. The consent form for health care professionals is in Appendix 7. All team members of the insulin pump clinic and the consultant in the general diabetes clinic were interviewed. Four health care professionals in total agreed to be interviewed.

Patients

Following the consultation, patients were invited to participate in an interview. Patient participants had already received information about the interview part of the study some weeks before the consultation so it was possible to discuss arrangements to meet at a mutually convenient time and place of their choosing. This was always arranged at least a day after the consultation in order to give sufficient time for patients to be sure that they wanted to participate. The consent form for patients is in Appendix 7. All the patients in part one of the study agreed to participate in follow up interviews.

4.8.3 Data Collection for Interviews

Health care professionals

Health care professionals' interviews in the hospital were scheduled towards the end of the data collection phase to allow a more comprehensive discussion based around the observed consultations. These interviews were not designed to explore individual consultations but rather intended to cover a more general overview of decision-making and issues of access to intensive regimens. Interviews with health care professionals from the hospital clinics were carried out at health care premises and were approximately fifty minutes in length. The topic guide was amended according to the group that was being interviewed.

Patients

Having discussed the study with interested participants and checked eligibility, where necessary arrangements were made for the interview to be carried out. None of the patients withdrew from the study after this stage. Although the observational and interviews parts of the study have been described separately, in practice they were running concurrently. Having observed and recorded a consultation the aim was to interview the patient participant as soon as possible after the appointment and this was achieved in the majority of cases.

Venue

It is often left to participants involved in qualitative interviews to decide the venue (Legard et al. 2003). Patients in all parts of the study were asked to give their preference for interview location. Although interviewing at home would appear to be less onerous for participants, some patients chose to be interviewed in the hospital. The majority of patients, however, opted for an interview at home (18) with 8 choosing to be interviewed in the hospital and 2 preferring their place of work. The hospital was occasionally a noisy venue and sometimes there were interruptions during the course of the interview. For the most part there were fewer interruptions when interviewing participants at home. When meeting participants at their home address the university's policy for lone working was utilised.

Prior to the interview and following consent I checked that I had data on participants relating to age, occupation, household composition, onset of diabetes and a brief record of the types of regimens patients had used in the past and were on currently. HbA1c was obtained from health care professionals for these patients.

Interview length

Interviews were scheduled to last approximately an hour. In practice, 14 interviews lasted between 50 and 70 minutes; 11 were longer than 70 minutes and 3 were less than 50 minutes. As participants had agreed to be interviewed for approximately one hour I ensured that they were willing to continue as the end of the hour approached. Before each interview I checked to make sure that participants had an hour available for the interview. Only two interviews posed a problem in this respect. In the majority of cases participants seemed to be happy to talk for approximately an hour and in many cases over an hour.

Interview approach

It was important to start interviews with a subject which was straightforward and allowed a mainly descriptive response (Patton 2002) hence individuals were asked to give a brief history of their condition since diagnosis. The remaining topic areas built on this initial discussion. As the purpose of the study was exploratory, the aim of the interview was to allow individuals to discuss their experiences in as full a way as possible. Using a topic guide provided a systematic approach whilst still allowing for spontaneity in questioning (Patton 2002). The topic guide enabled the key themes to be discussed in a sequence and manner that could be tailored to individual respondents (Arthur et al. 2003). This included being sensitive to the language used by respondents to ensure that questions were understandable (Patton 2002). Examples of topic guides used for patients and health care professionals are provided in Appendix 7.

The purpose behind qualitative interviewing is to enable individuals to respond in an individual manner. This was achieved through the use of open ended questions, phrased in a neutral and non-leading manner, followed up by probing participant's responses, enabling the interview to extend beyond a superficial level of questioning (Legard et al. 2003). This aim was to achieve depth of detail with a view to uncovering new areas and ideas that may not have been anticipated at the outset (Britten 1995).

Items of interest (not on the original topic guide) emerged during the course of interviews as individuals raised issues. Where applicable to the area of research, these were included in subsequent interviews and the topic guide was amended accordingly. In this way, the interview content evolved over the course of the study.

During the interview no notes were taken so as not to detract from the flow of conversation. Interviews were audio digitally recorded as this provided an accurate record of the encounter

(Legard et al. 2003). Following the conversation brief notes were made on impressions of the interview (Patton 2002). These supplemented the recordings and provided additional information for analysis (Byrne 2004). Reflecting on the outcome of the interview is an important element of ensuring the rigour of qualitative analysis (Patton 2002). Some of my impressions recorded immediately after interviews are provided in Box 4.2 below. These included an indication of how I felt the interview had gone as well as notes for analysis.

Whilst interviewing participants I was alert to the possible problems of individuals experiencing low blood glucose levels. It was made clear to participants that the interview could be stopped at any time for any reason. During the course of the interview, only two participants needed a break in order to raise blood glucose levels.

4.8.4 Interview Preparation

In order to achieve the best possible outcome from an interview, interviewers need to carry out thorough preparation on the topics for discussion (Denscombe 2010). As I do not have a nursing or medical background, I felt it was important to be as well informed as possible about type 1 diabetes so that interviews with patients would be meaningful. I took every opportunity to find out about the different regimens and particularly the complexities of multiple daily injections and insulin pumps. This included attending a meeting at the hospital prior to the study start in which the three main insulin pumps used by the department were introduced to patients. I subsequently researched on the internet about the operation of one of the pumps (Medtronic Veo™) using on line training facilities. This was useful not only in understanding the conversations about technical aspects of the pump but also to ensure that terminology was correctly recorded in transcriptions. I used a comprehensive introduction to diabetes written for children, adolescents and young people (Hanas 2012) found in the hospital library, to provide background information on medical terms or situations referred to by patients during the course of consultations and interviews.

In addition, prior to interviewing patients following their consultations, I ensured that I was fully informed about the content of the recorded consultation. In many cases this involved transcribing the consultation before the interview. If time did not permit I listened to the recording and noted key actions on the Field Notes Form. This form was taken to the interview as an aide memoire.

Box 4.2 Diary Extract 2

6/8/2012 Patient 8 – Insulin pump *Interviewed at work place in a board room. Interview was less than an hour. The participant said at the outset he wanted it to be over as quickly as possible because of work commitments. Hence the need to keep an eye on the time – more so than with other interviews. Some very useful insights from participant into his perspective on involvement in decision-making and the ways in which he ensures that he gets on with staff. Also reference, made to how pump was justified by doctor on the basis of lifestyle. This came after the interview had finished so with his permission I recorded this additional conversation.*

5/10/2012 Patient 9 – Insulin pump *Very long interview 1 hr 30 m Very difficult to get through questions as patient wanted to tell me a lot about the technical details of diabetes. Also wife present and joined in conversation (but not a great deal more at the end). Good rapport with patient. He and his wife were very welcoming. It is becoming clear that it is much easier to keep to the topic guide with some patients than with others. When it becomes difficult the interview is much lengthier.*

4.9 Data Collection: Part Three - Interviews (Primary Care)

4.9.1 Study Setting for Primary Care Interviews

Primary care – the general practice and its catchment area

The GP surgery selected had a population of 10,000 patients. Members of staff included eight doctors and three nurses. There were approximately thirty patients registered with type 1 diabetes during 2012. This represented a small proportion of the diabetes patients at the surgery overall who numbered approximately three hundred. The GP surgery is situated within an area in the city dominated by council housing. The area is ranked amongst the top ten percent most deprived areas in England for income, unemployment, crime and health (Office for National Statistics 2010a).

4.9.2 Sample for Primary Care Interviews

Two members of staff (one GP and one practice nurse) agreed to participate in the study and were interviewed. The primary sampling criteria for patients was individuals with type 1 diabetes not accessing specialist diabetes services. It was anticipated that this would be a small number and therefore the scope for applying other criteria to the sample was limited. The GP

practice identified adult patients with type 1 diabetes and sent a letter of invitation to all potential participants. Three patients responded to the invitation and agreed to participate in the study out of an original sample of the thirty patients with type 1 diabetes registered at the GP practice.

4.9.3 Recruitment for Primary Care Interviews

Health care professionals

Contact was made with the surgery in Autumn 2010 and I was invited to attend one of the practice staff meetings in December 2010. I presented an outline of the study. At this stage the study had not evolved into the current design. The GPs agreed in principle to allow recruitment of both patients and staff to be undertaken at the surgery. A further meeting took place in April 2011 with one of the GPs and a practice nurse. The study was presented and assistance was requested with recruiting patients. Prior to ethics approval, study documents were agreed with one of the GPs. Following ethics approval in October 2011, it was agreed that the study would commence at this site following the relocation of the surgery in 2012. An information leaflet was sent out a week prior to the date arranged for interviewing the GP and practice nurse. Written consent was obtained from both members of staff on the day of the interview. The consent form and information sheet for health care professionals are in Appendix 7.

Patients

Having agreed the process with the practice manager, recruiting patients was administered by the surgery. Thirty letters were sent out to patients with type 1 diabetes in June 2012. This included a letter inviting patients to participate in an interview, patient information leaflet and reply form with stamped addressed envelope (see Appendix 7). Patients who were interested returned the form. I contacted patients who had returned the form and discussed the study over the phone giving further details and arranging an interview venue. The low numbers of patients recruited at the GP practice reflect the relatively small number of patients with type 1 diabetes as opposed to type 2 diabetes.

4.9.4 Data Collection for Primary Care Interviews

Health care professionals

Interviews with health care professionals were carried out at health care premises and were approximately fifty minutes in length. The topic guide used in the hospital setting was amended according to the group that was being interviewed.

Patients

All patients chose to be interviewed in their own homes. The interview process is described in section 4.8. The topic guide was amended slightly to reflect that patients and health care professionals had not participated in an observed consultation.

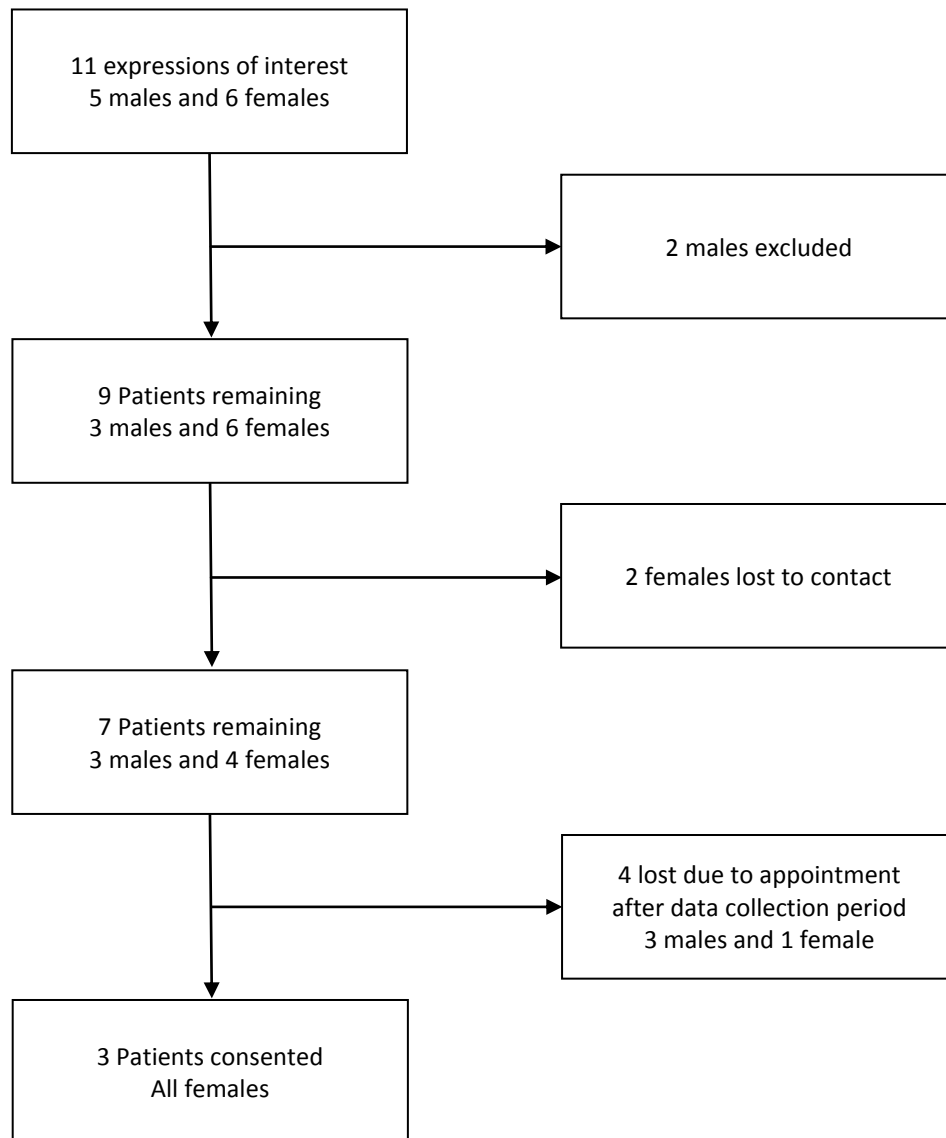
4.10 Difficulties with Data Collection

In the early part of the study it was agreed with secondary care staff that patients would be recruited at clinics on Monday and Wednesday of each week. It became apparent in the first few weeks that recruitment of insulin pump clinic patients would be relatively straight forward in comparison with recruitment at the general diabetes clinic. Patients responded both to letters and to face to face discussion with health care professionals at this clinic. Recruitment of patients attending the general diabetes clinic, however, proved to be slow. Although the majority of expressions of interest for the study came from face to face discussion with the doctor running the clinic this was infrequently carried out. Figure 4.1 shows the numbers of patients recruited at the general diabetes clinic initially expressing interest in the study compared with the numbers of patients who finally consented. The three patients who participated in the study were all contacted by letter towards the end of the data collection period.

From April 2012 onwards it was decided by the hospital that both of the clinics involved in the study would run on a Monday afternoon (instead of Monday and Wednesday). This presented an additional difficulty in terms of both recruitment and data collection since I could only be in one clinic at a time.

In May 2012 the general diabetes consultant left the clinic and was replaced by a locum consultant. There was a delay of approximately two months before the new consultant was consented into the study. This disruption to recruitment compounded difficulties in arranging for letters to be sent to patients. This was due to shortages of staff in the administrative team and the need for a health care professional to check on patient eligibility before inviting patients to participate. In contrast, the diabetes specialist nurse in the insulin pump clinic arranged personally for letters to be sent to patients. For these reasons recruitment inevitably focused on the insulin pump clinic as the study progressed.

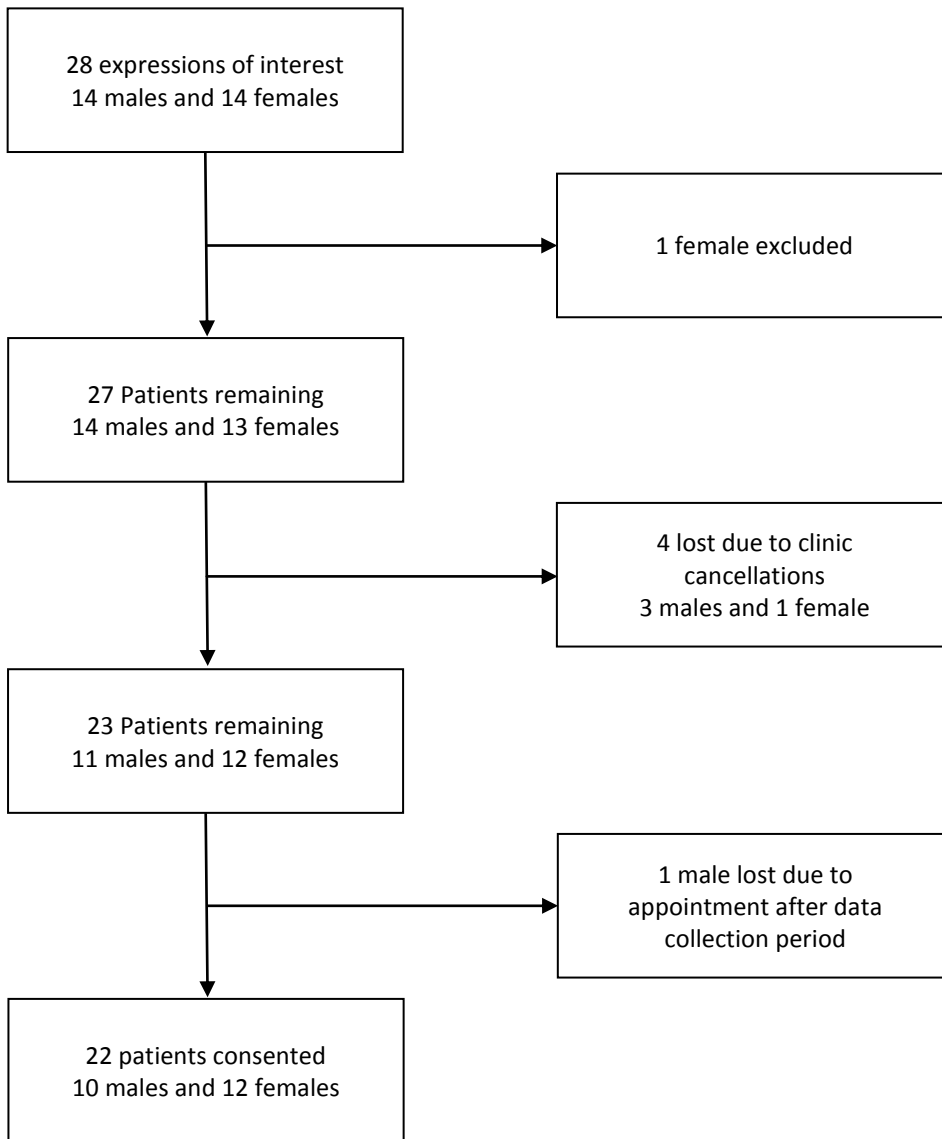
Figure 4.1 Patients recruited at the general diabetes clinic



Although more patients were recruited at the insulin pump clinic this did not always translate into opportunities to observe their consultations. Figure 4.2 shows the numbers of patients recruited at the insulin pump clinic initially expressing interest in the study compared with the numbers finally consented. Approximately half of the insulin pump clinics were cancelled during the course of the study. This led to a data collection period that was longer than originally planned. The majority of patients in the study were, however, recruited through the insulin pump clinic. One possible explanation for this may be the input given to recruitment by the diabetes specialist nurse who was part of the multi-disciplinary team running the clinic. After a number of problems with clinics being cancelled the recruitment switched to sending letters of invitation only. The nurse was well known to patients and the replies to letters were

returned to her. It is probable that the relationship patients had with support staff in the insulin pump clinic may have played a part in their decision to participate in the study. Patients who were approached by doctors also seemed likely to agree to participate.

Figure 4.2 Patients recruited at the insulin pump clinic



Recruiting patients on the day the recording was due to take place was not an option due to the ethical requirements for patients to have time to consider participating in the study and twenty four hours being deemed to be the minimum amount of time. No patient was involved in the study without having had the requisite amount of time to consider participating and in many cases this was measured in weeks rather than days.

4.11 Analysis

The following section describes the analysis of both the recorded consultations and the interviews (sections 4.11.2 and 4.11.3 respectively). Conversation analysis was used for the recorded consultations and thematic analysis was used for the interviews. The justification for their use is provided in the following sections. I begin by describing the process of preparing the data collected in consultations and interviews.

4.11.1 Preparing the Data

Large amounts of data are generated in qualitative research and one of the key tasks of the researcher is to reduce these to a manageable form (Spencer et al. 2003). The first stage of analysis for both consultations and interviews was to prepare the data and this was accomplished by transcribing the recordings. Transcribing is a time consuming process (Pope et al. 2006b). Each recorded hour may take between six or seven hours to transcribe (Pope et al. 2006b). The level of detail required depends on the type of analysis carried out (Pope et al. 2006a). In this study the level of detail required for transcribed consultations was greater than that required for the interviews. Five minutes of recorded material from a consultation took approximately two hours to transcribe. The interviews took approximately eight to ten hours for every one hour of interview.

It is generally recommended that researchers transcribe recordings destined for conversation analysis (ten Have 1999) whereas interview transcriptions are very often outsourced (Pope et al. 2006b). The majority of interviews were therefore outsourced to a professional transcriber so that time could be focused on transcribing the consultations. It is nevertheless important that a thorough check is carried out on returned transcriptions (Pope et al. 2006b) and this in itself was very time consuming.

4.11.2 Analysis of Clinic Observations

Conversation analysis was chosen as the means of analysing the recorded consultations. This was supplemented with the Field Notes Form (Appendix 7) and diary reflections.

Conversation analysis

Conversation analysis aims to explore the ways in which individuals interact with each other in order to discover recurrent practices involved in largely verbal communication (Drew et al. 2001). This is accomplished by examining social interaction explored through naturally

occurring conversation. The underlying premise behind conversation analysis is that social interaction is determined on a turn by turn basis through conversation. Conversation analysis is accomplished by analysing these turns at talk. Each successive turn is both influenced by a previous turn and also influences the turn that follows (Hutchby et al. 2008).

Whereas much of the early conversational analysis was 'pure' (based on 'ordinary conversation', later research had an 'applied' focus (analysing 'institutional interaction') (ten Have 1999, p. 162). However, conversational analysis has used ordinary conversation as a point of reference from which to compare other sorts of more formal conversation (Drew et al. 1992). For a comprehensive overview of institutional interaction see Drew and Heritage (1992) and Heritage (2004)

Conversation analysis has been used previously in order to advance understanding of the processes of health care delivery which relate to communication between health care professionals and patients (Drew et al. 2001). Within the provision of health care, the interactions between health care professionals and patients can have far reaching implications in terms of outcomes including the successful adoption of regimens and patient satisfaction (Drew et al. 2001). Conversation analysis has a role to play in analysing these interactions and importantly offering insights that have practical applications such as enabling patient participation (Drew et al. 2001).

It is important to establish at the outset that the conversations recorded in the secondary care diabetes clinic constituted 'institutional talk'. Whereas everyday conversation is informal, institutional talk, depending on setting, has varying degrees of formality (Sacks et al. 1974). Nevertheless conversation within institutional settings is not 'uni-modal' any more than it is in informal conversation and hence it is a simplification to describe talk in particular institutional settings as if there were only one type (Drew 2002). Ten Have (1991) describes three styles of talk within consultations. The first type of talk is exclusively medical. The second type is talk that although involving a medical orientation is less formal. The third type is small talk.

The constraints on lay individuals interacting in medical settings have been described as exhibiting features of 'interactional asymmetry' (Heritage 2004). This has been the subject of much research (Pilnick et al. 2011). Whilst acknowledging that asymmetry occurs in normal conversation, the particular features and requirements of institutional interaction in terms of the activities that must be performed constrain conversation in ways that is not experienced in everyday discourse (Heritage 2004). One example of this is the need in many institutional

activities involving professional and lay people, for questions to be asked by the former and answered by the latter (Heritage 2004). In this way members of institutions shape movement in conversation from topic to topic, determining initiation and closure of topics raised (Heritage 2004).

The relevance of question and answer formats in conversation analysis is that the answer given is termed 'conditionally relevant'; it is dependent on the question asked and the response is examined for this relevance by the initiator of the question. In consultations the opening sequence is usually determined by the health care professional initiating the questions since they may either 'open' up the potential responses or 'close' them down depending on the questions asked and the follow up sequences (Roter et al. 1992). In analysing talk in institutions the aim is to show how individuals 'build the context of their talk in and through their talk' (Heritage 2004, p. 224). The focus is on what individuals are doing in conversation as opposed to second guessing their motives.

Analysis process: consultations

There were four stages of analysis:

- Transcribing the recordings and reading the transcriptions.
- Building collections.
- Analysing individual consultations.
- Relationship with the thematic analysis.

First stage: transcribing the recordings

Analysis commenced with listening repeatedly to the recordings (Collins et al. 2006). One of the key features of conversation analysis is the requirement to provide transcriptions to a fine level of detail. It was important that the transcription could convey not just what was said but how it was said (ten Have 1999). Transcribing aims to 'capture the timing and placement of speech (e.g. overlaps and pauses/silences), sound qualities (such as sound stretching, emphasis, loudness, marked pitch change and certain intonational features) and a range of other features of the talk including in- and out-breaths, laughter and cutoff words or sounds' (Drew 2005). In conversation analysis pauses within turns and gaps between turns have particular significance (Davidson 1984; Pomerantz 1984) and have therefore been captured using Audacity™ (2.0.4), a software package, capable of providing precise measures of the timing of gaps and pauses to at least a tenth of a second.

I transcribed all the consultations for a number of reasons. First, transcribing talk for the purposes of conversation analysis is a much more time consuming activity than is usual with interviews data. Part of the time consuming nature of the activity also provides advantages. This is because the researcher has to listen more attentively to the detail of the interaction and this in turn helps with later analysis. Second, in conversation analysis, transcribing is viewed as part of the analytic process and serves as a 'major noticing device' (ten Have 1999, p.78). Third, as I was present in the consultations I had an advantage in terms of making sense of unclear conversation. Finally, transcribing talk is inevitably a selective process which I felt I would be better suited to undertake than a professional transcriber perhaps more familiar with interviews. The consultations very often involved more than three individuals and since it is usual for conversation to overlap it was important to ensure that this was reproduced as accurately as possible. In conversation analysis it is recognised that since the transcription is necessarily selective, analysis should always be carried out with both transcript and recordings together.

The first stage of transcribing involved using a similar orthographic notation to the interviews with a simplified version of conversation analysis notation adapted from Silverman (2006). For example overlapping speech was reproduced and approximate pauses inserted. The aim was to transcribe all the consultations to this level of detail in order to identify those parts of the transcript that warranted the additional analysis requiring the notation developed by Jefferson and reproduced by Atkinson and Heritage (1984). The current study used an adapted version of this notation (see Appendix 8). In this way an overall impression was gained of each recorded consultation.

Second stage: building collections

A fundamental aspect of the analysis was to determine what was occurring in each consultation in order to make comparisons across the dataset. Hence during the second stage of analysis the aim was to start the process of identifying patterns in the data (Collins et al. 2006) and this commenced with an examination of the content of each consultation. Consultation content was summarised (Silverman 2006) for all participants using data from transcriptions, the Field Notes Form and notes in my diary. Initially this was accomplished using a table in Microsoft word and comprised a list of over 50 elements (Box 4.3 contains elements in relation HbA1c and blood glucose levels). This was the beginning of the process of examining differences in patient-provider interaction between patients.

Box 4.3 Discussions in relation to HbA1c and blood glucose levels

Target levels discussed

Above target, below target, on target

HbA1c going up

HbA1c going down

Questions asked - HbA1c going up

Positive comments

Negative comments

Blood glucose levels/control discussed

Patient brings records/meter

Frequency of testing discussed

Patient raises problems with hypos

Health care professional raises problems with hypos

Patient raises problems with high blood glucose levels

In conversation analysis research, consultations are considered to comprise of phases of activity (Collins et al. 2007b). These phases in the consultation process, for example, opening sequences, have been used in conversation analysis to explore patient participation (Collins et al. 2007b). Phases are constructed from sequences of talk which in turn are made up of turns at talk. Hence consultations were examined for turns of talk in order to identify phases of activity. A number of turns of talk were identified as commonly occurring in the consultations. This was accomplished by a combination of annotating word document transcripts using comment boxes and the use of NVivo™ 9 to retrieve and examine common sequences.

These sequences were further summarised and the main phases within the consultation were categorised as follows:

- Opening sequence (pre-treatment phase)
 - Greetings
 - Information gathering
- Treatment Phase
 - Problem solving, advice and information giving
 - Decision-making
 - Examinations

- Closing sequence (post-treatment phase)
 - Summarising agreed action and follow up appointments
 - Farewells

It was through this process that the opening sequence was identified as an important part of the consultation since it contained differences both in the ways that patients within the sample reacted to the doctor's dialogue and in the ways that the doctor interacted with different patients. Hence considerable attention to similarities and differences both within and across cases was carried out. Checks were made using the attributes of the participants. Some of these drew on the data from the interviews or the Field Notes Forms. For example, analysis of the conversations about HbA1c looked at whether this test result value was rising, reducing or stable. It was through this process that I identified the opening sequence for the next stage of analysis.

Third stage: analysing individual consultations

Having built a collection of sequences (Toerien (2014) citing Drew (2003, p. 148)) and identified sections of interaction to transcribe in more detail, analysis proceeded on the basis of listening to the recording and adding the fine detail to the transcripts. It is important to stress that analysis was an iterative and sometimes messy process (Toerien 2014) and that this account inevitably provides a simplification of an activity that spanned many months. This stage involved analysing conversation on a turn by turn basis. Subsequently the analysis moved back and forth between looking at individual cases and in comparison with the other cases in an attempt to make some sense of the patterns observed. It was important during this process to attempt to account for deviant cases that did not appear to follow the usual pattern. These deviant cases are reported in Chapter 6 and are able to offer a more nuanced explanation of the interaction occurring between doctor and patient.

Fourth stage: relationship with interview data

The final stage of analysis occurred after many of the key themes had been identified in the interview data (reported in Chapter 5). Following an iterative process of moving between interview data and consultation data I became aware that the former findings also offered a framework to understand the consultation data. The interview analysis enabled me to return to the consultation data extracts already analysed and to re-focus on the factors that were likely to affect access. I re-examined some of the patterns already observed previously in the analysis in the light of the interview findings.

During this iterative process, two key themes were identified: ‘patient alignment’ and ‘patient involvement’. These were used as a framework to re-examine the consultation extracts using conversation analysis as described in the third stage above. Hence the focus of the conversation analysis became an examination of the turn by turn process of the interaction in relation to these key themes. A more detailed account of the rationale for the chosen framework for presenting the themes from the consultation data is provided in Chapter 6.

4.11.3 Analysis of Interviews

Thematic analysis

Thematic analysis was used to analyse the interview data. Thematic analysis is a ‘foundational method for qualitative analysis’ and as such provides a key skill essential for researchers (Braun et al. 2006, p.78). It is the most frequently used form of analysis in qualitative health research (Pope et al. 2006b). Thematic analysis was chosen for its ‘theoretical freedom’ since it may be used independently of ‘theoretical and epistemological approaches’ (Braun et al. 2006, p. 78).

Analysis commenced as soon as data collection began. Initially this was confined to diary reflections on both recorded consultations and interviews. During the data collection phase the majority of time was spent recruiting patients, attending consultations, interviewing participants followed by either transcribing or checking transcriptions that had been carried out by a third party. The aim of the study was to continue collecting data until ‘saturation point’ had been achieved (Pope et al. 2006b, p. 66). This was achieved by ensuring that the sample was as diverse as possible. The difficulties with data collection have been noted in section 4.10. The table below illustrates how the majority of participants were recruited in a very short time period (16 patients in three months versus 12 in the previous 7 months). Nevertheless it appears from the sample that reasonable diversity in patient characteristics was achieved.

In practical terms although some analysis had commenced in the earlier months it was not until most of the data had been collected that the analysis phase commenced more formally. Having analysed the interviews, repetition of themes was apparent; however, it was also noticeable that some of the participants recruited towards the end of the study brought additional insights to the findings and that without their input several themes would have been omitted. These insights related to individuals of lower socioeconomic status. These patients were purposively sampled and recruited with the assistance of the specialist diabetes

nurse towards the end of the data collection period. I reflect in Chapter 7 on whether the underrepresentation of this group of patients and the small sample of primary care patients may have had consequences for the achievement of saturation. The health care professional team looking after patients with type 1 diabetes in the specialist diabetes centre and in primary care was small. The implications of this small sample are discussed in Chapter 7.

Table 4.3 Recruitment of patient participants (March – December 2012)

Month	Patient Numbers	Cumulative total
March	2	2
April	2	4
May	1	5
June	1	6
July	4	10
August	1	11
September	1	12
October	7	19
November	7	26
December	2	28

Analysis process: interviews

There were four stages to analysis:

- Preparing and reading transcripts
- Coding
- Development of themes
- The role of theory in analysis

First stage: preparing and reading transcripts

The level of detail required for transcription depends upon the types of analysis to be carried out (Flick 2006; Pope et al. 2006b). Interviews were not transcribed to the same level of detail as the consultations since this was not required of the analysis (Flick 2006). They were, however, verbatim to the extent that repetitious words and hesitations had not been removed. These were removed when added to the thesis as extracts since they did not

enhance understanding and the resultant text was felt to be more readable. The first stage of analysis was familiarisation and involved reading and re-reading transcripts.

In carrying out the analysis it was important to note the prevalence of patterns or themes whilst observing that a greater number of instances of a particular theme does not denote its importance (Braun et al. 2006). A reflexive diary was kept on interviews and analysis noting down ideas as they emerged. These notes were held in a word document.

Second stage: coding

The next stage involved a form of condensing and sorting of data. Computer assisted qualitative data analysis software (CAQDAS) (NVivo™ 9) was used to facilitate the storage and retrieval of verbatim transcripts of interviews. Coding data allows organisation of research findings into a format suitable for analysis (Miles et al. 1994). Coding in this study entailed a line-by-line examination of the data within NVivo™ 9. Codes were assigned to varying lengths of text and were descriptive or interpretive in form (Miles et al. 1994). Each transcript was analysed for repetition of codes and continued until the transcription was fully coded. The analysis proceeded to the next transcribed interview. The aim was to code the transcript whilst also making comparisons with the previously coded transcript. Analysis proceeded, therefore, on the basis of comparing within and between cases (Spencer et al. 2003). This form of analysis appeared to be important for the study since the aim was to explore not just patient experiences in gaining access to services but also the similarities and differences between patients particularly with regard to socioeconomic status. Transcripts were coded with a combination of descriptive elements (for example 'attitudes to advice') and interpretive elements (for example 'stigma'). Initially the list of codes was extensive. As analysis progressed this list was refined and reduced. The final iteration of codes held in NVivo™ 9 were grouped together under preliminary overarching categories relating to: accessing services; attitudes towards advice; communication; decisions; diabetes management; information; psychological and emotional; stigma; and support. Following this stage, NVivo™ 9 was used as a data resource in terms of coded segments of transcripts, however, no further analysis was carried out within the software package.

Third stage: development of themes

A theme 'captures something important about the data in relation to the research question' (Braun et al. 2006). Hence in addition to identifying themes it was important to address the research question regarding inequity of access. The following procedure was adopted. First,

themes were developed by retrieving coded data extracts from NVivo™ 9. For each of the codes of interest a PDF was created from NVivo™ 9 containing a 'printout' of the lines of coded transcript for each relevant participant, for example, all the data in relation to 'supportive nurses'.

Second, themes were analysed in relation to differing patient characteristics. For example, a number of themes related to the different ways that patients experienced specialist services. These sub themes included the barriers and drivers involved in accessing services. Themes were developed iteratively through a process of writing up themes for discussion at meetings with supervisors, since writing is an integral part of the process (Braun et al. 2006).

Fourth stage: the role of theory in analysis

Although qualitative research findings may remain at the descriptive stage, which is acknowledged to be legitimate depending on the nature of the research question (Spencer et al. 2003), the analysis was strengthened by exploring the interconnectedness of themes and relationships between them (Pope et al. 2006b). Some researchers argue that description is never sufficient and that an understanding of 'the patterns, the recurrences, the whys' is required (Spencer et al. (2003, p. 205) citing Miles and Huberman (1994)).

Two key approaches to thematic analysis have been identified: inductive (bottom up) or 'theoretical' (analyst driven) (Braun et al. 2006). Inductive approaches do not attempt to fit the data to pre-existing templates or coding frames whilst theoretical thematic analysis is guided by the particular interests of the researcher (Braun et al. 2006). During the process of analysis I moved from an inductive to a theoretical approach. There were several iterations involved in this process. Whilst the study was exploratory in nature there were however two specific areas of interest: namely decision-making and access. Writing up themes therefore was driven by considerations of these issues. The approach was therefore 'theoretical' thematic since the data was coded with reference to these broad areas of interest. The other key aspect of this type of analysis is that in contrast to an inductive approach, searches are made of the literature for pre-existing theory which may be elaborated or expanded on by the current research project.

During the course of writing up themes, it was noted in conversation with my supervisors that one of the key theories previously found to be relevant in the literature review had particular saliency with the data. Themes were therefore reorganised and reframed using the key features of Candidacy theory (Dixon-Woods et al. 2005). This was the most productive part of

analysis since there were two key advantages to using Candidacy theory to frame the findings. First, access to health care is a complex area and the theory provided a way to frame the findings in a coherent way using concepts that had been used in other empirical studies. Second, using Candidacy theory to frame the findings facilitated further analysis and links were made between themes. Study themes were grouped around *gaining access to specialist services* and *patient eligibility for an intensive insulin regimen*. This facilitated a separation of factors relating to 'access-entry' and 'in-system' access concepts used by Dixon-Woods et al. (2005, p. 44)

Further analysis identified that disparities relating to attitudes to self-care, health literacy and involvement in decision-making were important factors relating to the Candidacy theory concepts of 'patient presentation' and also influential in relation to 'health care adjudications', 'offers' and 'resistance'. By re-examining patient accounts of their different approaches to self-care and decision-making, three patient types were identified: 'proactive'; 'collaborative' and 'support-seeking'. The themes relating to self-care and decision-making were therefore grouped around these three patient types and these in turn were related to patient presentation, adjudications, offers and resistance. It was at this final interpretive stage that the various themes were brought together to form a coherent 'story' (Braun et al. 2006) and the concept of 'patient-provider alignment' emerged as a key influence on gaining access.

Given that the focus of the study was socioeconomic disparity one option might have been to analyse data according to socioeconomic status (SES); however, it was important not to make assumptions about the influence of SES at the start of analysis. Hence themes were developed first, followed by the process of analysis described above (third stage) whereby the impact of SES was investigated subsequent to theme identification.

4.11.4 Relationship between Analysis of Interviews and Consultations

Having identified the key themes within the interview data (reported in Chapter 5) I became aware that these findings also offered a framework to understand the consultation data. Hence I returned to the consultation data and re-examined some of the patterns in the analysis in the light of the interview findings. Using the techniques of conversation analysis I explored the influence of patient alignment and patient involvement on patient ability to maintain access to an IIR.

4.11.5 Presentation of Findings

The findings are presented in the following two chapters: Chapter 5 (the findings of the thematic analysis) and Chapter 6 (the findings of the conversation analysis). Although the interviews were recorded after the consultations, the findings of the former are presented first because the analysis follows the experience of the patient in their health care journey. Thematic analysis provides an understanding of *gaining* access whereas Chapter 6 presents the findings on *maintaining* access.

Chapter 5. Gaining Access to Intensive Insulin Regimens

5.1 Introduction

This chapter presents the findings of the interviews with 28 patients and 6 health care professionals. The chapter addresses the aspect of the research which relates to gaining access to an IIR from the perspective of equity. This was accomplished through an exploration of the pathways involved in changing to an IIR and other influences on gaining access. Before describing the findings of these interviews in sections 5.5 and 5.6, I describe the sample, the study context, and the use of Candidacy theory to frame the study findings.

5.2 Description of the Sample

Interviews were carried out with 28 patients and 6 health care professionals. Two health care professionals (a practice nurse and a GP) were recruited in primary care. The remaining health care professionals comprised a consultant diabetologist (insulin pump clinic), a consultant diabetologist in the general diabetes clinic, a diabetes specialist nurse and a diabetes specialist dietitian. Their socio-demographic details are not presented in order to preserve anonymity. Table 4.1 in Chapter 4 provides a summary of the data collected.

There were 15 women and 13 men who participated in the interviews. Table 5.1 summarises the socio-demographic characteristics for patient participants including gender, age, occupation and education (27 were white British). There were more individuals in the 40-49 age category with few participants above the age of 60. All except 4 participants were living with a partner.

Given that the focus of the thesis is on socioeconomic inequity, it is important to understand the socioeconomic make-up of the sample. In terms of economic activity: 17 patients were employed in work; 4 patients were unemployed (3 in receipt of disability payments due to diabetes); 3 patients had retired; and 3 were homemakers, caring for children. Almost twice as many individuals (18) pursued a qualification post 16 years of age compared with those leaving school at 16 without qualifications (10). More of the participants in the sample were higher managerial, administrative or professional individuals than intermediate or routine and technical classes. In terms of insulin pump users, 11 participants were in higher managerial,

administrative or professional occupations compared with 2 participants in intermediate occupations and 5 in routine and manual occupations.

Table 5.1 Socio-demographic characteristics of patients in the sample

Characteristics	Number
Gender	
Male	13
Female	15
Age	
18-29	4
30-39	7
40-49	10
50-59	4
60-69	2
≥70	1
Socio-economic classification*	
Higher managerial, administrative and professional	11
Intermediate	7
Routine and manual	9
Not classified	1
Education	
Left school at 16 (no further qualifications)	10
Continued with education/qualifications post 16	18
Deprivation (IMD 2010)†	
Quintile 1 (Most deprived)	11
Quintile 2	6
Quintile 3	2
Quintile 4	6
Quintile 5 (Least Deprived)	3

*The Standard Occupational Classification 2010 (three classes version). Unemployed individuals were coded to their last occupation

†The Index of Multiple Deprivation 2010 (Department for Communities and Local Government 2011)

Table 5.1 also provides a measure of deprivation of the sample participants. The Index of Multiple Deprivation (IMD) 2010 uses 7 domains: income; employment, health and disability; education; crime; barriers to housing and services; and living environment (Department for Communities and Local Government 2011). Each Lower Layer Super Output Area (LSOA) in England is ranked using these domains, according to their relative deprivation, and increasing deprivation is indicated by a higher score. The IMD is a well used measure of relative deprivation and has been used by Government in the allocation resources and in identifying areas of greatest need for interventions (Department for Communities and Local Government

2011). The sample comprised 11 participants, categorised (by postcode) as living in the most deprived areas (Quintile 1) and 17 participants living in the relatively less deprived areas (quintiles 2, 3, 4 and 5).

All patient participants had a diagnosis of type 1 diabetes (this was a primary inclusion factor for the study). Each age group and gender was represented in both types of IIR: multiple daily injections and insulin pump regimens (Table 5.2).

Table 5.2 Clinical characteristics of patients in the sample

Characteristics	Number
Diabetes duration (years)	
1-5	3
6-10	3
11-15	5
16-20	4
≥21	13
Age at diabetes onset	
0-10	5
11-20	8
21-30	8
31-40	5
≥41	2
Treatment at time of study	
Insulin pump	18
Multiple daily injections (carbohydrate counting)	8
Basal bolus (not involving carbohydrate counting)	2
HbA1c	
<58mmol/mol (7.5%)	10
60mmol/mol (7.6%) to 85mmol/mol (9.9%)	15
≥86mmol/mol (10.0%)	3
Complications arising from diabetes	
Reported at least one complication	16
None reported	12

At the time of the study 18 patients were using a pump, 8 patients were on multiple daily injections (carbohydrate counting) and 2 patients were on multiple daily injections not involving carbohydrate counting. Three patients had previously been on an insulin pump and at the time of the study had reverted to multiple daily injections. Only 2 participants, therefore, were not on an intensified regimen. Many of the participants (13) had had a lengthy diabetes duration (above 21 years) whereas only 3 participants were in the below 5 years category. This is a reflection of the age ranges previously discussed since many participants

would have been diagnosed in childhood or early adulthood and many were now middle aged. In terms of HbA1c results, the last recorded figure for each patient shows that 10 participants were on or below target⁶ (that is, HbA1c under control) and 18 were above target (HbA1c value higher than recommended). A more detailed breakdown of socio-demographic and clinical characteristics is provided in Appendix 9 in order to provide context for the illustrative quotations in the findings.

5.3 Study Context

This section provides background context to the study findings. I describe the ways in which patient participants reported that they navigated their way through the system and health care professionals reported referral pathways. Since the health care professional sample was small (6 participants) I use their accounts in this chapter largely to provide study context. The patient participant sample provided the data for the majority of the reported findings (sections 5.5 and 5.6). Access to health care for diabetes services is probably also influenced by issues relating to the commissioning of services. The purpose of the study was not to investigate these wider system factors. Rather the study aimed to explore, largely from the patient perspective, how individuals gained access to services. To a large extent wider system factors, involving the commissioning of services, were not apparent to patient participants so discussions relating to these factors would not have been meaningful.

5.3.1 Pathways through the Health Care System

In this sample the majority of patients (25 participants) were recruited in a secondary care hospital. This single site comprised a number of specialist diabetes clinics. Recruitment took place in three of these clinics: a specialist general diabetes clinic (consultant clinic), an insulin pump clinic (multi-disciplinary team) and a joint diabetes specialist nurse and diabetes specialist nurse clinic for insulin pump users. Although the majority of participants in the sample were, at the time of the study, regularly attending specialist services, this had not always been the case for some. Table 5.3 provides details of patients (and their regimens) who were regular attenders and those who had joined the services more recently. There were 21 participants who had always regularly attended specialist services and 7 participants had experience of receiving their care from primary care for a period of time.

⁶ 6.5% -7.5% is the recommended target range (National Institute for Health and Care Excellence 2004)

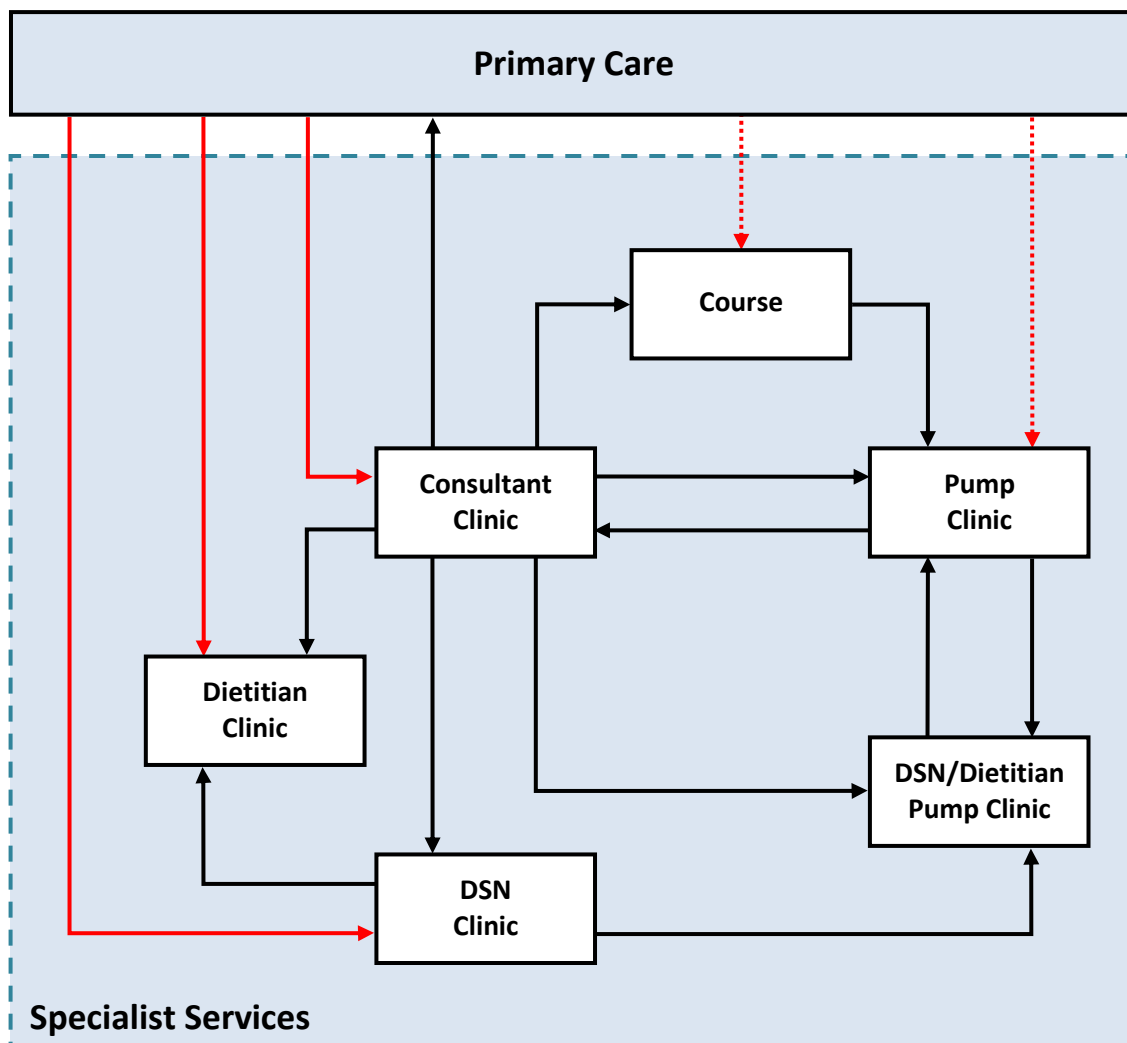
Table 5.3 Regular attenders and recent attenders

Regular Attenders (Specialist Services)		Recent Attenders (Previously attending GP surgery)	
<i>Patient</i>	<i>Regimen</i>	<i>Patient</i>	<i>Regimen</i>
P2 (F)	Pump	P1 (M)	MDI
P3 (F)	Pump	P5 (M)	MDI
P4 (F)	Pump	P17 (M)	Pump
P6 (F)	Pump	P22 (M)	Pump
P7 (F)	Pump	P25 (F)	MDI
P8 (M)	Pump	P26 (F)	MDI
P9 (M)	Pump	P27 (M)	Basal/Bolus
P10 (M)	Pump		
P11 (F)	Pump		
P12 (M)	Pump		
P13 (M)	Basal/Bolus		
P14 (M)	Pump		
P15 (F)	MDI (ex pump user)		
P16 (F)	Pump		
P18 (F)	Pump		
P19 (F)	Pump		
P20 (M)	MDI (ex pump user)		
P21 (F)	MDI (ex pump user)		
P23 (F)	Pump		
P24 (F)	MDI		
P28 (M)	MDI		

The possible routes to gaining access to an IIR in the study setting presented a complex picture. Based on the interview accounts of patients and health care professionals, Figure 5.1 depicts these pathways. The red arrows represent referrals from primary care to specialist services. Patients outside the specialist services required a referral from a member of the primary care team in order to attend the: consultant clinic; diabetes specialist dietitian clinic; diabetes specialist nurse clinic; insulin pump clinic; or Structured Education Programme. Having gained access to specialist services, patients could be referred by secondary care professionals from one clinic to another (represented by black arrows in Figure 5.1). Having gained access to specialist services, patients could also self-refer to diabetes specialist nurses;

however, in order to gain access to the diabetes specialist dietitian clinic, a referral from a health care professional was required. Patients on insulin pumps had open access to both the senior dietitian and the lead diabetes specialist nurse for the insulin pump clinic. This was in addition to having access to the routine multi-disciplinary appointments at the insulin pump clinic. This insulin pump clinic comprised a consultant, a dietitian and a diabetes specialist nurse.

Figure 5.1 Pathways to specialist services in the sample

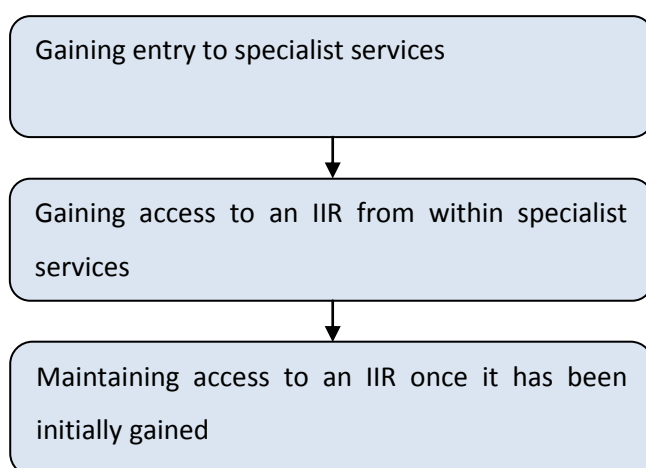


5.3.2 Access to Intensive Insulin Regimens through Specialist Services

In this sample some patients had received all their diabetes care in primary care in the past and some participants had always attended specialist services. At the time of the study the majority of patients in this sample received their principal care for diabetes through specialist services with only occasional visits to their GP.

Apparent in the interview accounts of patients and health care professionals were three stages of access relating to an IIR (see Figure 5.2). In this sample gaining access to specialist diabetes services (hereafter specialist services) in secondary care was found to be a prerequisite for gaining access to an IIR; this was the first stage. In specialist services individuals met with health care professionals to discuss their management of diabetes and to agree a plan for treatment regimens. The second stage of access related to the opportunities for individuals to change to more intensive regimens, having first accessed specialist services. The third stage related to the ways in which individuals – having gained access to an IIR – maintained their access to these specialist services and technologies. This chapter addresses the first two stages; the third stage is addressed in Chapter 6.

Figure 5.2 Three stages of access relating to an IIR



According to the accounts of both patients and health care professionals in this sample, access to an IIR was not available from GP practices. Hence in order to gain access to an IIR, a referral to specialist services was required. The two primary care health care professionals in the sample stated that they encouraged patients with type 1 diabetes to attend the specialist services at the local hospital for their diabetes care. They admitted that type 1 diabetes was outside their area of expertise and consequently felt unable to advise type 1 patients about aspects of an IIR such as carbohydrate counting, a necessary requirement of both multiple daily injections and insulin pump therapy. It should be noted that these comments were from one GP surgery and therefore may not be representative of the views of other primary care health care professionals. In contrast to the views of primary health care professionals, amongst the specialist services health care professionals there appeared to be a mix of views on the most appropriate health care services for patients with type 1 diabetes. Some health care professionals reported that individuals with well managed type 1 diabetes could be

followed up in primary care. For example one health care professional expressed the opinion that 'stable patients' could and should be managed in primary care because 'they don't get anything special and they don't need anything special' from specialist services (Health Care Professional 4 (Specialist Services)). Health Care Professional 3 (Specialist Services) also appeared to share this view.

It really depends on the competence of the GP, but certainly the annual reviews I don't think we need to see all the patients with type 1 diabetes. I mean we're sort of trying to provide a specialised service and we sort of divide diabetes in terms of the type 1 young adults transition clinic, complex type 1 diabetes and obviously pregnant women with type 1 diabetes. So complex type 1 diabetics would be people who have hypoglycaemic unawareness, complications due to their diabetes or even erratic blood glucose control...The straightforward type 1 diabetes doesn't necessarily need to be seen in secondary care but I think young adults transition patients do. Like I said it depends on the competence of the GPs whether they're happy to manage patients with type 1 diabetes.

(Health Care Professional 3 (Specialist Services))

It seemed, however, that this categorisation of patients might in some cases miss patients who should be seen by specialist services and this appeared to be acknowledged by Health Care Professional 3 in their concluding remarks regarding access to these services.

I'm sure there are patients who are being managed, well who are in the community who do have problems and we should be seeing. So might be a bit controversial to say but think we do need to work in more sort of close collaboration I think the secondary care so that we see appropriate people in the clinic.

(Health Care Professional 3 (Specialist Services))

This acknowledgment seemed to be relevant to comments made by Health Care Professional 2 that occasionally patients followed up in primary care did not seem to be referred in a timely enough way.

You get a sense that primary care feel that they should be managing things and they will try and manage things as much as they can and perhaps sometimes that goes on a bit longer than it should have done and by the time they get referred you think they should have been referred quite a while ago.

(Health Care Professional 2 (Specialist Services))

There appeared also to be a suggestion that being followed up in primary care, even if well managed, may be a disadvantage in terms of access to specialist updates

But I think there are some type 1's out there who were fairly stable and there was no reason that they needed to come and who were looked after by their GP and it's whether they get the same sort of updating and the same access to courses as people would do who were seeing our consultants.

(Health Care Professional 2 (Specialist Services))

Within the sample of patients relatively few had been referred from primary care to specialist services since the majority had attended specialist services since diagnosis. Out of 28 patients 2 had received a referral from a GP to the insulin pump clinic and one patient had been referred to the Structured Education Programme (a programme not available in the primary care setting for this sample of patients). This may have been an artefact of the sample since the majority were regular attenders at specialist services; however, GP practice health care professionals reported that they would not refer patients to an insulin pump clinic. Health Care Professional 6 (Primary Care) explained that initiating access to insulin pump therapy would be seen as solely within the remit of the hospital and that patients would be encouraged to discuss the matter with specialist health care professionals. This GP practice was in an area of deprivation and health care professionals reported that only one patient (a child) in their practice was on an insulin pump.

I: Have you ever had a patient ask about pumps?

S: Patients ask about pumps and we always say well it's a hospital decision it's not initiated in general practice and discuss it when you go up to the hospital.

(Health Care Professional 6 (Primary Care))

Within this sample both patients and health care professionals stated that the Structured Education Programme was only provided within the specialist services. In addition, although primary care health care professionals were able to refer patients directly to the Structured Education Programme (see Figure 5.1) it appeared that this was another pathway that was rarely used. Health Care Professional 2 (Specialist Services) stated that most patients attending the course received referrals from within specialist services. Hence the route from primary care to the insulin pump clinic and Structured Education appeared (from this sample) not to be well used.

Referrals from primary care to secondary care appeared, from patient accounts, to be prompted by difficulties managing their diabetes regimen. This was the experience of 6 out of 7 patients (see Table 5.3) who had been attending primary care only for their diabetes care. The exception was Patient 17 (Pump) who re-engaged with specialist services following a prolonged stay in hospital.

This study context provides the background for the accounts of patients and health care professionals. To recap, in this sample patients required access to specialist services in order to change to a more intensive regimen.

5.4 Framing Study Findings using Candidacy Theory

Since the health care professional sample was small (6 participants) the patient participant sample provided the data for the majority of the reported findings (sections 5.5 and 5.6). When undertaking an inductive analysis of the interview data I returned to papers and reports on the mid-range Candidacy theory (Dixon-Woods et al. 2005; Dixon-Woods et al. 2006) and found considerable overlap between components of this theory and my data. The process of identifying themes framed by Candidacy theory categories is described in Chapter 4 (section 4.11.3); however, it is useful to recap on the theory because it is so pertinent to the findings presented here.

Dixon-Woods et al. (2005) proposed that their theory offered an explanation of the barriers encountered by vulnerable groups in accessing health care. The theory proposed a 'set of central concepts', with candidacy as the 'core synthetic category' (Dixon-Woods et al. 2005, p.85). Candidacy theory was used to describe how an individual's eligibility for health care is jointly negotiated by themselves and their health care provider (Dixon-Woods et al. 2006). The six concepts are: identification; permeability; navigation; appearances; adjudications; and offers and resistance (see section 3.3.6 for a detailed explanation of the concepts).

In their description of Candidacy theory, Dixon-Woods et al. (2005) use the concepts of 'access-entry' (the ways individuals gain entry to health care systems) and 'in-system' access (Dixon-Woods et al. (2005, p. 44) citing Rosen (2001)). These map onto the three types of access I identified in my interviews (see section 5.3.2). 'Access-entry' depicts access to specialist services; 'in-system' access represents the way individuals gain and maintain access to an IIR.

The findings are structured by nesting the study themes within a framework of Candidacy theory concepts (Table 5.4). The Candidacy theory concepts and nested themes have been divided into two broad categories: those relating to *gaining access to specialist services* (section 5.5); and those relating to *patient eligibility for an IIR* (section 5.6). That is, section 5.5 (permeability and navigation) describes features of the health care system (ease of access and pathways to access respectively) relating to specialist services. Section 5.6 (presentation, adjudications, offers and resistance) explores the patient-provider interactions relating to gaining access to an IIR.

Table 5.4 Themes mapped to Candidacy theory concepts (Dixon-Woods et al. 2005)

Candidacy Theory	Study Themes
<i>Gaining access to specialist services</i>	
Permeability and Navigation	Disparities in access to specialist services The role of health literacy in navigating health care services
<i>Patient eligibility for an intensive insulin regimen</i>	
Presentation, Adjudications, Offers and Resistance	'Proactive' approach 'Collaborative' approach 'Support-seeking' approach Aspects of the service ameliorating socioeconomic disparities

5.5 Permeability and Navigation

5.5.1 Introduction

In this sample access to an IIR was largely dependent on gaining and maintaining access to specialist services. Two factors appeared to influence access-entry to specialist services. The first related to 'recursivity', that is, some patients were strongly influenced by their past experiences to seek future help (Rogers et al. 1999). These patients had a preference for specialist expertise. For another group of patients the dominant factor appeared to be permeability of services. That is, for some individuals in low socioeconomic groups, ease of access rather than past experiences with health care services appeared to be the most important factor in whether or not they chose to attend.

5.5.2 Disparities in Access to Specialist Services

A preference for specialist expertise

It was apparent from patient accounts that gaining access to an IIR was experienced very differently amongst the participants. Although the majority of participants had always attended specialist services (see Table 5.3) a number of participants had previously only received diabetes care at their GP practice. Many patient participants expressed a preference for specialist services (this also included the patients who had previously not attended specialist services). Patient preferences for specialist services appeared to be based on judgments about the skill and knowledge of health care professionals. Patient 8 (Pump) and Patient 3 (Pump) were typical in choosing to attend specialist services for their diabetes rather than GP led care.

But the GP he's fairly helpful but any problems with the diabetes I always phone up the hospital because they know more about it than the GP does.

(Patient 8 – Pump)

If I'd got a problem with my diabetes I wouldn't go to my GP. I'd probably ring the nurses here just through past experience of GP's changing things they shouldn't be changing and putting you on medication you shouldn't be on and things like that.

(Patient 3 – Pump)

Being able to access expertise appeared to be an important influence on preferences. According to the accounts of two patients who had received all their care from a GP surgery it appeared that patients believed that they had not always had access to the most up to date treatment and advice. Patient 25 (MDI) and Patient 2 (MDI) had been discharged back to primary care from specialist services and hence were able to reflect on the care offered by different parts of the health care system. Both patients reported that when they returned to specialist services after a period of being looked after by their GP surgery, advice had changed and they felt that they were out of date with current practice. This seemed to be the experience of Patient 25 (MDI) who despite having considerable input from a practice nurse, expressed several times in the course of her interview the need to be in touch with specialist services in order to remain up to date with type 1 diabetes and progress in its treatment.

Like I say if you don't go to the hospital then you get out of date, out of touch really with the way things have changed.

(Patient 25 – MDI)

Patient 25 (MDI) reported being told that she should not be injecting in her arms and Patient 26 (MDI) said that she was prescribed a more up to date insulin in place of the 'old' one. Patient 26 (MDI) also noted that the advice about HbA1c had changed. She was now advised to aim for an HbA1c of 7.5% rather than 7% as had been the case four years previously. These experiences appeared to influence their judgments in relation to the perceived expertise of health care professionals in special services. Patients seemed to weigh up the advantages of specialist services versus primary care in terms of their diabetes monitoring and to conclude that the former was preferable.

A number of patients described how practice staff and GPs seemed to have had difficulties understanding prescriptions for individuals with type 1 diabetes. For many patients in the sample, experience of health care professionals in the past appeared to strongly influence their preference for specialist services. The majority of patients in the sample had always accessed specialist services and seemed able to make judgments about what was available at the hospital compared with the care at their GP practice.

This strong preference for specialist services may be an artefact of the sample. It may not be surprising that these patients expressed a strong preference for specialist services because the majority of them were recruited from specialist services and had therefore already gained access to these services. Additionally most of the patients had adopted an IIR through attendance at specialist services. Nevertheless, past experience with health care professionals appeared to strongly influence the help-seeking behaviour of many of the participants in the sample.

Patients' problems attending specialist services

A key influence on access was the difference in patient perceptions about ease of access to specialist services. The majority of patients in the sample did not express any difficulties in accessing specialist services. This is not surprising since many were recruited in specialist services. Some participants in the sample, however, had dropped out of contact with specialist services in the past, either being unable or unwilling to attend appointments. Their experiences were able to illuminate how some patients' characteristics affected their views of

the permeability of specialist services and hence their ability to access these services. Permeability of access was affected by work related factors, lifestyle and transport.

Low paid work

Being unable to attend appointments resulted in an inability to access expertise. Missed appointments equated to missed opportunities to manage diabetes with more up to date and intensive regimens. Patients who had had problems attending appointments were amongst the least well off within the sample. Problems with maintaining access were mentioned by individuals with less skilled occupations rather than patients in skilled or professional work. Shift work was a problem mentioned by two participants. Patient 5 (Pump) described how for many years work would take precedence over appointments at the hospital for financial reasons.

P: I used to go to the diabetic nurses but I didn't used to go [to] the doctor. Used to say right have an appointment to go to and then cos of work with me working on the farm and timescales and not wanting to give up work I kept putting them off and putting them off and I'd go to one or two but not go to them all

I: Can you tell me some more about that in terms of why you couldn't go because of work

P: I'm more interested in the work at the time. Because I'm on the farm I'm always thinking I wanted to be there all the time any sort of like overtime came up I'd be there straight away and doing it cos I wanted the money because obviously some of the time of year you don't work any and I wanted to get that. But you can only do that for so long because when your health starts deteriorating and that you've got to think to yourself hang on a minute am I doing this for me or am I doing it for work. And at the end of the day I turned around and said I'm doing it for work I'm not doing it for me because if my health deteriorates I can't do my work.

(Patient 5 – Pump)

Health Care Professional 6 (Primary Care), who described the difficulties faced by patients taking time off work for hospital appointments, did not specify low paid workers, but indicated the need for patients to take the time as holiday, something professional occupations may not necessarily have to do. Health Care Professional 6 (Primary Care) gave an account of patients who felt that consultations in specialist services were not worth the effort required.

Well one of the comments is it's too impersonal or I get there and I've had to take a day off work and I'm up there and I'm in and out in half an hour. I wait there for an hour or two then I'm in and I'm out and it's a complete waste of time as far as they're concerned because somebody's just looked at all their results and said you're fine, you're not fine goodbye. So that's a whole half whole day's holiday because they often seem to take the whole day off for an appointment.

(Health Care Professional 6 (Primary Care))

Although difficulties with access due to work were predominantly mentioned by low paid working patients it also affected a few of the patients from professional classes. Two patients specifically described work as a hindrance to managing diabetes and had given up more stressful and well paid occupations, either to be at home full time, or to take up less demanding work (Patient 16 (Pump) and Patient 22 (Pump)). Patient 24 (MDI) who had recently retired from work as a health care professional, said that she would be able to prioritise diabetes now that she had left full time work.

The impact of low paid work on patients' ability to attend specialist services was apparent for two patients who re-engaged with services after becoming unemployed. Patient 5 (Pump) had been in low paid work and was reluctant to attend hospital appointments, feeling that this would penalise him financially. After he became unemployed, his worsening diabetes became a priority for him and he found that he now had the time to attend hospital appointments. Patient 27 (Basal/Bolus) who had disengaged with specialist services in the past, experienced a number of life changing events including marital breakdown. He became unemployed and suffered a serious bout of depression leading to attempted suicide. Whereas 25 years previously he had stopped attending specialist services owing to work commitments, becoming unemployed appeared to provide an opportunity to re-engage with services. In common with Patient 5 (Pump), diabetes became a priority for him.

Low paid work also affected access to the Structured Education Programme which was a pre-requisite to accessing an IIR. Attendance was required for one day a week over four weeks and several patients described being unable to attend the course when first invited. Being unable to attend a course whilst in work was an issue for some patients. It appeared to be dependent on how accommodating employers were in allowing patients time off work to attend. Patient 25 (MDI) and Patient 8 (Pump) described very different experiences in relation to how work fitted in with attendance at the course. Patient 25 (MDI) was employed in shift work in an administrative capacity whereas Patient 8 (Pump) was in a professional occupation.

I mean I could have got it straightaway if they'd have said one day a week I would have been able to sort of work around it perhaps change my day off at work if necessary and would have been able to do that but at the time it was getting a week off.

(Patient 25 – MDI)

My boss is brilliant. When I went on the course he said don't worry about it don't book it off as holiday just go off on the course.

(Patient 8 – Pump)

Health care professionals in specialist services expressed concerns that there had been difficulties recruiting patients to the Structured Education Programme and changes had been made to the course timetable in recent years in an attempt to improve attendance. Despite these changes health care professionals acknowledged that some individuals still experienced difficulties attending the course due to employment and in some cases the clinic had sent letters to employers explaining the benefits of the course.

It's a problem with timing because I mean we're talking one day a week for four weeks and obviously they're type 1 patients which tend to be younger therefore tend to be working so there's an issue with work. So they have offered some evening courses but again there's then trouble with childcare and commitments. So I think a lot of it is to do with sort of work commitments.... and of course we're in a recession. The last thing people want to do is put any jobs at risk. They don't want to give their employers any excuse so it may be tied in with job security as well.

(Health Care Professional 1 (Specialist Services))

'Chaotic' lifestyles

Missing an appointment at specialist services appeared to have serious implications beyond the missed opportunity to consult with health care professionals. There was some evidence that hospitals discharged patients who did not attend appointments. Health Care Professional 5 (Primary Care) described how one missed appointment could be sufficient to remove a patient from the system of recall and considerable effort might then be required by the patient to be reinstated in the system. Health Care Professional 5 (Primary Care), who worked in a surgery within an area of deprivation, described how 'chaotic' lifestyles could lead some of her population to miss hospital appointments. A number of factors conspired to make attendance at hospital less likely for this population. For example, the area has a large number of council

houses and high levels of population movement. As Health Care Professional 5 (Primary Care) reflected there appeared not to be a good 'fit' between the services on offer and her patients' characteristics.

S: I think a lot of our patients have really 'chaotic' lifestyles and that just doesn't fit very well with regular reviews at the hospital and so a lot just they move, they change their mobile phone numbers, they just lose contact with the hospital and particularly now the hospital very quickly discharges anyone who doesn't turn up. So then they get discharged and then if they do need to be seen at the hospital there needs to be a GP referral to refer them.

I: So if they don't turn up, the hospital will then discharge?

S: It depends. Some consultants will discharge them after one DNA [did not attend], not turning up. Some will give them another chance send them another appointment a few weeks later. A lot will give them another chance to be fair. But then if they DNA twice perhaps they moved house and they never told the hospital their new address or they told us and they thought that the hospital then would magically know (laughs) which they don't and so then if they don't turn up after a couple of appointments they'll be discharged even if their diabetes is terrible.

(Health Care Professional 5 (Primary Care))

In the above quote, Health Care Professional 5 (Primary Care) described what she perceived as a 'chaotic' lifestyle for patients attending her surgery. It appeared that patients were not necessarily averse to attending specialist services but that various factors acted as barriers to attendance. These included, first, the highly mobile nature of the population, second, individuals lacked the planning and organisational skills necessary to keep appointments, third, they had probably attained low levels of education and finally, some were homeless. 'Chaotic' lifestyles were not conducive to letting public bodies such as hospitals know about changes of address. If patients were not contactable then they did not receive appointments. Health Care Professional 5 (Primary Care) reflected that some of her patients would be more likely to attend specialist services if the system was easier to access.

I: So when you say 'chaotic' lifestyles can you expand on that a little bit?

S: Well we work in an area that is very deprived in the centre of (city name) so we have a large number of council houses. We have a lot of people moving in and moving out for re-housing. We have some homeless people we have a few hostels that we cover. A lot of people just have a 'chaotic' lifestyle so they're perhaps not very well organised.

They might have low levels of education and not very good at planning that sort of thing so appointments at hospitals can just go by the by (laughs).

I: Yes so is it the case that they would go to the hospital for instance if the hospital hadn't sort of lost touch with them or is it the case that some of them actually don't want to go?

S: Some just don't want to go and some probably would go if it was all very easy and they were reminded a few days before and it was just easier some would go.

(Health Care Professional 5 (Primary Care))

Transport

Permeability could be affected by transport to specialist services. The majority of participants in the sample expressed no difficulty getting to the hospital for specialist care. Although some comments were made about car parking problems and journey times which were up to fifty minutes in some cases, patients were not deterred from attending specialist services. The majority of sample participants were car owners so their experiences may have been very different from a patient travelling by bus or relying on others for transport. For example Patient 17 (Pump) needed two buses to get to the hospital

So it takes I'd say roughly say about forty five minutes to an hour. I say an hour to me. But altogether like Monday I had to be seen at quarter past four so basically I was out of the house for three hours basically because of the buses that's the main drawback

(Patient 17 – Pump)

One of the participants (Patient 1 (MDI)) who was unable to drive himself to the hospital described being influenced by the short distance to his GP compared with the distance to his local hospital and stated that this was an important factor for him in deciding where to receive follow up care. This appeared to contribute to a delay in his change to a more intensive regimen. It took at least a year before he was referred, by his GP, to the hospital following difficulties managing his regimen.

5.5.3 The Role of Health Literacy in Navigating Health Care Services

It appeared that in this sample the majority of patients relied on health care professionals to inform them about what was available in terms of treatment and to assist in navigating health care services. Some patients, however, appeared to be able to navigate specialist services more effectively than others and thus were not reliant on health care professionals. It seemed

that patient knowledge was important for independent navigation through specialist services and subsequent access to an IIR. This knowledge – or health literacy – appeared to be gained from regular attendance at specialist services, being a health care professional, having a friend or family member who was a health care professional, or knowing someone who had successfully navigated the system.

Some patients were more aware than others of the services on offer. For example Patient 24 (a health care professional) gave an account of her awareness that an insulin pump was, potentially, an option and her understanding that attending the Structured Education Programme was a requirement for eligibility. There appeared to be a proactive approach to the way in which this patient sought information in order to make a decision between an insulin pump or multiple daily injections regimen.

I've become aware about the insulin pump that many people are now on because I wondered if I would go that way. So I made some enquiries of my own and somebody, a friend of mine, introduced me to somebody that has one and I went to speak to her because I was thinking do I want to ask to go on this for myself? And I was aware that I think you have to have done the (course name) course or something like it before you can go onto this anyway. That was another thing that promoted me to want to do the (course name) because I had initially thought oh it sounds a good thing but having spoken to this girl who is on the pump I've actually... what my thought was that it sounds an awful lot of hassle.

(Patient 24 – MDI)

Within their accounts, some patients displayed an awareness of the medical hierarchy. Some patients described knowing the difference between a consultant and a junior member of staff which could ease their access to this expertise. For example, Patient 7 (Pump) a health care professional described how she was able to request to see a consultant rather than the registrar at her appointments.

When I was under (consultant name) I just used to say I'd like to see (consultant name) rather than one of the registrar. So I always got continuity that way.

(Patient 7 – Pump)

Other patients had familiarity with the system because they had visited the hospital for many years. There was evidence that being known to health care professionals enabled individuals to navigate services.

Knowing someone who has successfully navigated the system also provided an advantage. Patient 23 (Pump), a newly diagnosed patient, was acquainted with another individual with type 1 diabetes who had gained access to an insulin pump. Having learned about the technology and being made aware that, in the opinion of the family acquaintance, her regimen was unsatisfactory, she was able to navigate the system herself.

He (the family acquaintance) couldn't believe that I'd been sent home and I was on two units in the morning two units at lunch four at dinner and six at night and regardless of what I ate.... after he'd been and spoke to me I rang the hospital and asked if I could be put on a carbohydrate counting course so I could get used to how you count carbs and how you do have different doses of insulin every day. So I went on the course.

(Patient 23 – Pump)

One of the health care professionals who was interviewed associated this high level of health literacy with patients in professional occupations.

So I would think by the nature of the beast that it would naturally select more professional people because they tend generally to have not better skills, how can I put it, they would tend to gear themselves towards that. Also generally in health care you tend to find that professional people will seek out what is best for them. And I think that's right across the board whether it's pump therapy or not you will get professional well people making sure that they get the best out of the system because they know how the system works and they have the ability to use the phones and the internet and the computers and get where they want to be.

(Health Care Professional 1 (Specialist Services))

The different pathways taken by patients in accessing an IIR and the role of health literacy are contrasted in the experiences of Patient 11 (Pump) and Patient 5 (Pump). Occupational status and contact with other health care professionals appeared to be an advantage for Patient 11 in gaining access to an IIR. Patient 11, a health care professional, had found out about insulin pump therapy from another health care professional and through gaining this knowledge was able to persuade her GP that she was a potential candidate for the technology. As a consequence she was referred directly to the insulin pump clinic. In Patient 5 (low socioeconomic status) described a lack of awareness of other regimens prior to his re-engagement with specialist services. Patient 5, who was unemployed at the time of the study, received a referral to specialist services for the Structured Education Programme; however,

this was only after he had lost his job due to diabetes. Prior to this referral he was unaware that there was a course available to help him manage diabetes.

5.6 Presentation, Adjudications, Offers and Resistance

5.6.1 Introduction

Having described some of the influences on 'access-entry' in section 5.5, this section explores how 'in-system access' could determine access to an IIR. The focus in this section is health care interactions and the influence of patient presentation in determining access to an IIR. Before presenting the findings I introduce two key aspects of these interactions influencing socioeconomic disparities: patient-provider alignment and types of patient presentation.

Patient-provider alignment

Alignment in the context of this study was a complex multi-layered concept and appeared to play a key role in relation to equitable access. At the macro level, patient-provider alignment appeared to be determined by a good 'fit' between help-seeking actions carried out by patients and the response to those actions by health care professionals. In contrast, non-alignment described a poor 'fit' on occasions between the help sought by patients and the help provided by health care professionals, characterised in some cases by the patient's negative perceptions relating to patient-provider interactions.

The macro level concept was identified through analysis of themes and sub-themes within the interview data. It appeared to be influenced by many factors including patient motivation, patient health literacy, and levels of patient engagement in decision-making. This study also examined the concept of patient-provider alignment at the micro level of social interaction in the turn by turn unfolding of conversation. In Chapter 6, notions of patient-provider alignment and the factors that appeared to impact on the relationship are explored in detail using conversation analysis. As well as conversational alignment, Chapter 6 explores the influence of patient adherence on patient-provider communication.

Types of patient presentation

The ways that individuals presented themselves in health care interactions and their help-seeking behaviour appeared to influence the response from health care professionals in terms of adjudications and offers. I identified three main categories relating to the ways patients presented themselves in relation to self-care both in terms of coping with diabetes on a daily basis and in relation to treatment decision-making:

- 'proactive'
- 'collaborative'
- and 'support-seeking'

Patients adopting a 'proactive' approach to self-care appeared to view diabetes management as their responsibility and seemed to have a predominantly self-reliant stance in relation to their condition. Patients with a 'collaborative' approach to self-care viewed diabetes management as difficult and unpredictable in some cases and they described working in partnership with health care professionals to support their self-care efforts. Patients whose dominant approach to diabetes management was 'support-seeking' were characterised by low motivation and difficulties adhering to complex self-care regimens. Although their accounts of interactions with some health care professionals appeared to be negative, nevertheless their 'support-seeking' approach appeared to be part of their coping strategy.

These three categories were based on patient accounts spanning, in some cases, many years. Since these findings represent 'snapshots' in the lives of patients there is an acknowledgment that patient experiences may be characterised differently at various periods in their lives. Hence there was a dynamic element to patient categories in which it was apparent, for example, that some patients who had been in the 'support-seeking' category were now categorised as 'collaborative'. Thus patients may be identified variously as predominantly 'proactive', 'collaborative' or 'support-seeking' depending on a given time period. In presenting these three dominant characteristics, the purpose is not to deny that there are complexities in this area but rather to elucidate the potential of these characteristics to impact on equitable access.

The socioeconomic status (SES) of patients in the three categories is presented in Table 5.5. Professional social classes (SES 1) were mainly in the 'proactive' and 'collaborative' categories. Routine and Manual social classes (SES 2) were mainly in the 'collaborative' category. There were only a few 'support-seeking' patients and these were in the middle and low social classes (SES 2 and 3).

Table 5.5 Socioeconomic status for patient categories

Category	Numbers of patients in each category ⁷		
	SES 1	SES 2	SES 3
'Proactive'	8	2	1
'Collaborative'	2	5	6
'Support-Seeking'	0	1	2
Total	10	8	9
Socioeconomic status (SES) – Standard Occupation Classification Three classes: 1 = Higher Managerial and Professional; 2 = Intermediate; 3 = Routine and Manual (Office for National Statistics 2010b)			

Below I present the three different types of patient presentation and the factors that appeared to be relevant to patient-provider alignment (and therefore access to an IIR) in each case. Two approaches, 'proactive' and 'collaborative', appeared to facilitate access to an IIR. There appeared to be a good 'fit' between these patients' help-seeking approaches and the support and services provided by health care professionals. In contrast there appeared to be a poor 'fit' on occasions between patients who had a predominantly 'support-seeking' approach and their health care professionals. The few 'support-seeking' patients in the sample were mainly unemployed manual workers.

5.6.2 'Proactive' Approach

High levels of motivation to self-care

Testing blood glucose levels is a prerequisite of effectively managing an IIR. It is crucial that patients adopting an IIR have an awareness of their blood glucose levels at intervals throughout the day in order that decisions can be made regarding carbohydrate and insulin intake. Patients who displayed interest in managing their condition appeared to be viewed as potential candidates for an IIR by health care professionals in this sample.

We're looking for people who are motivated; who can self-care because it's a technology that a patient will have to take ownership of.

(Health Care Professional 3 (Specialist Services))

⁷ One patient was not classified according to Standard Occupation Classification guidelines

Patients with a 'proactive' approach to self-care described strategies that were indicative of high levels of motivation in this respect. Testing blood glucose levels was described as a regular and routine part of their regimen.

I often check my bloods really really frequently. Far too frequently sometimes ((laughs)) but it's probably six, seven times a day.

(Patient 8 – Pump)

Many of the patients adopting a 'proactive' approach to self-care described wanting 'control' of diabetes, and some stated that they had 'control' of their condition. These patients described diabetes management as their responsibility and something which had to be mastered.

I think you just take it in your stride in a way even then because you just adapt to it and I was never going to let it rule me I was going to rule it. So but I didn't want to be one of these that just oh I'm a diabetic I can't do this I can't eat that.

(Patient 7 – Pump)

Those patients with the onset of complications were keen to minimise further problems; however, a number of 'proactive' patients had had diabetes for many years without experiencing any problems. Hence taking 'control' of diabetes and developing expertise in self-care was viewed by these patients as a way to protect oneself against the long term complications of diabetes. An important aspect of taking 'control' appeared to be having the confidence and willingness to experiment with insulin doses.

I knew what quick acting insulin did and I knew what long acting insulin did and I learnt about the basal level and the bolus and that and I thought well if I'm running at 14 which is twice as high as my blood sugar should be when I'm about sort of in-between a meal for instance why don't I give myself some quick acting insulin which will work on that excess sugar and sort it to put it bluntly... so I started doing it and it worked and I could bring my blood sugars down within a couple of hours, bring them down to a reasonable level.

(Patient 11 – Pump)

High levels of health literacy

Patients with a 'proactive' approach to self-care appeared to have high levels of health literacy and described their knowledge about diabetes in participant interviews in a confident way. For

example, in the following extract Patient 22 (Pump) explained in detail the reasons why he occasionally experienced high blood glucose levels as a reaction to having low blood glucose levels (hypoglycaemia). His account demonstrated the importance of not just assimilating diabetes related knowledge but being able to apply the knowledge to problem solving in his daily routine.

So my high sugars aren't because I'm not controlling my carbs and I'm eating too much or I'm not dosing correctly. It's because I'm going hypo and it's bouncing back and then the occasional one where this gear plays up (insulin pump) and there's quite a lag you go high and then you think oh it could be this it could be that, I'll leave that in for now and just see what happens. Well you follow the protocol on the course that was given you, treat it, test after an hour, is it now going in the right direction. Well I had this happen to me either yesterday or the day before I was eighteen point something I thought why on earth am I that, what's going on. Immediate thought was oh this has failed. I was at the start of the day where it was due to be changed anyway but I thought I'll bung in a correction (insulin dose) it was big'un four point something units to correct it. Three quarters of an hour later it was sixteen point something I thought ah so that's working.

(Patient 22 – Pump)

Some patients felt that having a good knowledge of diabetes had enabled them to manage diabetes more effectively. This appeared to relate to a strongly held desire to live a 'normal' life and not to be restricted in any way by their condition.

I'd got a life to live and to lead so you just get on with it and I suppose having a nursing background as well that helped a lot, cos you've got that bit more knowledge about it so I don't know you just got on and did it.

(Patient 7 – Pump)

Health literacy was also related to a 'proactive' approach to information seeking about diabetes management outside of the consultation environment. The majority of active information seekers in this study were in the higher socioeconomic group. One of the most frequently mentioned sources of information was Diabetes UK. In contrast none of the participants from the lower socioeconomic groups mentioned actively seeking information from Diabetes UK.

'Proactive' patients also had skills in information assimilation and were able to use this knowledge to engage in health care interactions. Hence, although it was important to have gained knowledge (functional health literacy) it was also important to be able to critically apply this knowledge (critical health literacy) in order to engage with health care professionals (communicative health literacy).

An example of the use of information acquisition to gain access was the apparent advantage to some patients of gaining an awareness of other treatment options. It appeared that patients who had acquired knowledge through their own efforts felt that they had improved their chances of accessing an insulin pump. They believed that they would not have been able to access an IIR if they had not initiated access themselves since offers from health care professionals had not been forthcoming.

I: what part do you feel you've played in terms of deciding what insulin regimen to go onto?

P: I was like the instigator to actually get a pump. I don't think if I'd (not've) asked I would have ever been offered one.

(Patient 23 – Pump)

Influencing health care professional adjudications

This is not to suggest that gaining access to insulin pump was simply a matter of requesting the therapy. Adjudication occurred in that health care professionals stressed the importance of ensuring that the most 'eligible' patients gained access to an IIR. Although patient competence and potential commitment to the regimen were crucial attributes required by health care professionals clinical need was the primary justification. Difficulties in achieving acceptable glycaemic control despite attempts at following a multiple daily injection regimen was described as a major consideration whereas a request for a pump for lifestyle reasons was described as unlikely to succeed.

There usually needs to be some sort of clinical indication. So just if a patient happens to be type 1 but is well controlled for them just coming and saying I want a pump isn't enough. There usually needs to be some sort of clinical reason why a pump may benefit them and usually that's because they've done their level best to try and improve the diabetic control and get an HbA1c on target and they haven't achieved it. Or there may

be horrendous complications where a pump may help and that is quite rare I have to say. It may be a needle phobia or it may be disabling hypos that everything else hasn't been able to assist with.

(Health Care Professional 1 (Specialist Services))

It appeared, however, that well informed patients had an advantage in being able to present a case for insulin pump eligibility despite not strictly meeting all the necessary criteria. The characteristics of patients who appeared to assert themselves in consultations were encapsulated in the following account by Health Care Professional 6 (Specialist Services). In the opinion of this member of staff patients requesting an insulin pump tended to be characterised by possessing a high level of education and familiarity with different regimens, either through an organisation such as Diabetes UK or by finding out about services through acquaintances or family.

In terms of who would be more likely to ask about insulin pump therapy, I think a lot of people ask about therapies that they're aware that their friends or people they know. Others are very highly educated and they're more aware of what is available for them. Some of them they're sort of involved in Diabetes UK or they're members and therefore they're more aware.

(Health Care Professional 3 (Specialist Services))

A preference for 'active' involvement in decision-making

Patients with a 'proactive' approach described themselves as actively involved in health care decisions, both inside and outside of the consultation. As well as portraying confidence and self-reliance in terms of their own self-care management, they stated that they did not feel that they always had to follow the advice of health care professionals. This was apparent in their descriptions of the help that they sought from health care professionals and the use that they made of that advice. They appeared to adopt a discriminating approach to the advice offered by health care professionals in which, although they described listening to advice, they also valued their own experiential knowledge.

I tend to look at them more as giving advice rather than telling me what to do because my life is a little bit more active and 'chaotic' than their normal patient. So I think I tend to listen with interest to what they've got to say but then I choose to take it on board or modify it, or change it a little bit so that it'll work with me.

(Patient 8 – Pump)

It seemed from patient accounts that HbA1c targets were an important aspect of the advice they received from health care professionals in relation to managing diabetes⁸. These blood results also appeared to be an important indicator to health care professionals of patient commitment to an IIR and a way to judge how effectively patients were able to manage their condition. This is illustrated in the following quote from Health Care Professional 4 (Specialist Services).

So if we are looking at somebody going up going up within the target range if it goes up from 6.5 to 7 that would be reassurance that you are still within if you like relatively safe limits. You've been excellent and you've gone from A star to A so that that's the easy one but if somebody deteriorates from a 7.4 to a 10.4 that would clearly mean that that person is struggling with their glycaemic control and you would need to find out why if it's a persistent trend or if it's a one off. So if it's a one off there's usually a reason, a bereavement or relationship breakdown, a significant life event which said to them you've got other things in life to worry about. Glycaemic control is the last thing you need to worry about and at some point that will come back when they re-prioritise their lives. On the other hand if somebody has an HbA1c of 10 persistently then it probably means that we've put somebody on a pump who shouldn't be on a pump that's the sort of patient who then you have a conversation with them saying perhaps the pump's not for you.

(Health Care Professional 4 (Specialist Services))

A number of patients, however, adopted a different stance to the one recommended by health care professionals in relation to HbA1c target levels. Some patients had a preference for keeping their HbA1c level lower than recommended levels in order to minimise the long term complications of diabetes. Patient 7 stated that her objective was to try and maintain her blood glucose levels within the 'normal' range. Although this might appear to be a lack of alignment with health care professionals, it would seem that this dialogue with health care professionals was an important aspect of sharing decisions, since it allowed patients to voice their difference of opinion but also gave health care professionals an opportunity to explain current advice with regard to HbA1c, as illustrated in the following quote.

⁸ An exploration of the impact of the HbA1c result in relation to patient-provider communication is reported in Chapter 6. Blood glucose levels and HbA1c results played a prominent part in review appointments in the insulin pump clinic.

That consultant had a completely different attitude towards HbA1c's and said in order to try and get rid of the hypos I'd like you to have an average of 7.2 percent and I said I'm not happy with that, that's a bit too high for me that's bordering on being too high. So he said 7.5 percent is high but 7.2 percent would be better you might get rid of some of the hypos.

(Patient 4 – Pump)

These patients also described challenging the approach taken with their diabetes management in other respects. Several patients described an assertive approach to help-seeking behaviour that involved expressing dissatisfaction with their current regimen and requesting an alternative. Hence some patients with a 'proactive' approach had requested an insulin pump, that is, they had not waited to be offered an IIR by a health care professional. Depending on how they heard about the pump, they described how they 'pushed' for its introduction (Patient 8 and Patient 14) or initiated discussions about it with their health care professionals (Patient 3, Patient 4, Patient 9, Patient 11 and Patient 23).

Well I'm more I'm a bit more proactive than quite a few people and when something isn't right I do say and I was telling them I'm not happy things aren't working is there anything that you can do to help me out.

(Patient 8 – Pump)

I had to go up and might be a bit ham fisted and say look it's not helping I says there's something wrong I says so I'd like to know what you're going to do about it.

(Patient 9 – Pump)

Three insulin pump patients (patients 3, 8, and 11) described preparing a list of questions before attending consultations. Hence patients with a 'proactive' approach reported influencing some of the agenda in consultations, portraying themselves as having a primary role in initiating discussions about an IIR⁹. Having heard about alternative treatment regimens they appeared able to assert their candidacy for an IIR. They described an ability to assimilate information about an IIR, were able to make judgements about its potential benefits and had the confidence to act on these beliefs. This level of assertiveness was in contrast to the

⁹ In Chapter 6 the influence of patient involvement on maintaining access to an IIR is explored, including the ability of some patients to influence the consultation agenda (section 6.5).

majority of 'collaborative' patients who described having little knowledge about an IIR prior to being informed more fully by health care professionals.

Patient-provider goal alignment

Patients with a 'proactive' approach to gaining access to an IIR appeared to be aware of their eligibility status, that is, how they were perceived by health care professionals and the best way to proceed in order to achieve a successful outcome. It appeared that some overlap between health care professional goals and patient goals was an important influence in being able to achieve access to an IIR.

Some 'proactive' patients were strongly motivated to obtain access to an insulin pump although they differed in their reasons for wanting the therapy. Some patient goals were not within the health care professionals' criteria for accessing a pump. Nevertheless these patients described some congruence between their goals and those of health care professionals. Patient 11 (Pump) persuaded her GP to refer her to the insulin pump clinic. Her justification was that she would be healthier in the long run if she could improve her glycaemic control. Her GP was described as willing to refer her to an insulin pump clinic and it appeared that demonstrating a track record of high levels of motivation was an important factor.

I think she said that because she believes in me and she knows I try my hardest to look after myself and I won't I don't abuse the NHS and I don't abuse myself. I try my hardest and I was looking for a way of improving things for me and she said well why not you're entitled to that. So she wrote to him on my behalf and said I was interested and would he consider taking me on and he wrote back to her and said he'd be delighted to meet me. So I went up to (hospital name) to meet him and had a long interview with him and at the end of the interview he said well as far as I'm concerned you're exactly the type of person that I'm looking for so if you'd like to try a pump then I'm more than happy to put you on one.

(Patient 11 – Pump)

There were a number of important aspects to Patient 11's ability to gain access to an IIR that have salience for the current thesis. First, the patient's goals appeared to be congruent with medical goals prior to accessing the insulin pump (Patient 11's stated goals were to gain better control of the diabetes in order to improve her long term health). Second, Patient 11 had reasonable control, as measured by HbA1c, and by her own admission would not have been considered an eligible candidate for a pump at her local hospital. Nevertheless, the patient's

reported ability to talk in a way that aligned with the medical perspective in terms of future goals appeared to be advantageous in persuading the relevant health care professionals of her potential eligibility ('you're exactly the type of person that I'm looking for' (extract above)). Hence the combination of being both 'proactive' and aligned with medical goals appeared to be an advantage for a number of patients in the sample.

It appeared that being able to communicate effectively was also important. Hence an ability to align culturally with health care professionals was influential. Patient 11 (Pump) reported that as a health care professional she was aware of the best way to communicate with other health care professionals.

I mean I'm always quite direct with doctors and nurses and of course I speak their language.

(Patient 11 – Pump)

Patient 8 (Pump) and Patient 11 (Pump) described themselves as 'proactive' patients and were aware of the importance of building a rapport with staff. Patient 8 (Pump) was a professional who also understood the importance of effective communication and being able to get on with health care professionals.

I: So how would you describe your relationship with the staff at the hospital?

P: Yeah very good. You've got to keep them on your side haven't you really (laughs) no it's very good.

I: What do you mean by that?

P: You've got to work with them rather than against them. They're trying to help you and if you're not interested or you don't want to take part in the consultation I think the only person that's going to hurt is you so you've got to work. You've got to be fairly open and fairly easy to get along with.

(Patient 8 – Pump)

Some health care professionals were described by patients as being sympathetic to their goals in relation to quality of life (Patients 8 and 9). Patient 9 (Pump) recounted the conversation with his consultant regarding his reasons for wanting an insulin pump. He described the stigma involved in injecting and the inconvenience of having to go into small cramped toilets when away from home. He said that it had got the stage where he no longer wanted to go out.

I: So what would be the main reasons that would have been given for you going on the pump at that stage?

P: At that stage was a better quality of life for me.

I: Yes and did you discuss this in the in the consultation?

P: Yes I did yes because he did ask me and I told him I wanted a better quality of life than what I'd got now and he agreed with me and he said that this would be a fine example of getting you in. Getting you feeling better about yourself he said. 'It's not the pump as such', he says, 'it's how you feel about it. If you feel that this is going to be the thing that's going to change your life then it's a big thing'.

(Patient 9 – Pump)

Patient 8 (Pump) similarly described being concerned with quality of life issues. He had experienced difficulties managing diabetes with an intensive exercise programme and was also conscious of injecting in public because 'people don't want to see you injecting'.

Well the pump I think it was more a case of the pump giving me a little bit more freedom. I mean when I go out with my friends for a curry I can not now think about taking my, all my kit with me and nipping off to the toilet to dose up with each course. I can just sit down here and plug it in. Plus the fact I say about the sport I can adjust my dosages and use correction doses all the way during the day just to try and bring things to a steady playing field.

(Patient 8 – Pump)

Patient 8 (Pump) described his consultant as sympathetic to his request and he remembered that the justification for the pump was made on the basis of his sporting activities.

I: When you were asking to go on the pump what were the reasons given for going on the pump?

P: Sport mainly. It was entirely, that was my only reason and (consultant's name) you know I think he could see the sport thing as being a bit of a concern so he was very supporting.

(Patient 8 – Pump)

Although the health care professional perspective in this sample was that clinical need was the most important justification for an insulin pump it seemed that some patients had been able to persuade health care professionals that they were candidates for the regimen without necessarily fulfilling this criterion. Other factors that appeared to be important to health care

professionals in assessing patients included some of the attributes displayed by 'proactive' patients, that is: high levels of motivation; patient commitment and ability to manage a more complex regimen (potential or actual); high levels of health literacy; and a willingness to engage with health care professionals. It appeared therefore that there was a good 'fit' between these patients' goals and the adjudications of health care professionals.

What indicates to me that they're self-motivated; it's just people who are engaged in the consultation.... someone who has an interest in self-managing a condition and who has a good knowledge of their diabetes. I think those are the main issues.

(Health Care Professional 3 (Specialist Services))

It seemed that patient-provider alignment offered a plausible explanation for being able to gain access to an insulin pump under these circumstances.

5.6.3 'Collaborative' Approach

Motivation to resolve difficulties

Patients taking a 'collaborative' approach were also motivated; however, this motivation appeared to be borne out of a desire to resolve difficulties they faced rather than to self-care *per se*. Many described having had problems with diabetes management and being unable to satisfactorily achieve metabolic control.

My job's mainly been my difficulty to get the blood sugars right and even though I'm healthy and I exercise well which is good but it has its complications or makes a difference to your blood sugars so that has always been, I always used to say we're complicated.

(Patient 2 – Pump)

Many of these patients had had HbA1c results that were well above recommended levels, in some cases for many years. A number of these patients described diabetes management as unpredictable and difficult.

Things are going to happen over which you've got no control because you'll never beat mother nature she'll always throw this spanner in the works and I suppose the quality do I mean quality, the information that I receive in terms of whether that be verbal or the mechanism that I use for controlling my diabetes, that's improved greatly over the

years. But you're still talking about a human being and if you don't get it quite right you'll get a spanner in the works.

(Patient 16 – Pump)

Some patients described a lack of self-care in the past in which they had not followed recommended regimens and appeared not to have taken responsibility for managing their condition. For some this had resulted in hospital admissions for serious diabetic complications including coma.

P: I didn't test, diabetes it was just a pain in the backside to me then to the point that I actually ended up in hospital

I: How long ago was that then

P: Oh fourteen years maybe thirteen years. Fourteen years ago I went into a ketoacidic coma. Nearly died from what I've been told I had to be brought back round. Don't remember a lot about it at all.

(Patient 12 – Pump)

A number of patients in this group were concerned that they were now experiencing the onset of complications.

I'm still getting these low blood sugars and feeling tired and that's the thing that worries me because I've had them for so long whether if you can understand it, whether the damage has already been done.

(Patient 5 – Pump)

Other patients had in the past demonstrated a commitment to self-care and reported that in trying hard to meet targets had experienced problem associated with tightly controlling their blood glucose levels. It appeared that good HbA1c levels had been achieved but this had been at the expense of experiencing hypoglycaemia.

I still had a lot of hypos. My HbAc had been very good but I was always getting a lot of hypos morning afternoon and evening sometimes three a day.

(Patient 6 – Pump)

It seemed that amongst many of these patients there was an acknowledgment that other individuals assisted them with their difficulties. Although some patients described the support they received from family and partners, the most frequently mentioned source of support was

specialist services. It appeared that the majority of these patients had experienced many years of continuous care with the same department.

I mean if ever I'm in trouble for whatever reason my first port of call is (nurse's name) and if I can't talk to her one of the other nurses. They've been brilliant they have over the years can't fault them.

(Patient 14 – Pump)

Seeking and following advice

It seemed that many of the 'collaborative' patients strongly valued their health care professionals' advice and they reported acting on guidance as evidenced in the quotes below. These patients seemed to rely on health care professionals to initiate treatment changes. Hence there was a good 'fit' between the help that they sought from health care professionals and the support that they received since they appeared to be both motivated to improve their diabetes management and they valued the advice they received.

I've always had good care and I took everything on board all the advice which makes a difference and I accepted it straight away.

(Patient 2 – Pump)

To the best of my knowledge and ability I abide by the rules because I know that if I don't it will not only have an impact on me but it will have an impact on the people around me. So anything that can improve not only my life today but my long term existence bring it on let's give it a go (laughs).

(Patient 16 – Pump)

There appeared to be a strongly held view by many of these patients that their care was provided by experts. This linked with a feeling, expressed by patients, that they were comfortable deferring to the advice of specialist health care professionals.

The thing I've learnt with the diabetic centre is that I do whatever they tell me they're the experts at the end of the day, so I tend to go with whatever they say really nine times out of ten I'll run with whatever they suggest because at the end of the day they are the experts.

(Patient 12 – Pump)

A preference for health care professionals to initiate decisions

In contrast to 'proactive' patients, patients with a 'collaborative' approach appeared to view health care professionals as playing an important and in some cases dominant role in their treatment decision-making. Although some of the patients with a 'collaborative' approach had sought information from other sources, the majority described health care professionals as their main source of diabetes related information.

P: I don't think I've ever even looked anything up on the internet to do with being diabetic. I really do feel happy with the team that I've got who are looking after me

I: Where is your information coming from about diabetes then in the main

P: From the hospital without a shadow of a doubt.

(Patient 16 – Pump)

It was apparent that health care professionals were perceived as problem solvers by many patients.

If I ask them a question and if they answer my question with some advice I would take that on board cos that's what I've come to ask about. If they know a solution to the problem I'm having then I'll say yes that's what we'll do then and obviously if it doesn't work out then obviously I'll get back in touch and I'll say this has not worked this time can you suggest anything else I can do to try to fix it.

(Patient 10 – Pump)

Many patients who had experienced problems managing their regimens in the past described willingly accepting the advice of health care professionals in relation to an offer of an IIR.

I was offered to go on a pump and they gave me a basic outline of what that would mean which I was quite happy. I thought that sounded good... I just knew it was a good opportunity and I knew 'cos I'd been asked and not a lot of people got the chance that really just wanted to go with it and try it.

(Patient 2 – Pump)

So if the pump'd help me get my blood sugars back down I was all for it It's just if I was in that criteria where I could have the pump cos they're saying you've got to be in the right criteria or the right person to have the pump and I thought at the time well if it's going to help by all means I'll try it.

(Patient 5 – Pump)

In contrast to patients with a 'proactive' approach, these patients appeared to be more reliant on the advice of health care professionals in relation to decision-making. On the whole it appeared that it was their willingness to engage with health care professionals, to listen to their advice and suggestions and to implement recommendations that influenced their access to an IIR.

Resisting offers

This 'willingness' to go along with the health care professional agenda is explored more fully using the consultation data in Chapter 6. It appeared from the interview data that 'going along' with the doctor's agenda was the norm and that outright disagreements were rare. Although, in the interview data, these patients rarely voiced disagreeing with advice, in common with 'proactive' patients they acknowledged that not all advice was useful for their circumstances. An example was Patient 10 who described listening to advice in relation to his target HbA1c but decided that he needed to aim for blood glucose levels that were somewhat higher than recommended as this was more practicable for his circumstances.

They've suggested it (HbA1c) lower than what I preferred but obviously that's because that's what people that aren't diabetic have and obviously that's fine for them but obviously for me I'm comfortable where I am. So whether it's slightly higher than what it should be that's fine in my book it's probably not fine overall (laughs) but for me it's better off where I am than being six seven and not feeling myself.

(Patient 10 – Pump)

It is possible that expressions of satisfaction with health care decisions and advice, voiced in interviews, were strongly influenced by patients perceiving that they had gained access to 'desirable' technology that is relatively rarely used. Patients were aware that eligibility criteria had to be met and that insulin plumps were an expensive item.

Not all 'collaborative' patients were willing to 'go along' with health care professionals' suggestions to use an IIR immediately and in some cases decision-making spanned a number of

years. Resisting an offer of an IIR appeared to be influenced by reticence to change to a less familiar regimen, particularly one that was perceived as inconvenient. Patients appeared to weigh up the perceived severity of the condition versus the inconvenience of a change in regimen. Patient 6 (Pump) resisted an offer of an insulin pump for three years as she had had reservations about adopting the therapy. Eventually concerns about hypoglycaemia and weight gain outweighed her reluctance to consider the offer of an IIR.

So they recommended that the pump could help me with this for about three years...and I was very adamant that I didn't want to because I think I had it in my mind that it was a big thing and oh you'd be reliant on this thing that you'd have to carry with you all the time. You'd have to wear it all the time and I was very adamant that I didn't want that. But having then thinking well I didn't want the hypos and with that I was eating more and putting on weight that I didn't want to be putting on. And the nurse said well why don't you just try it without any insulin in it. We'll just give you a demo one try it for a week see how you get on and actually it is okay it is very small you can hide it

(Patient 6 – Pump)

When health care professionals suggested an IIR or the Structured Education Programme, a number of factors appeared to determine how receptive patients were to accepting the offers. These included: feeling unable to ignore hypoglycaemic episodes; having an incident related to a hypoglycaemic episode such as a driving ban; or suffering a diabetic coma. Many patients described transition points that encouraged or facilitated the move to a more intensive regimen. For example Patient 12 (Pump) described experiencing a turning point in his attitude to self-care following a diabetic coma.

I remember going to the toilet one morning and then woke up in hospital and it was about six days later and then from that point it was kind of like right (patient's name) you need to sort yourself out. It was scary don't remember a lot about it was scary

(Patient 12 – Pump)

For many patients these turning points represented a stage in the illness where management issues could no longer be ignored even if they had been in the past.

I started having lows again like quite it was years later then I was on four (injections) for quite a while and then I started having like severe lows in the sense that I was going to bed at night fine and then waking up either really low not knowing what I'm doing

or unconscious ..and I did almost jump out of a window when I was in a state and obviously that's kind of a major factor in it. That was just prior to the pump that was when it was getting serious and you're thinking that needs to be sorted now not later it needs dealing with.

(Patient 10 – Pump)

Being known to health care professionals for some time also appeared to be a factor in acceptance of advice. Continuity of care appeared to be a valued part of the service for a large number of patients and seemed to relate to positive perceptions of patient-provider communication.

I: Why did you want to see him?

P: because I really I had a nice rapport with him. I was happy to see him I liked seeing him and his team ... I've always seen the same Professor when I was in (name of city) I saw the same one and I prefer to see the same doctor I don't like. I prefer not to see the others what are they called when they come in they are doctors but they're SHOs is it?

(Patient 6 – Pump)

Patients who received advice that they perceived to be useful were likely to return for more help. It seemed therefore that help-seeking behaviour was influenced by past experiences and that this offers an explanation for gaining access to an IIR. Being willing to seek and accept advice from health care professionals seemed to be a key aspect of gaining access to an IIR.

5.6.4 'Support-Seeking' Approach

'Support seekers' appeared to lack motivation to manage their condition. They did not appear to be willing to follow some of the advice offered by health care professionals. In contrast to the 'proactive' patients and 'collaborative' patients they appeared disinterested in achieving metabolic control and in carrying out regimen activities including injecting insulin and regular blood glucose monitoring. This led to non-alignment with health care professionals. Dominant factors involved in patient-provider non-alignment related to: attitudes towards diabetes care; quality of patient-provider communication; and psychosocial problems. Although the majority of these patients had gained access to an IIR, it appeared that this may have been due largely to contact with diabetes specialist nurses rather than as a result of their routine clinic appointments.

Low motivation for self-care

'Support seekers' appeared to have low motivation in relation to diabetes self-care. Diabetes management was described as a problem and these difficulties dominated their accounts about their regimens.

Before I got fed up with injecting myself with bruises and felt like a pin cushion and eventually I said I'm not doing it again cos it hurts.

(Patient 20 – MDI)

In contrast to the 'proactive' and 'collaborative' patients they did not describe themselves as in 'control' or wanting 'control' or being responsible for self-care.

I didn't have brilliant control like at work. I'd maybe have my dinner and forget to have my injection before so I'd have it later but I'd still remember it. Or if I just missed injection like I'd eat something and not realise and not have my injection.

(Patient 21 – MDI)

Patient 20 (MDI) reported that he had abdicated responsibility for injecting himself for a number of years and was reliant on his wife to carry out this task. Whereas many of the participants in the study felt that they managed their condition with little help from family or partners, 'support seekers' tended to enlist the help of others.

I thought stuff it I chucked it I'm not doing it no more I come out in bruises lumps but that's part and parcel of obviously as you know injecting and I couldn't get used to it if I didn't do it my wife did it. I couldn't be bothered to inject myself tell you truth.

(Patient 20 – MDI)

If I have a hypo she knows when I've got a DK (diabetic ketoacidosis) cos she'll tell me. She'll come obviously to hospital with me and she knows the signs when you can taste the pear drops you can smell it. I think the last time I came in (to hospital) woke up and I was getting ready for work and she was the one that noticed cos I just couldn't function what I was doing and she could smell it on me. She was like I think you need to go to A&E I don't think you need to go to work and she brought me before she had to go to work and everything. And she'll sit there with me and that she's a big support in that respect.

(Patient 21 – MDI)

Some participants appeared to be aware of the judgments of others surrounding their lack of self-care. They labelled themselves as 'lazy' or 'naughty'. They described health care professionals as taking a judgmental stance. An example was the experience described by Patient 21 (MDI) with an on-call doctor during an admission to hospital for ketoacidosis brought on, she believed, by an illness and taking antibiotics:

I've had problems when I've been admitted before. I had one bad time where, I understand because obviously I work here I understand you just get the on call doctor who sees you. I remember seeing the respiratory consultant and he was actually, he was really rude to me and he really upset me and made me cry and he said he hasn't got time for diabetics like me at my age who just want to just put themselves in hospital. And I think that's bad that people see it that way at that age when you're not getting support from consultants as much as you should. And then they think you're not worth the time for it... I was probably only about eighteen, nineteen and he was just on about how we just want to drink ourselves into comas and things and how we could be helping people with lung problems and whatever 'cos he was a respiratory consultant and how diabetics my age just don't care .

(Patient 21 – MDI)

'Support seekers' could have some knowledge about diabetes self-care but admitted that they did not always follow advice.

I should have brought my insulin today but I've not bothered with it. So I don't bother carrying it around with me. I'm supposed to carry it round with me all the time, supposed to do in case you go into a hypo or you go to restaurant or cafe and obviously you've got to inject.

(Patient 20 – MDI)

Most reported, however, that they did not actively seek information via the internet although several could access the internet through computers or mobile phones. 'Support seekers' relied on health care professionals for information about diabetes management or in some cases family members with type 1 diabetes. Their accounts of self-care suggested that they did not appear to follow recommended routines for blood glucose testing. It seemed that one of the reasons for not checking blood glucose was a feeling that they knew when their blood glucose levels were high or low.

I: How many times a day would you check it do you think

P: Once a day if that sometimes I wouldn't even do that

I: Is there any reason for that that you can think of

P: I just think I'm probably lazy and when I come to work my mind isn't there to test my blood because I know when I feel ill and I know I can feel myself when my blood's high and I can feel when it's low, in some respects when it's like really high or low

(Patient 21 – MDI)

Some 'support-seeking' patients had experienced hospitalisations for ketoacidosis as a result of problems and difficulties managing their diabetes.

Perceived coercion in treatment decision-making

There appeared to be a lack of congruence between the goals of 'support seekers' and those of some of their health care professionals. Patients described their communication with some health care professionals in a negative way. These patients were mostly individuals who had struggled with diabetes. They described a one-sided style of communication in which they felt they were being coerced into following a particular regimen.

It was just a bad attitude she had with me she upset me a lot of the time I felt she didn't really talk to you she sort of really forced you. You didn't really get an option or there was no talking through it was her way or nothing.

(Patient 21 – MDI)

The level of coercion described seemed to suggest a lack of involvement in decision-making, from the patient's perspective. Patients used terms such as 'drilled' and 'pressured' to convey the directive approach they felt they had experienced.

He was still not happy with my control. I used to get quite upset cos he used to sort of drill it into me obviously about the control and that and then. I know he was trying to help you but he was just quite firm with that you need to get under control for your long term blood sugar and consequence and things like that.

(Patient 21 – MDI)

This could result in patients choosing to avoid contact with health care professionals. For example, Patient 20 (MDI) had difficulty injecting himself and did not follow the advice given by health care professionals. He described the interaction with his consultant as directive in

style. He decided not to return to the consultant clinic but chose instead to attend appointments with the diabetes specialist nurse who he found more helpful.

P: I think what it is like he used to shout at me. Obviously I did wrong not injecting for me snacks and everything else but he didn't shout, he just raised his voice a little.

I: What did he say? Do you remember?

P: Something about if your main meals you inject I says 'yes I do that' 'what about your snacks' I says 'I don't bother about them' and that's why my sugar's obviously went high and he just gave me a lecture basically not nasty or 'owt said if you don't do that I could go into a coma.

(Patient 20 – MDI)

Desire to be listened to

An important aspect of chronic care illness support and shared decision-making is the need for health care professionals to listen to patients. In this study, a number of patients, particularly those who had experienced difficulties with managing diabetes, talked about wanting health care professionals to listen to them. This was not mentioned by the majority of patients but was a recurrent theme amongst 'support-seeking' patients struggling with high HbA1c levels.

I mean trying to explain to doctor (consultant's name) I mean he doesn't know me on a regular basis I've only seen him twice but I know where he's coming from because I do listen to what he was saying but the other thing is I think he needs to listen to me more about how I'm feeling what I've been undertaking with certain things I mean I was homeless before I came here. I mean that put a shock in me.

(Patient 17 – Pump)

There was a feeling amongst some participants that their subjective experience was being ignored and there was a failure to look at the HbA1c results in context.

The consultant always comes back to figures, always comes back to hard facts and much less about context. So I think in reality if you found out more about the person to set those figures into context then that would be much more useful.

(Patient 18 – Pump)

A number of patients reported that they felt that some health care professionals seemed disinterested in them.

I didn't feel like he was. It wasn't he didn't care it just didn't really seem to, he didn't really seem to give you any feedback or try and help really he sort of he was quite relaxed about it and he didn't really help.

(Patient 21 – MDI)

Patient 18 (Pump) gave accounts of minimal interaction between herself and her consultant within the consultation. She described a lack of help in consultations and said that her main support was from the diabetes specialist nurse.

The consultant didn't know me didn't really have any interest in getting to know me. I'm just one of any number of people who've got diabetes coming through the clinic and there was certainly no sense of planning of what you would do next with diabetes because I did that with (diabetes specialist nurse's name) (laughs). So I would meet up in-between times with (diabetes specialist nurse's name) and that's where I'd get the benefit that's where I'd get my treatment plan sorted.

(Patient 18 – Pump)

In contrast patients who felt that their health care professionals were listening to them said that they were willing to try alternative regimens suggested by staff and to manage their regimen better. For example Patient 21 (MDI) explained that she had resisted going onto four injections per day. She explained that the large quantity of injected insulin resulted in bruising on her body and she described being self-conscious about her appearance. She described her consultant working at alternatives including different types of insulin and different quantities in order to eliminate this problem. Following these efforts she found she was able to reach a compromise and adopt the new regimen.

I found I did compromise with him because he wanted to listen and help and that's when I went onto four injections with him because they were smaller doses because he'd worked it out obviously in a different way so they were smaller doses I didn't mind as much.

(Patient 21 – MDI)

In Chapter 6 Patient 21's consultation is contrasted with that of another 'support-seeking' patient (Patient 20). These two consultations illuminate some of the interview findings in relation to patient perceptions about their involvement in decision-making and their desire to be 'heard' within the consultation. These interactions illustrate the impact of 'high' and 'low' patient involvement on their ability to maintain access to an IIR.

The impact of psychosocial problems

Depression

The aim of this study was not to explore co-morbid depression and diabetes hence the data on this aspect of patients' lives was not extensive; nevertheless, it did appear that depression could be a potentially important influence on equitable access. Having a lifelong serious condition can be overwhelming for patients (Holt et al. 2010) and depression is common amongst individuals with diabetes (Lustman et al. 2000). In this study several patients described having depression and some had suicidal thoughts.

And people say these people take overdoses with tablets. All I've got to do is put pen on stick to my leg and do it matter of seconds as they say. I've come close about three or four times on that. End it. But I've snapped out of it. I'm still I'm coping with it at the moment but I have good days and bad days with it at the end of the day. But I think, well my wife needs a husband and me daughter needs a dad, so that stops me from going (). But some mornings I get up say that's it I've had enough that doesn't happen all the time just now and again.

(Patient 20 – MDI)

It was apparent in some patients' accounts that depression related to a number of seemingly intractable problems with their lives. Patient 17 (Pump) described depression related to his marriage breakup and losing contact with his children.

I mean I got to the point where I didn't want to eat any more. All I was just doing was just drinking because I thought I've lost my kids. I wasn't going to have any contact and I thought that's it. I mean me children around me are not around me anymore. I mean people come round to my flat like I said they see all me photos and they say oh where's your children and then when you go through the depth of it sometimes I feel I can't talk about it and then when I do talk about it just want at that point, I just wanted to drink myself to death.

(Patient 17 – Pump)

Patient 17 (Pump) described the impact of his psychosocial problems on his health and the difficulties he had experienced seeking help for his depression.

I mean I've been smoking since I was seventeen I did pack up for three years when me first children were born. Stress of being separated and divorce brought the smoking back so I've been smoking basically for like I say since I were twenty well thirty. I mean I was depressed before. I do suffer with depression that's another thing that I find but the doctor GP will not give me anything for it until I sorted the alcohol out. Now I've sorted the alcohol out he's still not given me anything for me depression because I do sink into it you know when I talk about things like me upbringing or me children any of me marriages. It sends me into depression with it.

(Patient 17 – Pump)

Patient 27 (Basal/Bolus) had also experienced problems with marriage breakdown and loss of access to his child:

I mean I've been given some happy tablets to get over the depression I had over my second wife leaving and taking my little boy. They had no effect they didn't do anything. I did see a CSI programme where a guy did overdose himself on insulin. I did try that. It didn't work ((laughs)) my body said no no no go on. I did try and I did end up in (name of hospital) where I was told not to be very stupid.

(Patient 27 – Basal/Bolus)

Some health care professionals recognised the impact of social and psychological factors on patients' ability to manage their diabetes. Indeed psychological issues were described by both Health Care Professional 1 (Specialist Services) and Health Care Professional 3 (Specialist Services) as one of the most challenging aspects of helping patients to manage diabetes and an important barrier to self-care. These health care professionals felt that only once these factors had been resolved could patients achieve satisfactory control of their condition.

Insulin will work if it's injected (laughs) I know that seems a very simple statement to make but most of the time if we've got huge problems with control it's usually because the insulin isn't being injected or it's not being injected in the right place at the right time in the right quantity. And nine times out of ten if there's a problem with the treatment and with the diabetes it's not that they don't understand that, it's usually the social issues underneath that are causing the underlying problem. So you've got to be able to support folks through bereavement through suicide attempts through loss of jobs, through separation through child care issues. Most of those type of things are usually what's causing the problem once the knowledge has been delivered and once

they've got all those other things on board that they need, nine times out of ten my gut feeling is once you sort the social issue out the diabetes control becomes much better.

(Health Care Professional 1 (Specialist Services))

This view appeared to be borne out in some patients' accounts of the impact that depression could have on their ability to manage diabetes. Depression caused by bereavement, even when described as a temporary problem, could disrupt self-care.

I won't lie I nearly went to pieces especially over Dad dying but I had to hold it together. The worst part about that was my kids were coming on Boxing day and I'd got to keep my mouth shut until we'd all opened the pressies and had a good time ... but as far as the diabetes was concerned I struggled because I wasn't interested. At that moment in time this GP said you were emotionally a wreck and I was. So the diabetes went all over the place then but we're only talking about a fortnight maximum. You eventually deal with it and you move on.

(Patient 28 – MDI)

Depression was also experienced by 'proactive' and 'collaborative' patients, however, they tended to actively seek help when depressed and appeared to be able to access psychological services. This is illuminated by the experiences of two patients who were able to secure help for their depression. Patient 9 (Pump) described being overwhelmed by the medication he was required to take and consequently sought help from a therapist. Patient 15 (MDI) described the long term support she had received from a clinical psychologist. Their accounts contrast with those of Patient 17 (long term unemployed), referred to previously, who described experiencing problems accessing help for his depression.

it's very easy when you're on a lot of medication to how can I put it as I said to (wife) the other day I'd like to have one day when I've not got to take anything and I feel well I feel good about it but I know I can't do that so I suppose that's the situation you're looking for and I did get depressed. I did have depression at one time never took anything for it because I fought it myself. I did go to see a therapist and she was very good because even with diabetes and things like that I can't find anybody I can talk to other than them at the hospital see nobody's interested.

(Patient 9 – Pump)

A massive other thing is that I see a clinical psychologist (name) who I've now been seeing for about I'd probably say about three years. Before her I was seeing a lady called (name) who retired but before (name) I saw (name) for a time so she knows me from a long time ago (name) is worth her weight in gold. She knows everything about me, tries to help me, will be honest with me. So she massively helps my diabetes care and my management of my life as well I would say along with (diabetes specialist nurse). So yeah they're the people that I really listen to.

(Patient 15 – MDI)

Non-acceptance of diagnosis

Another psychological problem apparent in the sample was lack of acceptance of diagnosis. In some cases this was intertwined with depression.

It hit me all of a sudden what I could do because I thought you can't do this, used to do a lot of weight training, I can't weight train, I can't on motorbike scrambling, I can't do this can't do that. I just got bit of depression.

(Patient 21 – MDI)

Health care professionals made a link between motivation and non-acceptance, acknowledging that the latter was another factor that could prevent patients from managing diabetes effectively since motivation was difficult for patients who had not accepted their condition.

Some patients they have difficulty accepting their diagnosis so it's not that they're not motivated it's just that they have yet to accept. Then these are the patients that we need to sort of provide psychological help.

(Health Care Professional 3 (Specialist Services))

Although health care professionals acknowledged these difficulties and that support was required for patients with these problems it was apparent from patients' accounts that when they did not accept their diagnosis this could affect their interactions with medical staff and some did not feel supported in these consultations. The relationship between non-acceptance and motivation is important in two ways. First, given that patients who present as motivated ('proactive' and 'collaborative') are more likely to be judged as suitable for an IIR, non-acceptance could be a barrier to accessing an IIR in terms of health care professional

adjudication. Second, even when patients have been offered an IIR, non-acceptance of diagnosis could prevent these patients from accepting the therapy.

Deprivation

Several patients who reported problems with depression and difficulties adhering to treatment were in low socioeconomic groups. Although it appeared that psychological difficulties could render individuals vulnerable to having problems communicating with health care professionals regardless of socioeconomic status, patient-provider non-alignment did, however, appear to be linked with deprivation. One health care professional observed that patients from deprived areas required much more effort with regard to changing to an IIR.

It takes a lot more to convince a teenager from a deprived neighbourhood to say that it's cool to have a pump than say somebody who goes to a private school in an affluent neighbourhood because the social support they have is much less, the emotional support they have is much less, the core family support they have is much less and therefore it's a bigger problem to actually keep them on the pump and offer them a pump and motivate them on the importance of glycaemic control...I don't think it's a postcode lottery. It's just that we require more effort there and maybe it's the way the health service is designed rather than anything else. I don't think it's a conscious denial of these things.

(Health Care Professional 4 (Specialist Services))

It was the view of one health care professional that this patient group had a distrust of health care professionals issuing authoritarian advice. Health Care Professional 4 (Specialist Services) acknowledged that lack of continuity exacerbated this problem and created further problems in caring for these patients.

Continuity of care may overcome resistance to advice

Some participants resisted offers and advice. In this sample this was linked predominantly with psychosocial factors (described earlier) and low socioeconomic status. These few participants described a reluctance to seek help more generally for health problems and this resistance also seemed to be carried through into seeking help for diabetes care.

So most of the time I can say probably in five or six years I've probably went three times. Over five or six years because I just thought it were just I'll get on with it. Let me get on with it.

(Patient 5 – Pump)

It appeared that some patients who had overcome their resistance to offers of an IIR did so because they perceived that health care professionals were listening to them. The corollary of this was that some patients who perceived that they were being adversely judged by health care professionals and felt coerced into following the prescribed regimen experienced, in some cases, considerable delay before they were ready to accept offers of an alternative. It seemed that continuity of care was an important aspect of care for 'support seekers' since receptiveness to advice appeared to be related to perceptions of trust. Health Care Professional 4 (Specialist Services) described the issues in particular for patients from deprived backgrounds when they were seen by different health care professionals and did not experience continuity. As Health Care Professional 4 (Specialist Services) explained, the diabetes clinic was not organised to provide continuity of care for patients and therefore vulnerable patients were likely to be disadvantaged.

Well building trust requires continuity of care so if you see one person today and another person the next time that's not going to work.... when they come to the hospital based clinics they see a different consultant not necessarily every time they come but a significant part of the time you may see a consultant who you've not seen before.... it matters a lot to the patients so I think the health service managers have to look at continuity of care as being more important than it is, particularly in a clinic like this because it does help maintain trust. So if you work on something today and you have somebody else see the patient next time, in practice you actually go back about ten steps because the patient thinks you let him down and so yes continuity is very important.

(Health Care Professional 4 (Specialist Services))

5.6.5 Aspects of the Service Ameliorating Socioeconomic Disparities

In this final section I describe two aspects of specialist services that appeared to ameliorate socioeconomic disparities:

- The diabetes specialist nurses service
- The Structured Education Programme

Diabetes specialist nurses provided a permeable service

A common theme across the majority of patients' accounts was that diabetes specialist nurses made specialist services more permeable. It was clear from patients' descriptions that contact with diabetes specialist nurses in particular was highly valued. Many patients described the diabetes specialist nurses as their main support. Although patients described very supportive partners and families, in many cases these individuals were seen as secondary to the main support offered by diabetes specialist nurses. Participants described experiencing a very permeable service in which accessibility, responsiveness to patients' requests and communication style were held in high regard.

A number of 'proactive' and 'collaborative' patients described diabetes specialist nurses helping them to gain access to an IIR. This was possible because these health care professionals were able to initiate an IIR, or refer patients either to the Structured Education Programme or the insulin pump clinic (see Figure 5.1). An important finding, however, was that they appeared to ameliorate some of the problems faced by 'support-seeking' patients. This related to two aspects of communication described by patients. The first category related to *what* was being provided in terms of practical help and support. Hence in this category patients valued a proactive service coupled with practical and understandable advice. Second, patients placed value on *how* diabetes specialist nurses communicated with them. In relation to this second category patients reported a style of communication that appeared to be personal, empathetic and non-judgmental. Both aspects of communication appeared to be particularly important for 'support-seeking' patients.

Practical support

A commonly mentioned aspect of contact with diabetes specialist nurses was the proactive way that they encouraged patients to contact them. Patients described being given direct dial numbers, being able to leave messages and feeling confident that their calls would be returned. Several patients described contacting nurses at short notice to arrange appointments. Taking advantage of this responsive service patients were able to work with the diabetes specialist nurse to establish more effective ways to manage their blood glucose levels, a central part of the type 1 diabetes regimen.

you could ring and ask them questions and say my sugar's doing this and not quite sure why and they'd say have you tried this or has this happened because at the beginning you are a bit clueless as to why things affect your sugar.

(Patient 26 – MDI)

Since diabetes is a complex disease it is understandable that practical advice issued in a clear way was an attribute valued by participants. Patients described diabetes specialist nurses as being 'hands on', offering practical advice, and being able to explain complex concepts in an understandable way. Patients described understanding the explanations and found that the advice worked.

And (nurse's name) drew a diagram and explained to me and my mum how the insulin works and how it breaks down like it gives you energy and all stuff like that so that made it really helpful.

(Patient 23 – Pump)

She explained it very well and it worked so I was happy.

(Patient 27 – Basal/Bolus)

It would seem that patients in this sample followed the advice of nurses because their suggestions were practical, realistic and they worked. This interaction provided encouragement to attend further consultations with diabetes specialist nurses. In contrast patients observed that doctors focused on HbA1c results and in some cases were described as making unrealistic demands.

A personal approach

A common theme for most patients was that permeable communication was more likely to be attributed to diabetes specialist nurses than to doctors. Within the health care interaction permeable communication included a feeling of being comfortable with the health care professional and experiencing a personal approach. These features were largely attributed to communication with diabetes specialist nurses.

I think they know you more on a personal level, like with the consultant is at a different level and they're not so personal because they don't deal with you quite as often so that makes a lot of difference as well.

(Patient 2 – Pump)

In the majority of cases patients described doctors and diabetes specialist nurses as adopting a different approach to diabetes management, with nurses presented as having a flexible approach compared with a more strict approach adopted by doctors. Whilst doctors appeared to focus on encouraging patients to have 'strict' control, nurses seemed to adopt an approach that helped patients to resolve their difficulties with achieving glycaemic control. A key part of this communication appeared to be nurses' capacity to listen to patients.

I think they tend to listen they want to know what you've been doing and they go more into what you've eaten or done to produce that blood sugar reading and they sort of try and get a picture of everything and then adjust things slightly.

(Patient 25 – MDI)

I think the nurses were a lot more sort of perhaps realistic that nobody is going to be able to follow the regime that the doctors are saying that you have to follow. It's just you're not going to manage it and they don't want to panic you.

(Patient 26 – MDI)

It was clear from their accounts that many patients valued both the input of doctors and diabetes specialist nurses, particularly if they were able to achieve acceptable HbA1c results. However, the realistic and empathetic approach adopted by nurses appeared to be of more importance for patients who were struggling with glycaemic control and those who saw themselves as 'rebellious' because they did not follow the doctor's advice. These patients valued the non-judgmental approach adopted by nurses. This appeared to be particularly important for 'support-seeking' patients

I think she's completely on your level. She respects your views and your opinions compared to other people. So she's just helpful. She'll sit there and listen to you and support you.

(Patient 21 – MDI)

Health Care Professional 3 (Specialist Services) observed that diabetes specialist nurses were particularly skilled at identifying and helping patients with psychosocial problems.

I think one of the good points of having diabetes specialist nurses is that they spend a lot more time with patients and they pick up on these social factors and they're good at bringing that to my attention. And I think you have to understand that and sometimes

it's only when those factors are resolved that the person can actually really focus on their glycaemic control.

(Health Care Professional 3 (Specialist Services))

This appeared to be borne out in the accounts of several patients who had struggled with diabetes describing the support they had received from diabetes specialist nurses

It's when I see somebody else I just don't feel the same. It's not the same people what I can talk to, open up to. If it's (diabetes specialist nurse's name) I can open up to her and everything. Anybody else I couldn't do it. I know it sounds a bit daft but it's what I've got to get used to.

(Patient 20 – Pump)

This illustrates two important aspects of access for vulnerable patients. First, patients who had gained access to specialist services could be strongly influenced to continue accessing services they perceived to be helpful. The concept of 'recursivity', the notion that help-seeking behaviour is strongly influenced by previous health care experiences, was referred to in section 5.5.2. Second, the choices that some patients made in relation to accessing services were based on the permeability of the diabetes specialist nurse service. The combination of these two aspects of accessing care offers an explanation for vulnerable patients' preferences for seeking help from specialist diabetes nurses.

Structured Education Programme facilitated equitable access

Managing more complex regimens

One of the important disparities between patients in this sample related to knowledge and the use of knowledge in order to gain access. An extremely important source of information for patients in this sample which facilitated access to an IIR appeared to be the Structured Education Programme. Patients gained knowledge and the motivation to manage more complex regimens through attending the Structured Education Programme.

Patients who attended the course described being informed about the most up to date techniques for injecting insulin, were advised on re-use of needles and were shown the latest technology in terms of insulin and blood glucose monitoring. This was in addition to the main objective of the course which was to teach carbohydrate counting. Attending the course allowed individuals more time to think about diabetes management. They were able to look in

depth at difficulties they were having with their regimens and, with the help of health care professionals, identify solutions.

There were notable disparities in patient accounts relating to their self-care ability prior to the course. Some patients described confidently adjusting their insulin doses. Their accounts of self-care approaches are referred to in section 5.6.2. In contrast, it was common for patients who had been on multiple injections to describe their regimens prior to the course as being based on guess work and lack of understanding. Hence the majority of patients in this sample required the knowledge gained from the Structured Education Programme before they had the confidence to adjust insulin according to carbohydrate intake.

I went onto a carb course in January ...I suddenly understood everything and it suddenly became so much easier that for every ten gram of carbs I do one mil of insulin and it's suddenly it's not guess work anymore.... even after having it for thirty years ...I mean I adjusted my insulin don't get me wrong I did but ((sighs)) it just all really didn't make sense until the carb course funnily enough.

(Patient 6 – Pump)

Increased motivation

A key finding of this study seemed to suggest that motivation, one of the necessary criteria for an IIR stipulated by health care professionals, was facilitated by attendance at the Structured Education Programme. The majority of patients attending the course described the impact of the course as significant in terms of being able to manage diabetes more effectively. It seemed that the process of gaining access to an IIR led to individuals becoming more motivated. An example of this related to blood glucose monitoring which was an important indicator of patient motivation for health care professionals. It was also a part of the regimen that was disliked by many patients. However, several patients reported that after the Structured Education Programme they were both willing to undertake more testing and understood its importance as part of effectively managing diabetes.

But I do check in fact I check it more now I'm on pump than I did before.

(Patient 19 – Pump)

I'm definitely doing more blood monitoring than I used to do but the benefits far outweigh the discomfort for me because I'm actually seeing how well it is controlled for me. I mean it sounds a bit corny but my ego is big when it is within the regimen.

(Patient 28 – MDI)

Patient 12 (Pump) found that by gaining access to a pump he was motivated to reduce his HbA1c levels.

I think once you get on it and you do challenge yourself then to get your Hb down. I make sure I go and get my blood test done now before I go cos it's good for them to say to me your Hbs now come down again.

(Patient 12 – Pump)

A more holistic and fair approach to patient assessment

The process of gaining access to an IIR enabled some patients to acquire attributes valued by health care professionals (higher health literacy levels, motivation and confidence to manage a more complex regimen). It appeared, therefore, that assessing patients during the Structured Education Programme allowed health care professionals to make a more holistic assessment of patients since this was conducted over a period of several weeks and a diverse group of individuals appeared to be exposed to choices relating to an IIR. Commitment was assessed weekly on the course by requesting patients to bring their blood glucose records to each session. Ability to manage a more complex regimen was assessed through group work and an emphasis on patients taking an active role in helping each other. Hence patient assessment within the Structured Education Programme setting appeared to offer a more rigorous, holistic and fair approach.

...they do a programme of education some of which is sort of group work and problem solving...they're supposed to bring a record of their blood sugars and a record of their carbohydrate counting and we look at that at the start of each session. So again you start to get a feel for whether people have grasped it whether they're getting it right. Some people don't bring you anything so that says a lot I think. So over the weeks you get a feel for whether they've got to grips with what they're supposed to be doing. So it's a week by week assessment really.

(Health Care Professional 2 (Specialist Services))

5.7 Summary

This chapter presented findings in relation to gaining access to an IIR. The principal findings were that equitable access to an IIR could be impeded or facilitated by a complex mix of factors involving: the patient; the interface between the patient and the health care system; and communication between the patient and health care professionals. The themes presented in this chapter were framed using Candidacy theory and relate to two key aspects of gaining access to an IIR: 'access-entry' to specialist services and 'in-system' access.

'Access-entry' to specialist services, a necessary precursor for access to an IIR in this sample, was affected by socioeconomic issues. First, permeability of access was influenced by social circumstances including low paid work, 'chaotic' lives and transport difficulties; issues more likely to affect lower socioeconomic groups in comparison to those in professional classes. Second, navigation, in terms of having knowledge about available services and how to access them, appeared to facilitate access to specialist services. Navigation required high levels of health literacy, more likely to be present in professional social classes.

The dominant theme in relation to 'in-system' access, that is once patients had accessed specialist services, was patient-provider alignment defined by the 'goodness of fit' between help-seeking behaviour and the response by health care professionals. Health care professional adjudications relating to patient suitability for an IIR included non-clinical factors that were subject to disparities amongst the sample. Patient attributes valued by health care professionals included: motivation; ability to manage an IIR; and knowledge about diabetes management. It seemed that patient-provider alignment was influential in establishing candidacy for an IIR and that some patients and providers appeared to be more aligned than others. I identified three types of patient presentation in the sample: those taking a 'proactive' approach, a 'collaborative' approach and a 'support-seeking' approach. Patients in the latter group were predominantly from lower social classes.

Key influences on patient-provider alignment were patient motivation to self-care, health literacy, and patient involvement in decision-making. 'Proactive' and 'collaborative' patients presented these attributes to health care professionals and in so doing were judged to be good candidates for an IIR and were offered an IIR. 'Proactive' patients and 'collaborative' patients also viewed the control of blood glucose levels as a key part of managing their condition and described listening to the advice given by health care professionals. Many of these patients had regularly attended specialist services over a long period of time and most had experienced

problems with managing diabetes. Whilst not always able to achieve optimal HbA1c levels many patients described themselves as making efforts to do so. Hence there appeared to be congruence between their goals and those of their health care professionals.

'Support-seeking' patients tended not to be aligned with health care professionals. Key factors related to non-alignment appeared to be attitudes to self-care, psychosocial problems and poor patient-provider communication with some patients perceiving that they were not being listened to.

Deficits in attributes which health care professionals judged as necessary requirements for access to an IIR such as motivation to self-care, ability to manage an IIR and knowledge about diabetes management were modifiable through access to a Structured Education Programme. Although the Structured Education Programme (according to patient accounts) led to improvements in motivation and knowledge, assessment of some patients for an IIR appeared to occur before most patients had received this education.

It appeared that barriers to access were also ameliorated through contact with diabetes specialist nurses. The permeable nature of the diabetes specialist nurse service seemed to encourage patients to re-attend. Hence both candidacy theory and 'recursivity' (past experiences 'shape subsequent help-seeking behaviour' (Rogers et al. 1999, p. 88)) appeared to explain patients' help-seeking behaviour.

Chapter 6. Maintaining Access to Intensive Insulin Regimens

6.1 Introduction

Chapter 5 focused on two of the three stages which appeared to be necessary for access to an IIR: gaining access to specialist services and gaining access to an IIR from within specialist services (Figure 5.2). This chapter presents the findings in relation to the third stage; maintaining access to an IIR once access had been gained. The findings presented here use the data from the recorded consultations and focus on themes pertinent to the research question, that is, to what extent maintaining access to an IIR is an equitable process within health care interactions.

Considerable weight is given, in these findings, to the influence of the doctor within the consultation. This is despite the fact that the consultations often involved three members of a multi-disciplinary team responsible for the insulin pump clinic. It was clear that in the majority of cases the doctor strongly influenced the consultation agenda. He was involved in both the opening and closing of the consultation and generally directing communication flow.

The findings are presented in two sections. First, I explore the importance of patient alignment with the doctor's agenda and its impact on doctor-patient communication. Second, I describe the nature of patient involvement within the interactions. Before discussing the main findings the following two sections provide a description of the sample and the approach used to frame the study findings. Included in section 6.3 I provide an introduction to the terms used within the findings in relation to the themes of patient alignment and patient involvement. These two themes were the key findings in relation to equitable access.

6.2 Description of the Sample

The sample comprised secondary care consultations recorded for 25 patients. Four doctors, three diabetes specialist nurses and one dietitian (equal numbers of males and females) participated in the recorded consultations. Their socio-demographic details are not presented in order to preserve anonymity. Ten men and fifteen women (all white British) participated in the recorded consultations as patients. Table 6.1 summarises the socio-demographic characteristics for patient participants including gender, age, occupation and education. Reasonable diversity of age ranges and gender was achieved. However the largest group of

patients in the sample were in the 40-49 age category with few aged 60 years and above. This was because the majority of participants were recruited in the insulin pump clinic and there were fewer potential recruits in this age category. The study recruited the only patient at the hospital using an insulin pump in the 70 years and above age category.

Table 6.1 Socio-demographic characteristics of patients in the sample

Characteristics	Number
Gender	
Male	10
Female	15
Age	
18-29	4
30-39	5
40-49	9
50-59	4
60-69	2
≥70	1
Socio-economic classification*	
Higher managerial, administrative and professional	11
Intermediate	7
Routine and manual	6
Not classified	1
Education	
Left school at 16 (no further qualifications)	9
Continued with education/qualifications post 16	16

*The Standard Occupational Classification 2010 (three classes version). Unemployed individuals were coded to their last occupation

In terms of economic activity, 14 participants were employed in work, three had retired and four were unemployed. Three of these individuals were in receipt of disability payments due to diabetes. Three participants were homemakers. All except three participants were living with a partner. Nine participants left school at 16 gaining no further qualification. Sixteen participants pursued education post 16 years of age. More of the participants in the sample were from higher managerial, administrative and professional occupations (11) than in routine and manual occupations (6). Individual patient characteristics are provided in Appendix 9.

A large number (20) of the sample had had diabetes for more 10 years (Table 6.2). All patient participants had a diagnosis of type 1 diabetes. The majority of individuals in the sample had lived with diabetes for many years. Most of the participants (18) used an insulin pump. Three

other patients had previously been on an insulin pump and at the time of the study had reverted to multiple daily injections. Four patients were on multiple daily injections (never having been on an insulin pump). Fourteen individuals reported at least one complication arising from diabetes.

Table 6.2 Clinical characteristics of the patients in the sample

Characteristics	Number
Years since diagnosis	
1-5	3
6-10	2
11-15	5
16-20	4
≥21	11
Age at diabetes onset	
0-10	5
11-20	6
21-30	7
31-40	5
≥41	2
Treatment at time of study	
Insulin pump	18
Multiple daily injections (carbohydrate counting)	7
HbA1c	
<58mmol/mol (7.5%)	8
60mmol/mol (7.6%) to 85mmol/mol (9.9%)	14
≥86mmol/mol (10.0%)	3
Complications arising from diabetes	
Reported at least one complication	14
None reported	11

The HbA1c result was provided by health care professionals from the individuals' health care record for all except one patient (the exception was self-reported). Table 6.3 compares the study's HbA1c results with data from the National Diabetes Audit. The comparison, although not intended to draw statistical conclusions, indicates that in terms of the study sample, individuals had similar level of glycaemic control to the national average, despite the majority attending an insulin pump clinic. Many of the patients (68%) in the sample were not achieving

the target of 58mmol/mol (7.5%) or below¹⁰. However, all of the patients achieving an HbA1c of 7.5% or below (32%) were insulin pump users and all the patients with HbA1c levels greater than 10% in the study were on multiple daily injections.

Table 6.3 HbA1c comparison with National Diabetes Audit data for type 1 diabetes

	National Audit	Study Sample
HbA1c	2011-12	2012
<58mmol/mol (7.5%)	27.0%	32%
60mmol/mol (7.6%) to 85mmol/mol (9.9%)	54.9%	56%
≥86mmol/mol (10.0%)	18.1%	12%
% above 58mmol/mol (7.5%) target	73.0%	68%

(Health and Social Care Information Centre (HSCIC) 2013)

6.3 Framing the Findings of Consultations

6.3.1 Consultations: Content and Purpose

All of the consultations within this sample took place within secondary care and all the patients included in the sample were using an insulin pump or multiple daily injections (carbohydrate counting). Within the secondary care consultations, patients and health care professionals reviewed the current management of the patient’s diabetes with a particular focus on the intensive insulin regimen currently adopted by the patient. Their conversations involved decisions about day to day management of diabetes as well as regimen adjustments and changes, or initiation of medication. Health care professionals and patients also discussed issues related to lifestyle including the consumption of alcohol, smoking and weight reduction. These conversations were also important in terms of maintaining access to an IIR.

All except two appointments were scheduled for 15 minutes duration. Over half of the recorded appointments in the insulin pump clinic were longer than 15 minutes and three were over 30 minutes in duration (see Table 6.4). All three recordings in the general diabetes clinic were 15 minutes or less.

¹⁰ The recommended target for HbA1c at the time of the study was 58mmol/mol (7.5%) or below. This has since been changed to 48mmol/mol (6.5%) or lower (National Institute for Health and Care Excellence 2015).

Table 6.4 Duration of Insulin Pump Clinic Consultations

Code	Gender	Clinic Date	Clinic Duration (Minutes) ¹¹
P1	Male	28/03/2012	16
P2	Female	28/03/2012	13
P3	Female	16/04/2012	19
P4	Female	30/04/2012	39
P5	Male	28/05/2012	26
P6	Female	18/06/2012	12
P7	Female	16/07/2012	9
P8	Male	23/07/2012	24
P10	Male	08/10/2012	15
P11	Female	15/10/2012	35
P12	Male	15/10/2012	12
P14	Male	22/10/2012	15
P15	Female	22/10/2012	30
P17	Male	05/11/2012	21
P18	Female	12/11/2012	24
P19	Female	19/11/2012	10
P20	Male	19/11/2012	12
P21	Female	26/11/2012	43
P22	Male	26/11/2012	24
P23	Female	17/12/2012	10

6.3.2 Analysis

The analysis of the consultations was described in Chapter 4. To recap, there were four main stages to the analysis of the consultations. The first stage of analysis was carried out concurrently with the analysis of interviews. Initially, analysis of the consultations commenced with reading and re-reading transcriptions with no attempt to search for themes relating to *a priori* assumptions. The second stage involved examining regularly occurring sequences of interaction within the consultation data in order to build collections (Toerien 2014) citing (Drew 2003, p. 148). The third stage involved analysing individual conversations on a turn by turn basis. Finally, a more directed analysis of the consultations was influenced by:

¹¹ Rounded up to the nearest minute

- Noticeable variation in doctor-patient communication identified in the consultations.
- The interview findings in relation to the emerging importance of alignment between patients and health care professionals as a key influence on gaining access.

Dialogue within the consultations was divided into a number of phases. The process of identifying phases described in Chapter 4 (section 4.11.2) is commonly undertaken in conversation analytic research. Phases consist of the main sequences of activity within the consultation and may include: the opening dialogue; verbal and physical examinations; dialogue in relation to treatment decisions and the closing sequence (Collins et al. 2007b).

In the current study these phases broadly comprised 'pre-treatment', 'treatment' and 'post treatment'. It is important to note that this is a simplification. In some cases there was overlap of sequences where conversations that were started in one phase would be continued in another. Some of the content of the phases was either not present or differently ordered across the recordings but the broad shape was present in the majority of consultations.

The 'pre-treatment' phase included an opening sequence that comprised greetings by staff and patients (all consultations). This was followed in the majority of cases by a 'how are you' question from health care professional to patient. In the majority of cases this phase also included a review both of blood glucose levels and how well the patient was managing their regimen. The 'treatment' phase involved problem solving, advice giving and decision-making regarding regimen change or medication. This phase also involved gauging patient knowledge with regard to their current regimen. In the majority of recorded consultations 'treatment' was through talk. Physical examinations were carried out on 2 patients out of 25. The final phase (post treatment) involved agreeing the next review appointment, arrangements for additional appointments with the diabetes specialist nurse and or the diabetes specialist dietitian and farewells.

Two key resources were considered as a framework for analysis. These were the shared decision-making model proposed by Elwyn et al. (2004) and the Calgary-Cambridge guide (Kurtz et al. 2003; Silverman et al. 2005). The former model (Elwyn et al. (2004) (outlined in Chapter 3) provides a detailed guide in relation to the necessary steps involved in shared decision-making. Analysis suggested, however, that a broader framework was required than the one offered by this model of shared decision-making. The Calgary-Cambridge guide widely used in medical education in the UK aims to provide an evidence-based approach to teaching and assessing communication skills (Kurtz et al. 2003). The guide is informed by the need to

bring together the separate perspectives of both the patient and the doctor in order to facilitate a more patient-centred approach to communication. The guide encompasses 71 skills framed in an overall structure that mirrors the communication process. As well as incorporating shared decision-making skills, the guide covers the entire communication process from the opening sequence to the closing sequence. The Calgary-Cambridge guide appeared to have particular salience for the current thesis. For example, guidance is given on establishing rapport, gathering information, relationship building and involving the patient. Although the guide provides a 'gold standard' measure in relation to provider communication, the analysis suggested that the Calgary-Cambridge guide, with its focus on the skills required by health care professionals, would be insufficient to frame the findings in relation to patient communication. Hence although occasional reference is made to the guide in this chapter, the chosen framework for the findings related to both patient-provider alignment and patient involvement.

6.3.3 Introduction to Themes

It appeared that patient-provider communication in the insulin pump clinic was strongly influenced by two key factors:

- Patient alignment with health care professional goals in relation to diabetes management.
- Patient involvement in the interaction.

Alignment

In Chapter 5, I proposed that access to an IIR was related to the concept of patient-provider alignment. A good 'fit' between the help sought by patients and the services offered by health care professionals facilitated access to an IIR. In contrast a poor 'fit' (patient-provider non-alignment) appeared to militate against accessing an IIR. This 'macro' level concept emerged through analysis of interviews with both patients and health care professionals. In this chapter, however, I explore the concept of patient-provider alignment at the 'micro' level using conversation analysis in order to examine the factors that appeared to facilitate or diminish continued access to an IIR.

Alignment within the consultations presented a complex and nuanced picture. There were several aspects of alignment apparent in the findings. These comprised 'distal' influences

(external to the interaction) and 'proximal' influences (within the interaction) (Mehan 1991) and were as follows:

- Distal influences – Alignment with treatment goals or with members of the multi-disciplinary team outside the review appointment.
- Proximal influences – Alignment with the doctor's evaluation of progress towards goals, goal setting or other decision-making activity. Alignment with other members of the multi-disciplinary team within the consultation (diabetes specialist nurse or diabetes specialist dietitian).

It was evident that alignment could change from one appointment to the next and also moment by moment within the consultation. Alignment and non-alignment with the doctor's goals appeared to be of importance in maintaining access. Aligned patients either adhered to HbA1c targets set by the doctor, or made progress towards this goal. Non-aligned patients were those who appeared not to have adhered to the doctor's goals or had experienced deterioration in their results since the last appointment.

Patient involvement

Patient involvement appeared to be influential in maintaining access to an IIR and was more important in relation to maintaining access to an IIR than whether or not the patient was aligned or non-aligned with health care professional goals. For the purposes of simplicity I refer to a continuum of patient involvement from high to low. In relation to patient involvement I use an adapted patient typology developed in relation to 'active' and 'passive' patients (Brown et al. 2002). 'Active' patients included those who: engaged in the consultation in ways that enabled them to influence or set the agenda; asked questions; and were involved in decisions. These patients were more involved in communication with the doctor and the potential for patient involvement was enhanced. 'Active' patients were able to pre-empt discussions about poor results and hence lessen the potential for negative inferences from health care professionals. Some patients who appeared to be non-aligned with biomedical goals were nevertheless able to align with the doctor conversationally.

Although I use the term 'passive' to describe some patients in the sample, 'less active' would be a more accurate description since none were entirely 'passive'. Their consultations included some or all of the following features: they responded to the doctor's questions but were not involved in shaping the consultation agenda; communication was largely in one direction from

doctor to patient; and there were occasions when communication was difficult (the patient was not 'heard').

Conversational non-alignment between patient and doctor, on occasions, triggered an intervention from the diabetes specialist nurse or diabetes specialist dietitian. This action appeared to be supportive of patients and seemed to assist the patient in their communication with the doctor. Lack of involvement appeared to influence patients' ability to maintain access to an IIR.

Patients were identified as belonging to one of two categories 'high involvement' ('active') and 'low involvement' ('passive') through a process of looking at key sequences in the interaction related to regimen monitoring (blood glucose control) and noting which features of the 'active' and 'passive' typology used by Brown et al. (2002) predominated. Using the term 'involvement' acknowledges the impact of both the patient and the health care professional on the interaction.

Patient alignment, patient involvement and the relationship with socioeconomic status.

Since the HbA1c result appeared to be the dominant factor for the doctor I have used this target as the focus for presenting the findings about alignment. In addition, the HbA1c blood result was relevant to all patients in the sample and provided a consistent point of comparison for all of the consultations. In the following, therefore, I describe patients as either aligned or non-aligned with the HbA1c target.

In order to understand the relationships between patient alignment, patient involvement and socioeconomic status, the sample of patients attending the insulin pump clinic is characterised in Table 6.5. Within the sample, patients from professional social classes were predominantly aligned with target levels for the HbA1c whereas those from intermediate and manual social classes were predominantly non-aligned. Patients from professional social classes were all in the high involvement category, along with some patients from intermediate and manual classes. All the low involvement patients were from intermediate and manual classes.

Patients in the high involvement category were almost equally distributed between the aligned and non-aligned categories. There were far fewer patients in the low involvement category and the majority of these were categorised as non-aligned. All of these non-aligned and low involvement patients were from intermediate or manual social classes. This is in stark contrast

to high involvement patients who were also aligned and meeting the HbA1c target; these were all from the professional social classes.

Table 6.5 ‘High’ and ‘low’ involvement patients attending the insulin pump clinic

	High Involvement				Low Involvement		
Aligned	<i>Meeting the HbA1c target</i>		<i>Making improvements</i>		<i>Meeting the HbA1c target</i>		<i>Making improvements</i>
	<u>Patient</u>	<u>SES</u>	<u>Patient</u>	<u>SES</u>	None in sample	<u>Patient</u>	<u>SES</u>
	P3	1	P2	3		P5	3
	P4	1	P12	1			
	P7	1	P21	2			
	P11	1					
	P14	1					
P22	1						
Non-aligned	<i>Not meeting the HbA1c target and not making improvements</i>				<i>Not meeting the HbA1c target and not making improvements</i>		
	<u>Patient</u>	<u>SES</u>			<u>Patient</u>	<u>SES</u>	
	P1	3			P17	3	
	P6	3			P19	2	
	P8	1			P20	3	
	P10	3					
	P15	2					
	P18	1					
P23	N						

SES (Socioeconomic status) – Standard Occupation Classification
 Three classes: 1 = Higher Managerial and Professional; 2 = Intermediate;
 3 = Routine and Manual; N = Unclassified (Office for National Statistics 2010b).

Transcriptions

A description of the methods used to transcribe the recorded consultations is provided in Chapter 4 (see Appendix 8 for a key). In the transcription extracts below, participants are coded as follows: patients (P); doctor (D); diabetes specialist nurse (N); diabetes specialist dietitian (A); and patient’s partner (B).

6.3.4 Structure of Themes within the Chapter

The following summarises the themes reported in the chapter. First in section 6.4 I explore the impact of patient alignment on doctor-patient communication. This section introduces the important influence of the HbA1c target and investigates both patient and doctor communication in relation to the interaction. As a primary topic of conversation within the consultation, the impact of positioning the talk about blood glucose levels at the start of the

consultation is explored particularly in relation to rapport building and the disparities observed between patients. Having identified alignment as an influence on doctor communication, in section 6.5 I report the findings in relation to the impact of different levels of patient involvement.

6.4 Aspects of Patient Alignment Influencing Communication

It was apparent that although the insulin pump clinic comprised a multi-disciplinary team, the doctor largely influenced the consultation agenda. In this first section I therefore focus on the doctor's initial actions within the consultation. In addition, I have chosen a subset of 20 consultations in the sample that consists of all the consultations with one doctor in the insulin pump clinic. This provided consistency when making comparisons between patients.

In this first section, I present the findings in relation to the doctor's agenda with regard to biomedical measures such as the HbA1c result, patient weight and liver function tests. A key influence on doctor-patient interaction appeared to be alignment and non-alignment with biomedical goals.

6.4.1 The Doctor's Agenda

In the opening sequences of the majority of insulin pump clinic consultations, patients were collected from the waiting area immediately adjacent to the clinic rooms, either by the diabetes specialist nurse or the diabetes specialist dietitian. It was apparent from the short conversations that were captured as patients came through the door that the nurse and the patient, in most cases, knew one another. The tone was friendly as the nurse welcomed patients into the room with the statement 'come and have a seat'. Following the nurse's introductions, the consultation was then initiated by the doctor.

Doctors' questions establish agendas (Boyd et al. 2006). These questions, by setting topical agendas, require particular patient responses. Patient responses range from 'yes' or 'no' to more elaborate explanations, hence they also set action agendas (Boyd et al. 2006). It was apparent that discussions about blood glucose levels were of primary importance to the doctor and constituted the key topical agenda. This was indicated by the positioning of these discussions, in the majority of cases, at the start of the consultation. This finding is perhaps not surprising given that, Health Care Professional 4 (specialist services) had reported that the HbA1c result was seen as an important indicator of blood glucose control and suitability in relation to accessing an insulin pump (see Chapter 5, section 5.6.2). It should be noted that the

HbA1c result was also viewed by some patients as an important indicator of their own 'control'. Many patients reported that they took a keen interest in monitoring their HbA1c values and reductions in the value were perceived as evidence of successfully managing the regimen (section 5.5.2).

Discussions about blood glucose levels and HbA1c results were, however, prioritised over the patient's agenda. Hence the doctor determined what was discussed and the order in which it was discussed. For example, problems mentioned by patients in answer to the 'how are you' question were generally discussed once the doctor had concluded his agenda with blood glucose levels. This tendency to defer the patient's agenda until the doctor had concluded his business was a recurrent pattern in the recorded data.

The prioritisation of the HbA1c result is illustrated in the following extract. Two questions are asked by the doctor in this sequence. In the first case the doctor responds to the patient's reply about 'aches and pains' with a neutral response ('right') before moving on to another question. The doctor's second question in relation to the insulin pump at line 15 ('are you happy with the way things are going') is phrased to prefer¹² a 'yes' reply. The patient formulates the 'yes' response but adds a proviso that he has had a few problems (lines 18-20). Initially, this reply appears not to have been 'heard' by the doctor. Instead, rather than following up the patient's comments the doctor begins the agenda topic of the patient's HbA1c result at line 23. Here the patient's improvements in HbA1c are discussed (lines omitted) before reiterating the target at lines 34-35. Having concluded this business at line 37 the doctor returns to the patient's problems of hypos (line 40). The patient's earlier complaint of 'aches and pains' in response to the doctor's opening question is not addressed.

Extract 6.1 [Patient 5 (Insulin Pump) 28-05-12] (8-40)

8. D: And how have we been sir?
9. P: Alright yes (0.4) yes(.) apart from
10. a few aches and pains here and there .hhh

¹² In conversation analysis 'preference' refers to two different aspects of the structure of conversation (Sidnell 2010) citing (Schegloff 2007). First, it refers to the ways in which turns in conversation are designed or constructed to provide a preferred or dispreferred response. These responses are usually biased towards the preferred response. For example, the preferred response to invitation is acceptance and similarly apologies prefer absolution. Second, preference relates to the notion that with regard to the actions initiated by individuals, the preferred response is to progress the action.

11. D: Right.
 12. (0.4)
 13. P: hhh Yeah.
 14. (0.6)
 15. D: Are you are happy with the way things are
 16. going? (.) with the pump and every[thing?
 17. P: [Yes >oh
 18. yes< yes er obviously you're still
 19. getting a few odd low ones and then some
 20. high ones but the major:ity of `em are probably
 21. (0.5)
 22. P: [()]
 23. D: [That's]how your hi- (.) thats how your
 24. HbA1c's been doing
 25. ((showing the patient chart of HbA1c
 26. results on computer))

(Lines 27-33 omitted in which the doctor discusses the patient's improving HbA1c result)

34. D: and >we are now at seven point eight our
 35. target is seven point five<
 36. P: (.)Yeah ye[ah
 37. D: [So we're doing extremely we[ll
 38. N: [oh
 39. P: (.)Yeah it (.) yeah tis
 40. D: (.)So you said you were getting hypos

6.4.2 Patient Alignment with the HbA1c Target

Praising patient effort

The patient's HbA1c result was in most cases known to the doctor before the patient had entered the consultation since patients were asked to provide a blood sample in advance of the review appointment. This influence from outside the interaction had an effect on the ensuing conversation (Mehan 1991). A key influence on doctor-patient communication appeared to be the extent to which patients were able to demonstrate alignment with objective biomedical targets or that they were moving towards these goals.

A large number of patients in the sample received praise from the doctor in relation to their HbA1c result. Patients who had achieved their target HbA1c level or maintained target levels were commended. It was also the case that those who had made improvements towards targets including patients with HbA1c levels above the recommended target were commended. Therefore it appeared that compliments from doctor to patient were associated with the efforts made by patients rather than actual target levels.

Although patients with improving results were encouraged, there was, nevertheless, emphasis placed on the target required. This is illustrated in the extract below where the doctor focuses firstly on informing the patient that there has been a reduction in the HbA1c before reiterating that the result is above target. Although Patient 21 (MDI) had the highest HbA1c level in the dataset (143 mmol/mol (15.2%))¹³, beginning the consultation on a positive note (lines 5-9 and 13) allows the doctor to acknowledge the patient's efforts whilst still making the point that the HbA1c result is very high (lines 13-19) and restating the target (lines 14-15).

Extract 6.2 [Patient 21 (ex Insulin Pump user now on MDI) 26-11-12] (1-31)

1. N: Come and have a se:↑at
2. P: °Thank you°.
3. D: Hello there (0.3) how are you doing?
4. P: Okay hhh(0.3) [°(I think)°.
5. D: [Good well you're certainly doi::ng
6. uhm (0.4)a little bit better than (.) than we
7. expected because (0.4) yo:ur (0.4) >three month
8. test your HbA1c has dropped from a hundred and
9. fifty two to a hundred and< (0.5) forty three
10. (0.4)
11. P: is that go:od? hhh ((short laugh))
12. (0.5)
13. D: Well any drop is good (.) >I mean a hundred
14. and fo- we're we're< talking at a target
15. of fifty ni:ne.
16. P: (.) Oh hhh ((short laugh))
17. D: (.) So a hundred and forty three is horrendous

¹³ 6.5% -7.5% was the recommended target range at the time of the study

18. com- if you look
 19. at f- [fifty =
 20. P: [yeah
 21. D: = nine but .hhh if you look
 22. at the fact that [you were ()
 23. P: [yeah is that
 24. D: [()
 25. P: [when I was in hospital].
 26. (0.5)
 27. D: You were however a hundred and
 28. fifty two in June.
 29. (1.0)
 30. D: It's an improvement it's a
 31. definite impro^uvement

Patient effort leads to rapport

Nevertheless this opening sequence also demonstrates the priority placed by the doctor on encouraging patients who appeared to making improvements. It would also seem that the doctor's stance in framing the result in a positive light facilitates the beginnings of a rapport between doctor and patient. Initially it is apparent that the opening greeting and question by the doctor 'hello there (0.3) how are you doing?' receives a somewhat muted and tentative response from the patient who replies with 'okay' (line 4) before going on to downgrade this response with a quietly spoken 'I think'. This response appears to pre-empt the expected discussion about blood glucose levels. Although the patient's HbA1c is very high, the doctor presents the improved result in a positive light ('well you're certainly doi::ng uhm a little better than we expected') (lines 5-6). The patient's response at line 11 ('is that go:od?) questions this assessment. The doctor, however, continues to paint a positive picture by acknowledging that although the result is high it needs to be viewed in the context of an even higher result previously and therefore any 'drop' should be viewed positively. The authors of the Calgary-Cambridge guide emphasise the importance of developing rapport both at an early stage in the medical interview and throughout the consultation (Silverman et al. 2005). It would seem from the sequence below that the doctor was able to deal sensitively with what could have been a tense discussion around the patient's HbA1c result and was able to get the consultation off to a better start as a result. Positive talk allowed the beginnings of a rapport to be built between the patient and the doctor.

The HbA1c result was accorded prominence in the consultation and it was observed in the recordings of the insulin pump clinic that patients who displayed alignment with medical goals received talk that was positive and supportive. The opportunities for rapport building with these patients were therefore enhanced.

6.4.3 Alignment with other Medical Goals

Although the doctor prioritised discussions about blood glucose levels and HbA1c results in the majority of consultations (insulin pump clinic) there were two exceptions where this was not observed. This appeared to be the case for individuals who had health issues other than diabetes and who had made some progress towards other health goals. Ability to align with at least one of the other medical goals also seemed to influence the doctor's response. This appeared to be advantageous in terms of maintaining access to an IIR since the doctor's approach remained supportive, despite the patient not being able to achieve the HbA1c target. Evidence of the doctor's support is found in the extracts below in which the doctor explicitly aligns with the patient's expressed efforts to cut down his alcohol consumption and in the positive evaluation he gives of the patient's progress. The example given is one of the clearest in the recordings and is for Patient 17 whose HbA1c had risen slightly since the last review appointment and was 85mmol/mol (9.9%). Although the patient had not achieved the recommended HbA1c target there was some evidence of his cooperation with medical advice regarding his alcohol consumption. It would appear that evidence of alignment with one goal was sufficient for the doctor to take a more lenient approach with regard to the HbA1c result.

The discussion, between the doctor and the patient, relating to the HbA1c result takes place much later in the consultation than was usually the case and the result was downplayed. Instead the doctor focuses on the patient's other health issues which were: a recurrent chest infection; alcohol intake; and smoking (extract not shown). Of note are the doctor's positive comments in connection with the patient's reduction in alcohol consumption. In answer to the patient's remark that he has reduced his alcohol consumption 'see I caught one er habit out and that was me e::r drinking' (lines 224-225) the doctor replies positively with 'good good'. Although the patient downplays his initial comment at lines 224-225 indicating that he has not cut out alcohol altogether ('well I'm not saying that I've sto:pped drinking') the doctor is quick to reply in an affiliative way with 'you're being more sensible about it' (line 231). It can be seen from the patient's response at lines 233-234 that although his talk overlaps with that of the doctor, he hears the doctor's depiction of his attitude towards alcohol and is quick to agree ('yeah yeah that's the word that I've been trying to use on people'). It appears that the

doctor's assessment is based on more than the patient's verbal report since he has the results of a liver function test. Here as in the case of improvements in patient HbA1c test results the priority seems to be to offer a positive assessment of the patient's progress towards reducing his alcohol consumption 'your liver is showing a remarkable improvement'. Following this sequence the doctor discusses with the patient the need to decrease his alcohol consumption further. This occurs, however, after the doctor has given the patient the positive news about improvements in his liver function and the pattern in the data is observed again of the supportive comments from doctor to patient prior to a restating of the expected goal.

Extract 6.3 [Patient 17 (Insulin Pump) 5-11-12] (224-254)

224. P: See I caught one er habit out and
225. that was me e::r drinking.
226. (0.6)
227. D: ↑Good ↑good
228. P: Because well I'm not saying
229. that I've sto:pped [drinking]
230. D: [yeah yeah] but
231. you're being more [sensible about it].
232. P: [But I've got I've got =
233. P: = Yeah yeah that's the word that
234. I've been trying [to use on people
235. D: [Yeah that's fine yeah yeah
236. P: I've gone back to the way I used to be.
237. D: Okay right so let's (0.3)I mean (.) from m::y
238. point of vi:ew
239. (4.0) ((Doctors looks at the computer screen))
240. D: Your (0.7) your liver is showing
241. a remarkable improvement (.) so so what you're
242. doing seems to be (.) effective (.) in fact
243. (.)in Septe:mber two thousand and eleven you
244. were you were brilliant
245. (0.5)
246. P: [Yeah
247. D: [but you were really bad in July
248. of two thousand and ten(0.5)so over the
249. years you've actually(.)I'll show you where we
250. are or how the tests have (0.8)evolved so

251. (1.6) so you're not doing too badly.
252. (0.6) you're still high
253. P: Yeah
254. D: Still still drinking too- more than's good for you

Whereas the doctor provides a positive evaluation of the liver function test, the HbA1c result is downplayed (extract below). For example, the usual request from the doctor for the patient to account for a rising HbA1c result (observed in other consultations) is not made and there is no mention of the target. Instead the result appears to be of secondary importance to the patient's other problems. Although the HbA1c result has gone up (a deterioration) the doctor reports the result with little comment and returns to the discussion of the patient's ongoing chest infection and alcohol consumption (lines 334-336).

At line 334 the doctor uses a supportive 'we' in connection with the work that is needed to sort out the chest infection and the alcohol consumption. The message to the patient relating to the work that is required (lines 334-336) is tempered with the doctor's supportive and encouraging stance with his comment at line 343 'it's moving in the right direction' and at lines 349-350 'so you don't have very far to go really'. A further illustration of the doctor giving the patient some leeway is evident following a noticeable 1.6 second delay¹⁴ in the patient's response to the doctor's remark about the need to stop smoking (line 355). At line 360 the doctor orients to the patient's expressed reluctance ('yeah well that's one thing that e::r (0.2) I've been wanting to do (1.1) but at the moment' (lines 356-358)) by emphasising the importance of tackling the issues one at a time (line 360). The patient aligns with the doctor's comments at line 361 with a prompt response 'yeah that's what I keep saying to myself' indicating his agreement.

It would seem that in these two extracts in relation to patient involvement the doctor demonstrates a number of skills identified in the Calgary-Cambridge guide. These relate to picking up on verbal cues from the patient. For example the doctor appears to discern the noticeable pauses in the patient's response to his comment about tackling smoking now that the patient's alcohol consumption has reduced. Thus the doctor appears to adjust his comments in the light of the patient's reaction, that is, he downgrades his previous remarks since the patient has indicated that this may be a step too far at this stage and instead uses the

¹⁴ Delays of one second or more denote some difficulty in response

phrase 'one at a time' (line 360). There is evidence then of closely 'listening' to the patient in these extracts. It is also noticeable that the doctor facilitates the patient's responses for example by offering an interpretation in the lines already discussed 'you're being more sensible about it' and there would appear to be evidence that this is received as helpful as judged by the patients' response at lines 233-234.

The overriding impression, however, in these two extracts is also one of the doctor directing the agenda while giving the patient information and instruction. There is little overt solicitation of the patient's viewpoint in this discussion which is another recognised skill in facilitating patient involvement identified in the Calgary-Cambridge guide. The lack of response to the patient's question about HbA1c up to this stage in the consultation points again to the importance placed by the doctor in pursuing his own agenda and prioritising this before moving on to the patients concerns. It also suggests that some patients experience difficulty being 'heard' within the consultation.

Extract 6.4 [Patient 17 (Insulin Pump) 5-11-12] (308-361)

308. P: What's me blood ra:nge?
309. (1.0)
310. D: Your HbA1c was erm
311. (2.7) ((Doctor looks up result))
312. P: Cos last time I had it done it were (0.9)
313. eight wannit
314. D: Yes so n- (0.7) no it was ni:ne when it was
315. done last time.
316. P: Yeah nine
317. D: (.)Unfortunately [it's closer
318. P: [come up
319. D: to nine point seven now.
320. (0.3)
321. P: Nine point seven [()
322. D: [Seven to ten [yeah =
323. P: [its come up
324. seven yeah
325. D: = It's about nine point seven
326. to ten really
327. (0.9)

328. P: Yeah

329. D: >Somewhere between nine point nine and
330. ten I would say is the exact amount
331. but it's definitely more than nine point seven<
332. (0.6)

333. P: Right

334. D: Less than ten (0.8) so we have
335. a bit of wo:rk to do sort out infections
336. sort out these calories from alcohol
(lines 337-342 not shown)

343. D: But it's mo::ving in the right direction
344. the liver's certainly improved remarkably
345. (0.4) from a hundred and forty four (0.3) your
346. your liver enzymes came down forty
347. seven and the normal's around forty

348. P: [Ah hah

349. D: [() normal so (0.7) you don't have very far
350. to go really
351. (0.6)

352. P: [No

353. D: [to get that sorted. (2.7) >↑so one down ↑one
354. to go the smoking's next<.
355. (1.6)

356. P: yeah well that's one thing that
357. e::r (0.2) I've been wanting to do (1.1) but
358. at the moment
359. (0.5)

360. D: >One at a time<

361. P: Yeah that's what I keep saying to myself

6.4.4 HbA1c Target Non-Alignment

So far the findings have focused on the apparent prominence of biomedical goals and the impact that adhering to these goals appeared to have on doctor-patient communication. The opening sequence in the consultation appeared to set this agenda. Patients without a recent

HbA1c result or those with rising blood glucose levels as evidenced by the HbA1c result¹⁵, who therefore appeared not to be aligned with the doctor's goals, seemed to receive a more abrupt start to the consultation. As noted in section 6.4.2 patient alignment led to enhanced communication which built rapport. Many consultations involved either praise or positive talk from the doctor about the work that patient's had accomplished in following recommended regimens. This talk was absent in the early sequences of consultations in which patients appeared to be non-aligned with medical goals.

In the extract below Patient 10 (Pump) arrives at the consultation with his partner. The answer 'ye:ah not too bad' in reply to the doctor's question, 'and how are you keeping', appears to foreshadow the perhaps expected news about his deteriorating HbA1c result. 'How are you' type questions have been found to have an ambiguous quality. Patients could view them either as a general enquiry or alternatively as relating to medical matters (Heritage et al. 2006a). It would seem that many patients in the sample viewed the question as pertaining to medical matters. Hence some appeared to be 'hedging their bets' in their responses. They appeared to be both diffident in offering more than was required and also reluctant to give too positive an assessment in relation to their regimen management. In taking this approach patients avoided the scenario of stating that they were doing better than the objective evidence of the HbA1c result would seem to indicate. It appeared that the doctor treats the opening response to his question as an evaluation relating to medical matters since in most cases the next turn in his conversation relates to blood sugars.

Extract 6.5 [Patient 10 (Insulin Pump) 8-10-12 (2-7)]

2. D: Hello there I'm Professor (name)
3. B: Nice to meet you
4. (0.4)
5. D: And how have you been keeping?
6. P: (0.2)Ye:ah not too bad
7. D: °Right° (0.9) and e:rm (0.2) blood sugars

In the previous extract the patient's response to the doctor's initial question appeared to foreshadow a discussion about problems with blood glucose control. This pattern was

¹⁵ In this sample it appeared that patients arranged for a blood test in order that the HbA1c result would be available for the review appointment and a small number of patients arrived at their appointment without having arranged the blood test.

observed in most of the patients who had either experienced deterioration in their HbA1c result or who had not arranged for a recent HbA1c result. In the extract below for Patient 6 (Pump) the consultation opens in a similar way to many in the sample. The doctor uses a typical opening question in the apparently non-constraining format 'how are you doing' (line 1). Whereas this opening question appeared to be treated by most patients as relating to medical matters it is unclear here whether Patient 6 refers to general or medical matters. The doctor appears to treat the evaluation of 'very well' as relating to medical matters and specifically to the patient's regimen management as evidenced by his 'news' to the patient that her HbA1c has risen.

In reply to the announcement that the HbA1c has risen (lines 14-15) the patient's response acknowledges the rise in the value ('it's gone up a bit hasn't it'). The patient's choice of words ('a bit') indicates a downplaying of the rise. The doctor appears to echo the patient in his response describing the rise as having gone up 'a little bit', however, there is also an insistence that the patient gives an account for the rise and this suggests that even a rise of 'a little bit' is unacceptable. Once again the HbA1c result takes precedence in the discussion. This is accomplished by the doctor in two ways. First there is an emphasis on the patient's previous adherence to goals (lines 19-21) and second there is a request for an explanation in relation to the deterioration. In contrast to the opening sequences amongst patients with 'good' news about blood glucose levels, these extracts appear to be constrained in content. At line 25 two questions are asked: first, has the patient carried out regular blood glucose monitoring and second, if so, do these records shed light on the rise. This has the effect of limiting the conversation to the doctor's focus on regimen adherence.

Extract 6.6 [Patient 6 (Insulin Pump) 18-06-12] (12-28)

12. D: How are you doing
13. P: Very well thank you
14. D: Good and er (0.3) your HbA1c (1.4)
15. it's seven point six percent.
16. (0.7)
17. P: It's gone up a bit hasn't it?
18. N: O::[h
19. D: [It has hasn't it? erm (.) you've been
20. well below well below seven point five
21. (0.4)consistently seven point three seven
22. point fours(.)hhh it::s (.)gone up a

23. little [bit =
 24. P: [Rig[ht
 25. D: =[have you have you done your
 26. blood suga:rs (.) and do they (0.4)do
 27. they suggest a reason why as to why
 28. it might have gone up

Although some patients appeared to be non-aligned with medical goals and received abrupt starts to their consultations they were subsequently able to accomplish alignment with the doctor in other ways. For example, some patients were able to pre-empt the discussion about the deteriorating HbA1c result. The following section presents the findings in relation to patients who were actively involved in maintaining the doctor's support, some of whom were non-aligned with medical goals.

6.5 The Impact of Patient Involvement on Maintaining Access to an IIR

So far the findings have focused on the priority given to discussions about HbA1c results (or other objective measures of adherence to medical advice) in the insulin pump clinic. Patient alignment or non-alignment with objective measures appeared to influence the doctor's communication in each case. An additional and arguably more important influence on the interaction, however, was patient involvement in the consultation.

It appeared that in this sample, some patients were able to influence the interaction with the doctor. This was accomplished in a number of ways. For example, some patients were able to deflect potentially negative criticism regarding a rise in their HbA1c result by giving an account of their difficulties before the subject of the HbA1c result was raised. Others were able to display a commitment to the regimen or to indicate that they had been working with the other team members to improve their regimen (the specialist diabetes nurse and dietitian). In consequence they were able to influence the continuing health care adjudications in relation to their suitability for an insulin pump.

Some patients appeared to be more involved in discussions with the doctor. This was particularly noticeable for patients who were aligned with health care professional goals. There were approximately equal numbers of 'high involvement/aligned' and 'high involvement/non-aligned' patients in the sample (9 and 7 respectively). In contrast there were very few low involvement patients (4) in the sample. The following section presents the ways that patients actively worked at maintaining alignment with the doctor.

6.5.1 Agreeing with the Doctor about Poor Outcomes

In section 6.4 it was noticeable that disagreements with the doctor's comments or recommendations for HbA1c targets were rare amongst all patients. The majority of patients appeared to align actively with the doctor's stance by agreeing with his comments. For example, Patient 6's response to hearing that the HbA1c has risen to 7.6% (60 mmol/mol) (Extract 6.6 line 17) was to say 'it's gone up a bit hasn't it' without the need for the doctor's evaluation. In the extract below Patient 1 (MDI) aligns with the doctor's comparison of his result (11.2%) with the target (7.5%) at line 206 ('that's huge yeah'), displaying his understanding about the seriousness of the result.

Extract 6.7 [Patient 1 (MDI) 28-3-12] (196-210)

196. D: Okay I think(.) the proof of the pudding's in the
197. eating (.) so we'll do a HbA1c.
198. (0.2)
199. P: Yeah
200. (.)
201. D: Er (.)when it was last checked in October
202. it was eleven point two.
203. (0.4)
204. P: Yeah [my
205. D: [I told you seven [point five is
206. P: [That's huge yeah ()
207. I remember (that I know)
208. (.)
209. D: Seven point five is the is the
210. area so let's do one toda:y

Similarly, Patient 10 (Pump) acknowledges the doctor's comments about his deterioration in blood glucose levels (extract below). The doctor constructs his evaluation of the current HbA1c result through a comparison with the patient's previous results. His announcement of the current value is elongated for emphasis ('It's:: sevent::y ni::ne) (line 42). He refers to the nurse to corroborate the previous result and hence to emphasise the deterioration in the patient's

result. The patient pre-empts the doctors evaluation at lines 53-55 with his own assessment at line 52, 'yeah () bad' and is then heard to agree with the doctor in overlap¹⁶ ('yeah') at line 56.

Extract 6.8 [Patient 10 (Insulin Pump) 8-10-12] (42-56)

42. D: It's:: sevent::y ni::ne in the
43. new units >compared to
44. seventy two before< .hhh
45. P: Yeah
46. D: So that's eight point nine we said?
47. N: Yes
48. D: nine point four it's [gone up
49. N: [nine point four
50. P: Yeah
51. D: So that's way above your usual sort of situation
52. P: [Yeah () bad
53. D: [where you were sixty eight (2.8) sixty two
54. and ()sixty seven (0.6)so so this
55. is >a significant deterior[ation<
56. P: [Yeah

On the whole, therefore, the majority of patients attending the clinic, aligned with the doctor's stance regarding the HbA1c within the consultation, whether or not they were achieving the HbA1c targets. Patients both displayed an expectation that there would be a discussion about rising or deteriorating blood glucose levels and were in alignment with the doctor's view that improvements were required. Conversation analysis does not make psychological claims about the kinds of responses individuals make in the course of conversation; however, it appeared that individuals 'displayed' agreement. It seems reasonable to argue on the basis of these conversations that patients oriented to discussions about unacceptable results and that this was an expected part of the review process.

¹⁶ Overlap in speech is not haphazard (Jefferson 1983; Schegloff 2000). It has been demonstrated that speakers monitor closely the potential end of a turn constructional unit in order to start their turn at a turn relevant place (Schegloff 2000). There are a number of reasons why speakers overlap speech (Schegloff 2000). Overlap in talk is 'frequently ... co-operative, affiliative and supportive' (Drew 2009, p 72).

It is interesting to note the apparent readiness with which some patients agreed with the doctor about HbA1c targets in this consultation data; particularly in light of the interview findings presented in Chapter 5 that many patients reported not always agreeing with health care professionals in relation to this target. This included patients who viewed the target as too low and those who perceived that it was too high. One can speculate that the seemingly ready agreement with the doctor in relation to targets is that patients know that, outside of the consultation, they are at liberty to manage their regimen in the way they perceive works for them. However, it was also apparent from the findings in Chapter 5 that many patients perceived that it was important to 'get on' with health care professionals within consultations. The consultation findings appear to illuminate this process of 'getting on' with health care professionals and for this sample of patients the activity largely involved the patient aligning with the doctor.

6.5.2 Pre-empting the Doctor's Remarks about the HbA1c Result

Managing diabetes is difficult and from time to time patients experienced problems with home life or work life impinging on their ability to manage the regimen. Some patients were able to take advantage of the opening questions in the consultations to state their problems and to pre-empt the expected conversation about deterioration in blood glucose levels, hence momentarily interrupting the doctor's agenda. In this section two illustrations of patients actively pre-empting discussions about the HbA1c result are presented. Communication from the doctor differs in the two cases. In keeping with the findings in previous sections this appears to relate to how well the patient is adhering to the target HbA1c result. Patient 10 (Pump) has a deteriorating HbA1c result and Patient 14 (Pump) has a result that is well within target (a good result).

Patient 10 actively defends his position as a patient with a deteriorating HbA1c result. He is able to pre-empt the discussion about blood glucose levels by talking about his difficulties. In conversation analytic terms the aligning action is from patient to doctor with little leeway given to the patient. In contrast Patient 14's disclosures of difficulty are met with an empathetic and affiliative response from the doctor. The terms affiliation and alignment have particular meanings and are related to 'preference' (Lindstrom et al. 2013). The term affiliation is also associated with individuals taking a supportive stance with a speaker (Lindstrom et al. 2013). In general terms aligning activity is 'going along with' or cooperating with a particular stance. Affiliation describes cooperation in stronger terms. Individuals do not merely go along with suggestions; they actively collaborate in the process of agreement (Stivers 2008).

Defending a deteriorating HbA1c (poor control)¹⁷ – Patient 10

In lines 9-16 (extract below) the patient aligns with the doctor's enquiry whilst also presenting a defence against the projected announcement of the HbA1c result. It was noted in the previous section that the patient's response to the doctor's 'how are you' question (an elongated *ye:ah* followed by 'not too bad') orients to the doctor's enquiry as medical rather than simply general in nature. 'Not too bad' is recognisably a downgraded version of the usual response given to an inquiry and foreshadows a 'trouble telling' (Jefferson 1980). This 'negative import' (Jefferson 1980, p. 155) is acknowledged as such by the doctor with a neutral and quietly spoken 'right' and he proceeds to the question about blood sugars. The delay in response followed by an elongated *u::hm* indicates the patient's difficulty in replying (line 9). The fluctuations in blood sugars are accounted for by circumstances beyond the patient's control. In line 9 the patient states that his blood sugar levels have 'been up and down at the minute' displaying that he is aware of his values and by implication has been carrying out the necessary blood glucose tests. The aligning action throughout the conversation is predominantly mono-directional, from patient to doctor. As discussed in the previous section, aligning behaviour from doctor to patient was reserved for those who seemed to be aligning with medical goals. For instance at line 36 the doctor offers no comment or assessment of the patient's preceding account. The doctor's response is oriented to the medical concerns of a rising HbA1c and he continues with the agenda of discussing blood sugar levels, asking the patient if his account offers an explanation for the HbA1c result: 'uhm could you think that that explains this'. The patient's aligning response, however, at line 39 is made without hesitation¹⁸, giving a 'yes' response to the doctor's question at line 36, and adding that he had anticipated a rise.

It can be seen that the doctor's primary agenda was a discussion about the HbA1c result and less about following up on the difficulties the patient expresses regarding his use of the insulin pump during shift work. Nevertheless, Patient 10 gives an account of why he had been unable to align with the medical goals. He reveals his difficulties to the doctor and is able to proactively limit some of the negativity surrounding the increase in HbA1c. In addition, bringing problems to the consultation invites the multi-disciplinary team to offer advice, and to arrange follow up appointments with the patient in order to address his difficulties.

¹⁷ HbA1c result was 79 mmol/mol (9.4%)

¹⁸ A latched response is indicated by the '=' symbol

Extract 6.9 [Patient 10 (Insulin Pump) 8-10-12] (2-39)

2. D: Hello there I'm Professor (name)
3. B:¹⁹ Nice to meet you
4. (0.4)
5. D: And how have you been keeping?
6. P: Ye:ah not too bad
7. D: °Right° (0.9) and e:rm (0.2) blood sugars
8. (0.5)
9. P: U::hm they've been a bit up and down
10. at the minute they have I've been going
11. through a bit of a (1.0) patch >haven't we< (.)
12. u::hm (0.8)I di- I had some issues at work (.)
13. and things and it was affecting me >I
14. wasn't eating and things so that was affecting
15. it< .hhhh and at the minute I've e:rm (0.3) I've
16. started another job and erm working (0.4)like
17. half two in the morning, and it's like (0.3)
18. my basal it's kind of (.)
19. B: ([])
20. P: [it's]thrown [it out
21. B: [huh huh [.hhhh hhh
22. P: [so it's like normally
23. I've got my basal that runs overnight
24. (0.4)and obviously because 'm (0.4)changing
25. what I'm doing (.7)
26. I[t's
27. B: [its
28. P: I need it changing
29. (0.8)
30. B: [()
31. P: [>but obviously you can't change it all
32. the time cos you don't always do the same shift<
33. if that makes sense (0.9).hhh so it's kind of
34. a (.) temporary (1.5) °(thing)°

¹⁹ The patient's partner accompanied him to the appointment

35. (.)
36. D: Uhm so could you think that that explains this
37. ((looking at the blood glucose
38. results on the computer))
39. P: = yes I I I anticipated a rise

Gaining the doctor's support with a below target HbA1c (good control)²⁰ – Patient 14

Apparent in the following extract is the doctor's prioritisation of the HbA1c result. However, the patient influences the agenda by drawing the doctor into a discussion of his difficulties. In this instance the patient has achieved an HbA1c result that is within the target range. It appears that the combination of the patient aligning with medical goals and expressing his difficulties within the consultation elicits an affiliative style of communication from the doctor. In contrast to the previous consultation with Patient 10, the communication from the doctor is more patient-centred. Of note is the patient's evaluation of his HbA1c result 'oh that's not bad' (line 28) and his expressed satisfaction with his result at line 35. Offering opinions is another feature of high involvement patients in this sample.

In the extract below, the doctor's question 'and how have you been sir' (line 5) receives a noticeable delay of 1.5 seconds, indicating difficulty in response. His reply of 'fair' is qualified with 'problems with the wife at the moment'. On hearing the patient's problems with his wife the doctor responds sympathetically at line 10 with 'oh dear'. It is of note, however, that the diabetes specialist dietitian rather than the doctor follows up the patient's disclosure with a question at line 12 'is she is she not so well or'. This tendency for the specialist diabetes dietitian and specialist diabetes nurse to align with patient's expressed difficulties was a recurring pattern in the recorded consultations. The doctor changes the subject at line 20 and continues the discussion of blood glucose levels with the patient (lines 20-38) before resuming the patient's agenda at line 39 'what kind of stresses and strains are your wife's health problems putting on you' (this is a further example of the pattern in communication discussed in section 6.2.1).

The use of 'oh dear' by the doctor was unusual in the recorded consultations. 'Oh' has significance in conversation analysis research. It has been found that it is a change of state marker, registering the receipt of news (Heritage 1984). The tendency for doctors to avoid

²⁰ Patient 14's HbA1c results were below target levels at 50 mmol/mol (6.7%)

news marks and to adopt a more neutral response has been noted (ten Have 1991). Generally in sequences of medical talk in primary care, doctors use neutral receipts such as 'okay' or 'right' (Drew 2002). This is explained in part by the need for doctors to contain the talk within a tight time frame of on average 7.5 minutes per consultation (Drew 2002). When doctors occasionally depart from medical talk and engage in more social talk, they talk in a more conversational way (Drew 2002). There is therefore a contrast between medical talk on the one hand and a more empathetic approach when doctors converse on a more social level with patients (Drew 2002). In most of the recorded consultations the doctor adopts a neutral stance to the receipt of news by patients. In this consultation, however, there is a display of sympathy in the doctor's response of 'oh dear' with an acknowledgment that the patient has provided news.

Extract 6.10 [Patient 14 (Insulin Pump) 22-10-12] (1-41)

1. D: Hello Mr () I'm (Dr's name)
2. P: Pleased to meet you
3. D: You've met one of my colleagues before
4. P: Ye:s we have
5. D: And how have you been sir?
6. (1.5)
7. P: °Er fair fair (1.0) () problems with
8. the wife at the moment
9. and it's causing me some hassle°
10. D: ↑O:h dear
11. (2.8)
12. A: Is she is she not so well or
13. (2.9)
14. P: Dementia
15. A: O:h[dear yeah
16. D: [()
17. P: Got a check up organised in a
18. week's time
19. A: mm (2.3) oh [dear
20. D: [well you seem [to be
21. P: [()
22. D: You seem to be doing well with your
23. diabetes↑ perfect control [according to the

24. P: [()

25. D: In in new money it's fifty millimoles

26. per mol which

27. should correspond to six point seven

28. P: [Oh that's not bad]

29. D: [as a percentage yes]so we've changed over

30. to these new unit[s and

31. P: [Yes yes I'm

32. aware of that yes (1.0) oh well

33. D: So anything below fifty nine would

34. be considered (.)

35. P: () Satisfied with that

36. D: Fifty's very good

37. P: Good

38. D: Couldn't be better (1.8) and

39. what kind o:f stresses and strains

40. are your wife's health problems putting

41. on you?

Having discussed the patient's HbA1c result the doctor returns to the topic of the patient's problems. The doctor displays affiliation with the patient in offering to write a letter of support to his GP and in commending the patient for his 'stoic approach' (extract below). Not only had Patient 14 achieved his HbA1c targets, he appeared to have done so in the face of difficulties. This engendered positive and partnership building communication from the doctor.

Extract 6.11 [Patient 14 (Insulin Pump) 22-10-12] (82-105)

82. D: and and I'm going to put that down

83. in my letter (0.9)that that (1.0)it's none

84. of my business but (0.6) it is my business

85. if it's going to affect you (0.5)

86. P: [()

87. D: [the fact that it hasn't (.) >the

88. fact that it hasn't affected

89. your blood sugar control is a different

90. matter<

91. P: >well I'm very surprised at that I really am<

92. D: But it's it's clearly having an

93. affect on you and and you are (0.9) showing
94. a brave face and having a stoic approach
95. to the thing but that doesn't mean that
96. you're not affected
97. P: Mmm
98. (0.7)
99. D: and I think we should (.) we should not
100. have a service which responds only to
101. those who complain
102. (0.8)
103. P: Fair enough
104. D: At at least that's the way I work
105. P: °Thank you°

6.5.3 Displaying Commitment to the Regimen

Giving an account of working with health care professionals

Some patients were able to display alignment with the doctor by giving an account of working with health care professionals. In between review appointments with the multi-disciplinary team, patients were offered appointments with the diabetes specialist nurse and diabetes specialist dietitian. Attending these sessions was an opportunity for patients and health care professionals to work together to resolve problems with the regimen. One way that patients could align with health care professionals in the consultation was to draw attention to the work that they had accomplished since their last appointment, particularly in relation to these other appointments with staff.

The following extract for Patient 2 (Pump) illustrates how, by reporting these sessions to the doctor, patients were able to display their commitment to the regimen and to elicit support from the team members. This is a further example of a high involvement patient being able to 'voice' concerns at the beginning of the consultation and to pre-empt the expected discussion about blood glucose levels. The patient presents herself as someone whose HbA1c result had gone down, but due to circumstances beyond her control (stresses in her life), has experienced recent high blood glucose levels. In fact the patient's HbA1c has gone down (although still above target at 73 mmol/mol (8.8%)).

Having been asked a question by the doctor at line 5, the patient draws the diabetes specialist nurse into the conversation, firstly at line 8 and again with a request at line 12 for the nurse to

corroborate her account. Both patient and nurse use 'we' in relation to the work that they accomplished together. The continuers ('mm' 'yeah') used by the nurse at lines 13 and 16 display alignment and serve to encourage the patient to continue her account (Schegloff 2000). The nurse's affiliation with the patient is displayed in the sequences of overlapping speech (lines 22 and 23) in which the patient's account is upgraded from 'everything was working kind of quite well with how we were going' to the nurse's assessment 'we were getting better weren't we'.

The affiliation displayed is bi-directional. Having started to give an account using 'I' ('I was on the way with a better regimen') at line 22 the patient changes from the first person pronoun to 'we were going'. This is echoed through the conversation by the nurse's use of 'we'. It would appear that both patient and nurse give an account of a collaborative relationship in which they have been working together in the accomplishment of a joint goal. This extract also illustrates the way that some patients elicit assistance and receive support from the specialist diabetes nurse or specialist diabetes dietitian in communicating with the doctor.

Extract 6.12 [Patient 2 (Insulin Pump) 28-03-12] (1-36)

1. N: Come and have a seat
2. D: Hello hello Good [morning (patients name)
3. P: [pleased to meet you
4. P: .hhhhh
5. D: How are you doing?
6. P: How am I doing? >that's a good question
7. uhm I'm I'm reasonable with my circumstances
8. I'm just saying to Linda²¹<
9. uhm this last month I've been had quite a lot of
10. stress ↑so my blood sugars are (0.4) hi↑gher
11. than normal .hhhh uhm (0.8)I rang Linda up I think
12. it was the end of February wasn't it?
13. N: mm [ye↑ah
14. P: [and gave an HbA1(0.6)result didn't I?
15. [and it had gone down=
16. N: [Yeah

²¹ Linda is the pseudonym given to the diabetes specialist nurse attending the consultation.

17. P: =Now I don't know how much it had
18. gone down from the one previously .hhhh(0.6)but
19. I was on the way with a better .hhhh regimen
20. .hhh and uhm and you know seemed to be tightening
21. up (1.0) everything was working kind of quite
22. well with how we were [going
23. N: [We were getting
24. better weren't we
25. P: with .hhh our classes and uhm (.)exercise
26. D: °Mhm°
27. P: erm I've been swimming so I've been taking the
28. monitor off
29. D: [°Right°
30. P: [for no more than an (0.4)hour
31. N: mm
32. P: and it hadn't made (0.7)drastic differences
33. [either =
34. N: [good
35. P: = way
36. N: Good

Bringing blood glucose records to consultations

One of the essential parts of the diabetes review was to examine the patient's blood glucose records. These records helped to identify trends or patterns over time. Keeping records of blood glucose levels is a proactive rather than reactive way to manage diabetes. Many of the patients in the sample brought blood glucose records to the consultation. Some were handwritten, some brought computer printouts from their blood glucose meters and one patient brought a SiDiary™²².

There were no comments about lack of records from doctor to patient. Patients who brought their records to the consultation, however, displayed both an interest in managing their diabetes condition and provided health care professionals with the means to help solve problems. It seemed that patients who displayed interest in their own diabetes management by taking advantage of capturing blood glucose data from monitors received reciprocal

²² SiDiary™ is software designed to manage data on diabetes management

interest from the doctor. Patients who brought computer printouts tended to hand them over to the doctor as they arrived in the consultation. It appeared that actively engaging the doctor's interest in this way was not dependent on the patient achieving the target HbA1c result.

Patient 22 (Pump) arrived at his consultation and handed over the computer printout of his blood glucose levels. Initially the doctor and the patient discuss the patient's progress with addressing his issues with hypoglycaemia raised at the last consultation. The printout is used immediately by the doctor in discussion with the patient. In the following extract for Patient 22, the computer printout became a topic of mutual interest to both the patient and the doctor. The conversation changed from the usual question and answer format, observed in the early part of most consultations, to a more collaborative discussion seen in the overlapping turns at 51-52, 54-55, 61-62, 71-72, 72-73 and 74-75. For example, in answer to the doctor's question at lines 46-49 in relation to producing another graph, instead of a minimal 'yes' response the patient expands his reply, thus displaying both his knowledge and willingness to cooperate with the doctor. Further displays of knowledge are apparent at line 72 as the patient correctly identifies the graph that the doctor requires ('oh it's like scat- scatter') and at line 74 ('yeah I have seen that yeah'). The degree to which the patient displayed his knowledge to the doctor and the proactive way that the patient started the consultation was relatively uncommon in this sample and demonstrated the high literacy levels of this patient from a professional social class. The conversation sequence concluded with the doctor asking the patient to e-mail the records to him personally. Being able to display an interest in managing diabetes proactively within the consultation seemed to be an advantage to patients in terms of collaborating more closely with the doctor in the future.

Extract 6.13 [Patient 22 (Insulin Pump) 26-11-12] (46-79)

46. D: Would it be possible for you t::o (0.5) to also
47. do the uhm(0.6)the weekly or monthly
48. summary in terms of times? because I think
49. there's a big graph that comes up
50. (0.7)
51. P: there's (0.5) many many diff[erent variants on how
52. D: [yes yes yes
53. P: that can be presented so if you
54. [told me
55. D: [So so so what we're interested in

56. essentially this daily summary
57. (0.3)
58. P: Yeah
59. D: with the times of the day(0.6)but(0.7)
60. with the (0.8) dots or the nu:mbers (0.4)
61. grouped in each time [with the average
62. P: [the one with the
63. average right
64. D: It's it's a graph which looks something
65. like this it it get's you the graph
66. (0.3)
67. P: yeah
68. D: and you've got the (.) the days and you've
69. got the lines (0.7) and it tells you
70. (2.7)
71. D: [where ((doctor drawing an example))
72. P: [oh it's like scat- scatt[er
73. D: [yeah it's a scatter
74. P: yeah I have [seen that yeah
75. D: [so it's a scatter one
76. so the scatter one helps us to see tre:nds (0.5)
77. because this all this does is is the
78. visual (0.3) depiction of just a straight
79. forward table

Whereas Patient 22 had an HbA1c within target (58 mmol/mol (7.5%)), Patient 18 (Pump) had an above target HbA1c of 83 mmol/mol (9.7%). Despite having an HbA1c of 9.7%, little was said about the result. The doctor and other team members displayed considerable interest in the patient's SiDiary™ (diabetes management software) and on several occasions it became a topic of conversation. It appeared that displaying a readiness to explore ways to improve diabetes management, using technology available to the patient, outweighed the lack of alignment with blood glucose levels. Instead, the patient received reciprocal interest from the doctor.

The doctor's request for the patient's blood glucose levels to be e-mailed is formulated as a suggestion and receives an immediate reply 'yes absolutely' (line 328) and a comment

indicative of affiliation²³ 'yeah that would keep me on track' (line 334). It seemed that proactive patients who brought computer printouts or other more sophisticated forms of analysis of blood glucose levels were able to initiate a style of communication that was more personal and collaborative.

Extract 6.14 [Patient 18 (Insulin Pump) 12-11-12] (318-338)

318. D: So we probably need to review
319. those (1.2) more frequently than quarterly
320. (0.6) which is the conventional way most
321. diabetes clinics are run (1.2) so if there's
322. any way that we can >review the blood
323. glucose without you having to come up here<
324. P: [Yeah
325. D: [That would also be helpful [so one way is if you =
326. P: [()
327. D: = can e-mail it [to us
328. P: [yes absolutely of course
329. D: If I give you an e-mail address do
330. you think you could you [could
331. P: [Yeah
332. D: e-mail the results hhhh say in about
333. (1.0) fortnight to three weeks?
334. P: Yeah that would keep me on track (.)
335. I think I can e-mail it out of this SiDiary
336. (3.2)
337. D: You should be able to
338. P: I think I can (.) cos that's actually dead good

6.5.4 Influencing the Doctor's Agenda

Some patients were able to influence the doctor's agenda. There were two ways in which this was accomplished. First, patients were able to give an extended reply to the doctor's question. Second, some patients were able to influence the trajectory of the consultation by asking the doctor questions.

²³ Affiliative responses are stronger than alignment

Changing the topic of conversation

In the following extract Patient 15 (MDI) avoids the doctor's agenda with regard to blood glucose levels. The patient had not obtained an HbA1c result prior to the consultation however, the last recorded result was very high (83 mmol/mol (9.7%)). Providing an extended reply to a doctors question enabled Patient 15 to depart momentarily from the consultation agenda (Stivers et al. 2001). Extended replies serve three possible purposes (Stivers et al. 2001). First, they are employed in cases where providing a definite answer is difficult. Second, they are used in support of answers by providing additional details. Third, they are deployed defensively to avert negative inferences that might arise without the elaborated answers. In this consultation the patient appears to be averting a negative judgment from the doctor by changing the agenda topic to her primary concerns, namely her decision to revert to multiple daily injections from insulin pump therapy.

Patient 15 (extract below) displays difficulty in answering the doctor's first question 'how are you doing' as indicated by a two second delay and an elongated 'm::m' and 'o↑ka::y'. This response foreshadows the difficulty in responding to the doctors next question about 'BMs'²⁴ at line 10 as evidenced by 'erm' and 'well' indicators of problems in response (Pomerantz 1984). Rather than answer the question about 'BMs' Patient 15 digresses, reporting that she had reverted to multiple daily injections, having come off her insulin pump, following a discussion with a friend who also has type 1 diabetes.

Extract 6.15 [Patient 15 (ex Insulin Pump user now on MDI) 22-10-12] (7-28)

7. D: How are you doing
8. 2.0)
9. P: M::m o↑ka::y
10. D: Right and from your BM's point of view
11. (1.10)
12. P: BM's:: ↑erm ↓well tch (0.7)>I hav- I
13. reverted back to my injections< (0.8)I spo-
14. when I saw (nurse) last time
15. >I was just going back onto my pump wasn't I?<
16. A: Just been on holiday hadn't you? [yeah
17. P: [Yeah erm

²⁴ BM is another term for blood glucose levels

18. and (0.5) I think it's because I've met
19. up with my .hhhh(0.6)erm friend who I look up
20. to >who's been diabetic for probably ten
21. years or more than me< .hhhh (.) erm she's
22. now (.) expecting her baby tomorrow
23. actually she's being induced tomorrow .hhhh
24. but erm I've met up with her a few
25. times recently .hhhh and erm she manages
26. very well on the pens and (.)I thought I was
27. going to give it (0.7) another go
28. D: Okay

By digressing, the patient changes the topic of conversation away from a discussion relating to blood glucose levels. Following the patient's turn the doctor does not return to this topic of blood glucose levels, rather the conversation continues with the patient's agenda relating to the patient's decision to come off the insulin pump.

Another way that patients influenced the doctor's agenda was by asking questions. This was most clearly seen in the consultations involving Patient 15 (MDI) and Patient 21 (MDI) (both in the high involvement category). Patient 15's remarks (extract below), although not in the interrogative form, are treated as a question by the doctor and he responds accordingly. The consultation had been running for 15 minutes and the doctor's response to this question ran for a further 5 minutes. Following this, two further questions were asked by the patient extending the consultation by another 10 minutes. The consultation lasted 30 minutes in total. It was apparent in both these consultations that patients were able to influence both the topic of conversation and the length of the consultation. Actively involved patients appeared to be able to extend their allotted time with the doctor and were able to address some of their concerns.

Extract 6.16 [Patient 15 (ex Insulin Pump user now on MDI) 22-10-12] (245-253)

245. P: Yeah (1.6) and >obviously< well people keep
246. saying to me .hhhh(0.4)so ↑why have you got
247. a kidney infection then? and .hhhh
248. other than saying (0.2) well diabetes
249. control (.) sugar levels .hhhh(0.3)and probably
250. not drinking(0.6)as much water as I should do.
251. (0.8)

252. D: I think the question has been answered
253. because they did an ultrasound scan

Patient 21 (MDI) also asked several questions in her consultation. The question at line 460 (extract below) was asked at 21 minutes into the consultation just as the doctor is concluding business. The consultation ran for 43 minutes. Regular review appointment slots were 15 minutes in length so this represents a considerable extension to the usual consultation length.

Extract 6.17 [Patient 21 (ex Insulin Pump user now on MDI) 26-11-12] (458-477)

458. D: (we'll see you) on the fourteenth of January
459. (2.6)
460. P: Will I be able to see someone about my feet
461. again?
462. (1.7)
463. N: [() Foot clinic as well
464. P: [I think I've got =
465. = I think I've got problems with
466. my big toes again [cos
467. D: [right =
468. P: = had problems with the nails before
469. D: Let's (best get you) on the couch
470. ((patient moves to couch))
471. (2.8)
472. it would be absolutely daft for me to send you to
473. the foot clinic
474. (0.4)
475. P: ((patient laughs))
476. D: and see you there again myself so
477. (we should this out now) ((short laugh))

6.5.5 Involvement in Decision-making: the Impact of both the Patient and the Doctor

In the previous sections attention was given to the important influence that patient alignment with biomedical goals had on doctor-patient communication. In addition the ability of some patients to maintain alignment with the doctor even when unable to meet biomedical targets was influenced by the extent to which patients engaged in the consultation in order to deflect or mitigate negative connotations surrounding their HbA1c results. Hence high patient

involvement appeared to be an important aspect of maintaining the doctor's support and in turn facilitated continued access to an insulin pump. The following section explores in more detail aspects of patient involvement that may influence the maintenance of access to IIR and hence may have an impact on equity.

Two patients' consultations have been chosen for the following reasons. First they are the only patients in the sample where maintaining access to an IIR was imminently at risk. Both consultations contain decision-making sequences in relation to maintaining access to an IIR. Second, key decision-making sequences in both consultations illustrate differing levels of patient involvement and differing styles of communication from doctor to patient. In both consultations, the importance of both the patient and doctor in influencing the interaction is explored. Another key factor in relation to these two patients is their relative positioning in different quadrants in the 'patient alignment/involvement' diagram (Table 6.5). Patient 21 is shown as 'aligned/high involvement'. In contrast Patient 20 is in the 'non-aligned/low involvement' category. The following analysis shows how differing outcomes for these patients, both from lower social classes, are impacted by alignment and involvement.

Patient 21, at the time of the study was on MDI therapy having decided not to continue on an insulin pump some months previously. Patient 20, at the time of the study was also on MDI therapy, having decided to disconnect his insulin pump some days before the consultation. Neither patient had arranged for a recent HbA1c result before the consultation. Patient 20 and Patient 21 had the two highest HbA1c results in the sample at 14% (130 mmol/mol) and 15.2%(143 mmol/mol) respectively. Hence both patients were currently non-aligned with target levels for their HbA1c and were well above a level that would give cause for concern in relation to diabetes complications. However, although high, Patient 20 had made progress towards reducing her HbA1c levels.

In the first example (Patient 21) sequences of interaction are presented showing the patient and the doctor negotiating a decision to change the patient's regimen. Alignment and patient involvement were found to be crucial to the patient's maintenance of access to the MDI regimen. This consultation was one of few in which the doctor adopted an empathetic stance towards the patient (the doctor's neutral stance was discussed previously). This appeared to be influenced in part by the patient's display of emotion. It also appeared that the doctor's empathetic and affiliative stance was a key influence on the patient's willingness to adopt his suggestions. In the second example (Patient 20), issues of patient and doctor non-alignment

coupled with low involvement by the patient within the interaction appeared to have had an important influence on the patient's loss of access to an insulin pump.

Case 1 – The 'actively' involved patient

In the extracts that follow a number of influences on doctor-patient communication and decision-making are discussed. First, a change of approach from regimen-focused to an exploration of the patient's underlying difficulties in following the regimen appeared to lead to greater patient involvement. Second, the latter approach appeared to influence the patient and the doctor eventually reaching an agreement on treatment.

The consultation begins with a review of the patient's last recorded HbA1c. It will be recalled that the doctor had commended the patient for making a small improvement in relation to her last recorded HbA1c result (Extract 6.2) hence the consultation commenced in a positive way with rapport building action undertaken by the doctor. Decision-making was divided into three main sequences shown in Box 6.1. These key decision-making sequences were completed in 13 minutes although the consultation ran for 43 minutes in total (the longest in the sample). We join the interaction following an information gathering sequence in relation to the patient's current insulin regimen.

Box 6.1 Summary of regimen change proposals and decisions for Patient 21

Proposal 1 – A change from multiple daily injections and one long acting insulin to multiple daily injections with two long acting insulin injections.

Outcome – Pre-emptively rejected by patient who is concerned that she will forget to take the additional injection.

Proposal 2 – A change from multiple daily injections and one long acting insulin injection to twice daily insulin injections (comprising a short and long acting component).

Outcome – Accepted by patient but subsequently rejected by the doctor.

Proposal 3 – Reversal of the decision to adopt twice daily injections in favour of regimen status quo with the proviso that patient eats breakfast.

Outcome – Accepted by patient if work place can be more accommodating.

Proposal 1: Resisting the doctor's agenda

The following extract introduces the doctor's approach to decision-making which at this stage in the consultation focuses on the technical features and problems with the patient's regimen as opposed to soliciting the patient's views as the process unfolds. Patient involvement in decision-making was discussed in Chapter 3 and the benefits for patients were noted. The Calgary-Cambridge guide places great emphasis on the skills required to involve patients and to ensure that shared decision-making is accomplished. The extract below shows the patient's influence in asserting her own agenda even when her input is not sought by the doctor.

The patient's statement that her blood glucose levels are high at tea time, despite all her efforts, announces a problem that needs to be addressed (lines 78-79) and is responded to with the doctor directing a question to the diabetes specialist nurse ('can we give her a twice daily?')²⁵. The phrase 'can we give her' (line 81) is an approach to decision-making that excludes rather than includes the patient since it involves the nurse in the doctor's initial thoughts about a possible solution rather than the patient. Although not the recipient of the doctor's turn, the patient treats the doctor's question as a suggested option. She quickly involves herself in the interaction by voicing her opinion on the proposal (line 84 onwards) and pre-emptively resists the doctor's suggestion. In doing so the patient reveals her preference for one long acting insulin injection rather than two injections because she struggles 'to remember it'.

Extract 6.18 [Patient 21 (ex Insulin Pump user now on MDI) 26-11-12] (78-87)

78. P: ↑It's still really high at tea time
79. though. (1.0) no matter what I do.
80. (0.8)
81. D: Can we give her a twice daily (0.8) long
82. acting insulin. (.) Is that an option?
83. (0.6)
84. P: () I (0.5) I struggle to remember it in
85. the morning that's my only issue (0.6)
86. I can't (0.5) that's why I like doing
87. it all at once at night

²⁵ Twice daily insulin injections comprising both short and long acting insulin

Proposal 2: Regimen focused decision-making

The patient's resistance is met with information from the doctor to the patient and some 'educating' in relation to the merits of 24 hour insulin ('it can be twenty four hours in some people but it's clearly not twenty four hours in you') (extract not shown). This is the context for the extract below relating to the second regimen change proposal (see Box 6.1) and follows on from the patient's revelation that she does not eat breakfast. In the latter discussion there was evidence of a display of empathy with the patient's circumstances ('you've been dealt a bad hand isn't it with type 1 diabetes you can't do a lot of the things you want to do...') (extract not shown). Nevertheless, at this stage the dialogue is dominated by commentary from the doctor and minimal input from the patient with the doctor explaining the consequences of the patient's current regimen. In terms of decision-making the doctor's approach is 'unilateral'²⁶ (see Collins et al. 2005), evidenced in the following extract.

Extract 6.19 [Patient 21 (ex Insulin Pump user now on MDI) 26-11-12] (141-156)

141. D: s:o (.) if (0.5) we put priorities on (0.8) rules
142. we make for ourselves now (2.2) and say
143. it doesn't matter what it happens
144. °in the fut↑ure° (1.1) then that's fine
145. >we're we're all adults we're responsible
146. people and we face consequences< .hhh but
147. I don't (.) think (.) that that's really (0.4)
148. going to suit (0.3) suit you in the long term
149. P: [°°Mhmm°°
150. D: [Right so we will have to make some
151. adjustments (0.7) unfortunately it means
152. that (0.5) if you are (.) having to take
153. insulin insulin has to be there (0.3) when
154. your body needs it (1.0) not when it's
155. convenient to give it
156. P: °°Mhmm°°

²⁶ Unilateral decision-making comprises a predominantly autonomous approach by the doctor whereas a bilateral approach involves the patient in the decision-making.

Doctors' use of the pronoun 'we' has been investigated in relation to decision-making (Skelton et al. 2002). Three main uses of 'we' have been identified: the first has the effect of including patients ('you and I') and hence facilitates shared decision-making; the second has the effect of excluding patients ('we doctors'); and finally the word can be used to mean 'everyone' (Skelton et al. 2002). At first glance 'we' (line 150) appears to have an inclusive quality that suggests a shared approach. The coupling of 'we' with 'will have to', however, indicates an imperative quality that directs the patient, having the effect of both delimiting choice and signalling that there is an obligation to 'make adjustments'. Hence there appears to be an element of pressure being applied to the patient in this interaction. This is the context for the extract below (lines 163-212) illustrating the doctor's style of communication and the way that he designs his turns in order to secure the patient's agreement with his suggestions.

The doctor, although clearly influenced by the patient's revelations in relation to regimen difficulties and dietary habits, has not up to this point elicited the patient's views in the decision-making process. The following sequence shows the doctor building a case to substantiate his suggestion that the patient should revert to twice daily injections. The issue of breakfast, although part of the problem presented, is not tackled. Instead the proposed solution is framed in terms of the insulin regimen.

The turn by turn analysis shows the ways that the decision outcome is influenced by the doctor. This is accomplished through the design of his turns to prefer a 'yes' response from the patient. The doctor's first attempt at establishing a case falters as the patient offers a dispreferred response at line 166 'well no' and corrects his understanding of her last meal of the day. The doctor's reply ('that's again' at line 173) signifies to the patient that the positioning of the last meal is somewhat irrelevant in the case of the number of hours 'food free'. The design of the turn both states the number of hours estimated to be food free and invites the patient to agree with this (isn't it?) at line 176. Having established that there is a problem with having an extended gap between supper and the patient's next meal (lines 181-187), the patient's response is a neutral 'right' (line 188). At the doctor's next turn however, a link is made between lack of breakfast and blood sugar levels that 'are all over the place' (lines 190-196) and again the patient is invited to agree with the doctor's assessment (line 196). At this point the patient aligns with the doctor's assessment with a quietly spoken 'yeah' at lines 194 and 197. Finally the doctor presents the solution which is to ensure steady insulin throughout the day. Although presented as a 'suggestion' and something that the patient might want to 'consider' (line 205), twice daily injections (a retrograde step) is the only option on the table and hence there is a directive quality to the decision-making ('so what I would

suggest is we start going (.) we go back to the pen and maybe consider twice daily insulin until this improves') (lines 202-206).

The patient's agreement with the doctor is evidenced by her remark that the doctor's suggested regimen may have other benefits: 'it might stop the hypos in the night as well' (line 210). The context of this decision should be noted however, since the patient's ready acceptance may be because a twice daily insulin regimen is not as complicated as an IIR and the patient has already stated a preference for fewer injections and reluctance to eat breakfast. At this stage in the consultation the patient has 'lost' access to an IIR.

Extract 6.20 [Patient 21 (ex Insulin Pump user now on MDI) 26-11-12] (163-212)

163. D: And the way I see it is (0.5) that you're
164. having a gap between your evening meal
165. (0.5)>and about midday isn't it?<
166. P: (.) Well no cos I have (supper) before I go to bed
167. (0.5)
168. D: Okay
169. (0.6)
170. P: >I eat supper but I don't eat breakfast<
171. D: Right (.) well that means that(0.4)if
172. your supper's around what ten o'clock?
173. (1.0) that's again nearly
174. what twelve hours [of
175. P: [Mmm
176. D: (0.8)fourteen hours of (1.4) >food free isn't it<
177. (1.0) and that's the time when most
178. people's bodies need food in the morning
179. P: Mhmm
180. (0.9)
181. D: So it's possible (0.4)for you to go without
182. say ten hours (.) or twelve hours overnight (0.9)
183. but then your body's geared for that but
184. it's not geared to having to do a normal
185. day's work (.) and be then be without it .hhh >and
186. have the added burden of having to
187. have insulin<
188. P: °Right°

189. (0.8)

190. D: So (.) this (.)really (.) tells us that

191. your blood sugar's are all over the place (1.0)

192. >and and< obviously if you look at your

193. blood sugars (.) [when you check

194. P: [[°yeah°

195. D: them you will find they're all over the

196. place [isn't it

197. P: [°yeah°

198. (0.9)

199. D: >So the first thing we need to do is to

200. make sure that you get some steady insulin

201. throughout the day< (0.5) and Lantus doesn't

202. seem to be doing the job (1.7) so what

203. I would suggest is we

204. start going (.) we go back to the pen (0.7) and

205. maybe consider twice daily insulin until

206. this improves

207. P: °Yeah°

208. (1.2)

209. D: Okay but otherwise y- y'know (0.7)

210. P: >It might stop the hypos in the night as well<

211. D: °Yeah that's what I'm hoping it'll do°

212. P: Okay

The decision-making sequences up to this stage epitomise the contrary objectives of some patients and their doctors. It typifies the struggle between the 'medical world' and the 'life world' (Mishler 1984). It can be seen that the doctor's focus up to this stage in the consultation has been to attend to the patient's regimen. He is 'mandated' to explore every way to prevent the patient doing harm (Boyd and Heritage 2006). He displays his commitment to this task ('my job's to keep you fit and well') (extract not shown). His approach up to this stage, however, has been 'task oriented' with a focus on the regimen (insulin and diet). There has not been an elicitation of the patient's views (although there has been a display of empathy with the patient). That noted, the patient has agreed to the change in regimen. It is clear from the next phase in the decision-making process that the decision for the patient to revert back to twice daily injections is not acceptable to the doctor despite having secured the patient's agreement (extract above).

Proposal 3: Adopting a patient-centred approach leads to agreement

The extract below shows the impact of a change in communication approach from the doctor to the patient part way through the sequence. This change involved less of a focus on the regimen and more of a patient-centred approach, exploring the patient's difficulties. This appeared to lead to an optimal decision outcome for both the patient and the doctor. That is, the doctor's concerns about the patient 'going backwards' and the patient's difficulties in adhering to the regimens were addressed. This was accomplished, however, within a framework of eliciting the patient's problems and her worries (the psychosocial factors).

The extract below begins with the doctor attempting to get to the bottom of what is preventing the patient from being able to follow his advice regarding meals and insulin. From line 230 to 249 the conversation appears to have stalled in terms of reaching a decision about the patient's regimen. From line 230 to 240 the doctor's communication is dominated by giving the patient information. In addition the doctor appears to pre-judge the patient's attitude towards her regimen at lines 236-240 'but where you are now takes a lot of effort and a lot of compromise which you are- don't seem to be (0.4) ready for yet'.

At line 242 the doctor changes tack and asks the patient 'is there any particular reason for that I mean'. This is a key change within the doctor's dialogue at approximately 10 minutes into the consultation and it is the first occasion that the doctor has attempted to elicit the patient's perspective on her difficulties. It may be that the doctor has detected that patient is becoming upset (less obvious from the audio recording).

From line 253 'so we need to work round that don't we' the doctor's talk becomes much less regimen oriented and more patient-centred as the causes of the patient's inability to adhere to advice are revealed. The patient's response 'I don't really feel I have time' is accompanied with a display of emotion (lines 251-252). As the conversation unfolds the doctor offers to help the patient (lines 262-263 and 267-268). The doctor's display of empathy and willingness to help the patient appeared to be a turning point in the patient's stance towards the doctor's advice.

At line 284 the doctor suggests a collaborative and supportive arrangement to resolve the patient's problem 'right so I think first of all we need to work together on that don't we'. In this instance the use of 'we' appears to be indicative of including both patient and doctor in the process since 'we' is coupled with 'together'. This contrasts with the use 'we' at line 150 (Extract 6.19 above). Although there is greater emphasis on including the patient's perspective

in the decision-making the doctor's turn of talk continues to be phrased to prefer a 'yes' response.

Nevertheless at this stage in the consultation there is greater emphasis on including the patient's perspective in the decision-making. For example, although phrased to prefer a 'yes' response, 'd'you think it would help' elicits the patient's perspective on his proposal (line 267) and receives a promptly aligning 'yeah' (line 269) from the patient. It is evident that during this extract there has been a significant shift from the regimen focus at the outset to a move to attend to the patient's difficulties and finally to offers of help with their resolution.

Extract 6.21 [Patient 21 (ex Insulin Pump user now on MDI) 26-11-12] (230-285)

230. D: we are actually taking a step back
231. P: Right
232. (1.0)
233. D: And we are genuinely going
234. backwards because we usually move
235. from that (0.3) to ↑where you are now
236. (0.5)but where you are now takes
237. a lo::t of effort
238. P: Mhm
239. D: And a lot of compromise which you
240. ar- don't seem to be (0.4) ready for yet
241. P: [()
242. D: [Is there is there any particular reason
243. for that I mean
244. P: No I just don't eat in the morning
245. (3.5)
246. D: How much of that is engraved in stone
247. Is that is that something that's
248. a never never never
249. I won't do it at [any cost?
250. P: [it's not that it's just(0.7)
251. I don't I don't really feel I have time
252. or () ((gets upset))
253. D: So we need to work round that don't
254. we? (2.2) () (1.2)is there no possibility
255. for you to come to work and and grab a few

256. minutes for breakfast?

257. P: No cos that would mean I'd just

258. come earlier so

259. D: Yeah (3.0) phase working? is there

260. is there anything which would allow you to (1.0) I

261. mean if- you work in a hospital so so

262. is it possible for us to

263. talk to somebody and and [and

264. P: [I've got to go cos

265. I've been in hospital so much I've got

266. to go to occupational health

267. D: D'you think it would help if we if could (0.9)

268. if Linda²⁷ and I could come along with you?

269. P: Yeah

270. D: Yeah so why don't we do that? because

271. we can then (.)if you've been unwell there

272. are ways in which you can (.) have a phased

273. return to work isn't it? (1.0) is that

274. what you're going [through? or

275. P: [I haven't come back [yet

276. D: [okay

277. P: from being off from when I was

278. in hospital ((upset))

279. D: Right

280. P: I go back to work tomorrow

281. D: Okay are you worried you're going

282. to lose your job?

283. P: Yeah ((upset))

284. D: Right so I think first of all we need

285. to work together on that don't we?

In the following extract the decision to go back to two injections a day was reversed and the patient's commitment, in principle, to having some breakfast appeared to be secured (lines 313-315). At line 301 further evidence of a more inclusive approach to decision-making is observed with the doctor's use of 'shall we start afresh then?' At line 303 the doctor's use of 'I

²⁷ A pseudonym for the name of the nurse present at the consultation

think' suggests a reflective stance on the previous decision and signals the possibility of a change of opinion. The regimen currently adopted by the patient is presented as the best option. Although the decision-making approach now appears to be one of negotiating with the patient (that is, the patient may be encouraged to eat breakfast if work issues can be resolved), the way that the doctor's turn is designed to prefer a 'yes' response from the patient shows how the doctor continues to direct the decision-making (lines 301-302 and 313-315). At line 315 the patient gives the preferred response showing alignment with the doctor's suggestion. However, it would appear that at this stage in the decision-making process the patient has been offered a proposal which meets her requirements.

Extract 6.22 [Patient 21 (ex Insulin Pump user now on MDI) 26-11-12] (301-315)

301. D: Yeah (0.9) so ca- shall we start afresh then?
302. P: Yeah
303. D: Okay so I think rather than go back to
304. two two injections a day (1.0) because
305. what you're on is (.) the best possible thing
306. thing to do
307. P: Mmhm
308. D: Mm
309. P: Yeah
310. D: Er so let's let's play it that way
311. (0.7) we'll meet people at occupational
312. health (0.8) so so assuming that we can work
313. something out for you (.) will you be then
314. prepared to have some breakfast?
315. P: °Yeah°

Affiliation can lead to the maintenance of access

It appeared that the doctor's affiliative stance was an influence on the patient's ability to maintain access to an IIR. The alternative option, initially proposed, was a step backwards in regimen terms; instead the patient was able to remain on the multiple daily injection regimen. It appeared that the turning point in the communication between the patient and the doctor occurred at the stage where the patient revealed her problems with a display of emotion and in response received an affiliative stance from the doctor. For some patients at least, particularly those experiencing problems with adhering to the diabetes regimen, an approach

that was less task-oriented and more patient-centred appeared to be helpful. Communication between the patient and the doctor appeared to change when the patient's psychosocial concerns were addressed. Viewed from the doctor's perspective, however, addressing the patient's concerns was feasible once the patient had been able to verbalise her problems.

The doctor's affiliative stance appeared to have been influenced by a combination of needing to progress the consultation and the patient revealing her difficulties with a display of emotion. As noted previously the patient's improvements in HbA1c result had also received positive comments at the outset of the consultation. It is important to note that addressing these sorts of problems with patients may be very time consuming. This consultation was the longest in the dataset lasting 43 minutes. Whilst some patients were able to reveal their difficulties to the doctor other patient's appeared not to do so and this seemed to influence their communication with the doctor.

Case 2 – Losing access: issues of non-alignment and low patient involvement

In contrast to Patient 21 (MDI), Patient 20 (MDI) was categorised as one of four low involvement patients. The focus of analysis was on both doctor and patient communication. One of the important findings was that in comparison to 'non-aligned/high involvement' patients, 'non-aligned/low involvement' patients appeared to be at greater risk of losing access. This was due in part to these patients experiencing some difficulties communicating with the doctor and as such being less able to present as credible candidates for continuing access. Help was given, however, by the diabetes specialist nurse and the diabetes specialist dietitian and this was able to somewhat lessen the difficulties in communication between the doctor and the patient that sometimes arose. Hence there appeared to be an important role played by these members of the multi-disciplinary team in helping 'passive' patients to maintain access.

Patient 20 was non-aligned with medical goals and there were observable non-alignments between the doctor and the patient during the course of the consultation. The key finding was that non-alignment and low involvement seemed to affect this patient's ability to maintain access to an insulin pump. This example is unique within the recorded data since no other patient lost access to an insulin pump as a consequence of a doctor's decision. Patient 20 had not attended consultant appointments for some time, relying instead on the diabetes specialist nurse and diabetes specialist dietitian for his diabetes support. He was therefore not aligned with the requirement to attend for regular appointments at the insulin pump clinic. Several days prior to the consultation Patient 20 had detached himself from the insulin

pump²⁸. He had reverted to an injection regimen. In the ensuing consultation the patient and the health care professionals discussed the decision not to replace his insulin pump²⁹ but rather for him to continue on multiple daily injection therapy.

Although announcing his change of mind at the beginning of the consultation and expressing a wish to continue on the insulin pump, the patient acquiesces entirely in the face of the doctor's decision not to renew the insulin pump. Despite the importance of the decision, the consultation is one of the shortest in the recorded consultations at 11 minutes in length. Non-alignments in communication may be observed from the outset of the consultation. At line 12 it can be seen that the patient overlaps the doctor's name with 'alright mate'.

Extract 6.23 [Patient 20 (ex Insulin Pump user now on MDI) 19-11-12] (11-14)

11. D: Hello I'm Professor [(name given)].
12. P: [Alright mate
13. D: Hello you've met my colleague (doctors name)
14. when you were here before I think.

This was unusual in two respects. First, the normative response would usually be some form of 'hello' in return from the patient. Second, it was an unusually familiar term for a patient to use and was the only example of this in the recordings. This level of familiarity had not been invited by the doctor since he had referred to himself as a professor. The doctor carries out a 'repair' by repeating the 'hello' and launches the introductions once again.

Unusually in the recorded consultations the nurse leads the conversation at line 16. In all of the other consultations in the sample, the opening sequence is conducted by the doctor. At lines 18 to 20 the diabetes specialist nurse invites the patient to agree with her assessment that he is doing better on the injections. Although there would seem to be some alignment with the nurse's comment – there is a token 'yeah' (line 21) – the patient does not engage with the nurse's conversation. Rather than giving a reply to the question, the patient starts an account of his blood glucose levels. This non-alignment is met with an elongated and quietly spoken 'O::kay'. The nurse's response appears to anticipate difficulty at the next turn with

²⁸ An insulin pump may be detached for one hour each day. Since the insulin pump delivers short acting insulin only, detaching the pump for any longer than one hour may be life threatening.

²⁹ Patient 20's insulin pump was due for renewal

the patient's announcement 'I want to go back on the pump though' at line 27. This remark is treated as 'trouble' by the nurse. This is indicated by a short pause before her response, which is an elongated 'a:hh' followed by a 0.5 second pause and 'right'.

Extract 6.24 [Patient 20 (ex Insulin Pump user now on MDI) 19-11-12] (16-29)

16. N: We were just saying that we thought you were
17. off your pump at the moment last time we met =
18. N: =[>you were off it and you were doing better
19. P: [Mmm
20. N: on the injections<.
21. P: Yeah
22. N: [Is that
23. P: [I've had a I've had a few(0.8)highs a::nd the
24. lowest I've had this week is about seven
25. point five I think
26. N: °O::kay°
27. P: I want to go back on pump though.
28. (0.5)
29. N: °A:hh° (0.5)right

It is noteworthy that at this stage the nurse drops out of the discussion and after a short pause at line 30 (see extract below) the doctor interjects immediately with the remark to the patient 'that's where we might have a few few few issues'. There is no pause following this remark, the turn is 'latched' with 'because', effectively curtailing the patient's response. There is a brief overlap where the patient is heard to utter 'a::h' with no further comment and he immediately drops out of his turn, allowing the doctor to continue. There are significant pauses in lines 35-37 as the doctor's words are chosen with care. The doctor's reasoning is not judgmental; the patient is not 'blamed' for the withdrawal of the insulin pump, rather the reasons are couched in terms that the insulin pump is unsuitable for him.

The style of communication from the doctor to the patient in this sequence is 'unilateral' (Collins et al. 2005). The doctor communicates in a series of statements. The patient has very little input in terms of decision-making and does not present a case for continuing with the insulin pump. It was observed throughout the recorded data that this style of communication was more apparent in non-aligning patients.

Extract 6.25 [Patient 20 (ex Insulin Pump user now on MDI) 19-11-12] (30-61)

30. (0.4)
31. D: Tch (0.7) that's where we might have a few few
32. few issues =
33. D: =[Because (1.5) generally (0.5) people (0.1) on
34. P: [A::h)
35. D: the pump (1.9) we have guidance on on on on
36. the fact that pumps work for some people (0.4) and
37. they don't work for some p[people
38. P: [Yeah
39. (0.5) [(I know)
40. D: [and just looking at the levels
41. that you've been having (0.8) it did
42. appear that you're one of the people
43. for whom the pump doesn't work
44. [because you =
45. P: [(ah right)
46. D: = <You've had more trouble> with
47. [it than good with it
48. P: [.hhh huh huh huh huh
49. D: So so I don't think the fault is (0.2)
50. lies with you (0.6) it lies more with the fact
51. that maybe you're just not one of the people
52. [who
53. P: [(fair enough =)
54. = [()
55. D: [pump's are designed for .hhh so what we need
56. to do is probably to see you a bit more often
57. (0.7) with your injections and and fine tune
58. those (0.6) e::r (0.1) than (0.7) >put you on
59. a pump because if you're<(0.4) the pumps
60. are usually good for people who get lots of
61. hypos

The doctor invokes 'guidance' (line 35) as the principle by which the decision has been reached. In doing so he adopts a neutral position, effectively distancing himself from the decision. The decision is presented to the patient as a *fait accompli* and hence not open to

further discussion or debate. The message heard by the patient is that insulin pumps work for some people but are no longer suitable for him.

The doctor alludes to some of the difficulties that the patient has had with the insulin pump (lines 46-47) 'you've had more trouble with it than good with it'³⁰. At this point there is patient laughter overlapping the doctor's remarks (line 48). It has been suggested that laughter is sometimes used by patients in ways other than to display amusement and joking in medical encounters (Haakana 2001). It may be used as a resource to deal with delicate aspects of the consultation since 'by laughing the patient displays that [she/he] is aware of the problem and thereby re-projects a picture of the reasonable patient who knows what is problematic within an occasion' (Haakana 2001 p 214). The delicate situation here is that although the patient displays a desire to go back on the insulin pump he is told that this is no longer an option for him. By responding with 'fair enough' at line 53, the patient displays that he is a 'reasonable' patient. He adopts an aligning stance with regard to the doctor's decision and makes no further request for an insulin pump.

It is noticeable that the doctor carries on with his explanation running from lines 49 onwards without gauging a reaction or soliciting the patient's opinion on the matter. The key decision-making can be measured in a couple of minutes and involves minimal input from the patient. At the conclusion of the doctor's talk with the patient, the nurse rather than the doctor attempts to solicit some reasons for his change of mind about the insulin pump ('what made you say oh (.) I want to go back on it', lines 94-95). This is the first time the patient's viewpoint has been sought throughout the decision-making process.

Patient 20 was unable to present himself as a candidate for insulin pump renewal. The following was apparent: that he had been unable to achieve HbA1c targets; that he had experienced repeated hospital admissions for ketoacidosis; that he had not had a recent HbA1c result; and that he had removed his insulin pump a few days before the consultation. These issues emerged during the consultation. Although the nurse solicits the patient's reasons for his change in mind about the insulin pump, the patient's reasons for detaching the insulin pump and inability to adhere to the regimen are neither sought nor elicited.

³⁰ The patients repeated admissions for ketoacidosis are discussed later in the consultation

Although it is apparent from his response to the nurse 'well I'll stop on needle anyway' (line 104) that this decision is not without difficulty ('well' indicates a dispreferred response (Pomerantz 1984)), he is unable, even when invited by the nurse to give reasons for his change of mind, to answer in anything but a minimal way (lines 98 and 102).

Extract 6.26 [Patient 20 (ex Insulin Pump user now on MDI) 19-11-12] (92-105)

92. (1.0)
93. D: [()
94. N: [What what made you say oh (.) I want to go
95. back on it you know how you've come in
96. and you've just said
97. [()
98. P: [Injecting myself ha ha hhh.
99. (0.2)
100. N: Cos that's always been an issue with it
101. (0.3)
102. P: Mm[m
103. N: [You [you've
104. P: [well I'll stop on needle anyway
105. on pens so I'm not bothered [()

It would appear that adopting a 'passive' stance in the consultation adversely influenced the patient's interaction with the doctor and that this had a negative impact on the patient's ability to maintain access to an insulin pump. In contrast with the findings on high involvement patients discussed in section 6.3, the patient was unable to build a rapport with the doctor or to voice concerns with his regimen, other than minimally. As with other non-aligning patients, he experienced 'unilateral' (Collins et al. 2005) communication from the doctor and in common with other patients who experienced difficulty communicating in the consultation he received a supportive stance from the nurse and dietitian. The following extract illustrates how the nurse is able to explain the doctor's terminology to the patient in ways that are understandable to him.

Extract 6.27 [Patient 20 (ex Insulin Pump user now on MDI) 19-11-12] (176-225)

176. D: So do we have any any details Linda³¹
177. on on (1.0) ketoacidosis³² and (.) >spontaneous
178. ketoacidosis as opposed to provoked ketoacidosis?<
179. (1.7)
180. N: No
181. (1.5)
182. P: That for (.) stomach acid? =
183. N: = y- y'know the last time you came
184. in (.) [and
185. P: [mmm
186. N: we admitted you (0.3)that was because you'd
187. you'd not been [well
188. P: [ketone yeah
189. N: hadn't you you'd had a prob[lem?
190. P: [yeah
191. N: At your ↑mum's (.) was it? (.) gone to your mum's
192. for your Sunday dinner and felt poorly
193. P: Yeah
194. N: So you'd taken your pump off
195. (0.4)
196. P: [Yeah
197. N: [And then you'd had no insulin (0.6) and then
198. you came in to see me for a routine appoint[ment
199. P: [yes
200. N: and you were quite high with blood ketones
201. (0.5)
202. P: Yeah I were
203. N: And we shipped you onto
204. (1.0)
205. P: They go up (.) they go up every so often
206. in three or four days it's like (0.3) nought point

³¹ A pseudonym for the name of the nurse present at the consultation

³² Ketocidosis is a life threatening condition requiring intensive treatment in hospital

207. eight something like that
 208. (1.4)
 209. N: So y'know when you've you've ended up with
 210. ketones ↑like that
 211. P: Yeah
 212. N: has it usually been because you've been bit
 213. poorly beforehand
 214. (0.5)
 215. P: [I think so
 216. N: [or has something happened
 217. P: I'm not quite sure to be honest with you
 218. (0.3)
 219. N: That's what the doctor was asking
 220. P: Oh right yeah well [it's ()
 221. N: [Did it just happen
 222. or is it something we've done (0.4)
 223. to make it happen
 224. P: ↑No it's just happ↑ened (.) I think just
 225. come out at blue (1.4) that's all it is

It is apparent from the patient's remark at line 182 that he is unclear about the term 'ketoacidosis'. It is noticeable that it is the nurse not the doctor who begins an explanation at line 183. This is couched in terms of asking the patient to recollect when he was last in hospital. The communication is 'bilateral' (Collins et al. 2005) in style. It is phrased in language that the patient understands and the nurse gauges this understanding at each stage before progressing further (lines 183-84, 186-87, 189, 191-92, 197-198, 200). It also provides further explanation to the patient, in understandable language, regarding the decision to withdraw the insulin pump. The nurse asks the patient to recollect that he had taken his insulin pump off whilst at his mothers' house. At each stage in recollecting his past history, the nurse stops in order to check that the patient is in agreement with her understanding of events. For example it can be seen that her use of 'you were quite high with blood ketones' (line 200) is understandable to the patient with his acknowledgment token 'yeah I were' (line 202). This contrasts with his lack of understanding of the term 'ketoacidosis' used by the doctor.

During the course of the consultation it is apparent that the diabetes specialist nurse and the diabetes specialist dietitian are familiar with the patient and he is able to converse easily with them. Whilst the patient finds it easier to talk to these health care professionals rather than

the doctor, it appears that the doctor also interacts minimally with the patient. Apart from the opening sequence most of the conversation in 11 minutes is between the patient and the diabetes specialist nurse. With respect to issues of losing or maintaining access it would appear that some patients are disadvantaged when they have an inability to communicate effectively with the doctor. The potential for rapport and trust building discussed in previous sections was predominantly observed in consultations with patients that aligned with medical goals. Patient 20's discussion with the doctor was limited. Despite the support offered by the diabetes specialist nurse and the diabetes specialist dietitian, the patient was unable to present a case for continuing on the insulin pump and it was clear that considerations of safety overruled the patient's wishes to remain on the device.

6.6 Summary

This chapter has presented the findings relating to the influences on maintaining access that are related to socioeconomic factors. The key influences on maintaining access were:

- Patient alignment
- Patient involvement

Two aspects of alignment were identified as important influences for maintaining access: alignment with objective biomedical goals and conversational alignment within the consultation. The early part of consultations within the sample was dominated by discussions about blood glucose levels and targets. This was the doctor's choice of agenda; however, the majority of patients aligned with this topic and in their orientation to the discussion demonstrated an expectation of the goals of the consultation.

Alignment with the treatment regimen was not the only influence on maintaining access. Being actively involved in the consultation was arguably more important. Some high involvement patients who had not been able to align with biomedical goals were nevertheless able to display a commitment to the regimen and hence achieved alignment with the doctor.

Key findings included the dominance of the doctor's agenda and in key decision-making sequences, one-sided communication from the doctor to the patient. It was noted that the design of the doctor's turns were formulated to prefer an affirmative response from the patient. Hence, although patient involvement and shared decision-making are promoted as the ideal, in practice it seemed that in this sample, patients for the most part were 'working hard' to maintain alignment with health care professionals as opposed to having their perspectives

sought. This somewhat unequal relationship appears to be at odds with the notion of shared decision-making.

This reinforces the findings reported in Chapter 5, that even when some patients disagree with aspects of diabetes management advice they tend to 'go along' with suggestions within the consultation. These findings also illuminate 'support-seeking' patients' comments reported in Chapter 5 that decision-making is sometimes experienced as a 'pressured' interaction. It may be that accessing an insulin pump creates greater tensions in the doctor-patient relationship that precludes shared decision-making since there are external influences including the requirement to demonstrate capacity to benefit from the technology that would not perhaps be manifest in review appointments for other type diabetes regimens.

The possible combinations of patient involvement and alignment are presented in the matrix in Table 6.6. Although a simplification, the diagram depicts the relative importance of the factors in each quadrant. Patient involvement was the dominant factor influencing maintenance of access to an intensive regimen. There were approximately equal representations of 'high involvement/aligned' and 'high involvement/non-aligned' patients. Low involvement patients were predominantly non-aligned. This may have been an artefact of the sample or may suggest the presence of issues for low involvement patients in terms of gaining initial access or maintaining access.

In relation to socioeconomic status (SES), in this sample the matrix indicates that in relation to low patient involvement, patients in the lower SES category predominated. In contrast, the high involvement category comprised patients from all SES categories. This may be a consequence of education and experience of an IIR leading to a more 'active' patient. It was noted in section 6.3.3 that in the 'high involvement/aligned' category, patients in the high SES category predominated.

The key findings in relation to equitable access were that high involvement patients in professional social classes who were non-aligned with biomedical targets appeared to be at an advantage in terms of maintaining access to an IIR compared with their counterparts in the low involvement category (comprising intermediate and manual social classes). Patients who had experienced problems adhering to their regimen and were less able to account for deteriorations in their HbA1c result appeared to be at a disadvantage, particularly in the opening sequences but also more generally since they received less rapport building communication from the doctor. Members of the multi-disciplinary team (the diabetes

specialist nurse and the diabetes specialist dietitian) were able to provide support for patients experiencing difficulty communicating within the consultation. However, support for patients who were non-aligned could only go so far in assisting patients. Where issues of safety were concerned, ultimately, an insulin pump could be withdrawn.

Table 6.6 Matrix showing patient involvement and alignment

	High Involvement	Low Involvement
Aligned	<ul style="list-style-type: none"> Continued access very likely Support given where necessary <u>Mainly high SES</u> 	<ul style="list-style-type: none"> Continued access likely Support given where necessary <u>Low SES group</u>
Non-aligned	<ul style="list-style-type: none"> Continued access likely Support essential for access <u>Mix of SES groups</u> 	<ul style="list-style-type: none"> Greater risk of losing access Support essential for access <u>Intermediate and manual SES</u>

The majority of patients in this sample worked to maintain alignment with health care professionals. Patients who were actively involved in the consultation appeared to have an advantage compared with patients who adopted a ‘passive’ stance within the interaction. In terms of maintaining access to an IIR it appeared that patients experiencing difficulties adhering to the regimen were able to elicit support from the other members of the multi-disciplinary team. The implications of these findings in relation to equitable access are discussed in Chapter 7.

Chapter 7. Discussion and Conclusions

7.1 Introduction

This chapter draws together the findings of the socioeconomic systematic review in Chapter 3 and the primary research findings in Chapters 5 and 6. The key findings are discussed in section 7.2 in relation to the relevant bodies of literature. The aim of the primary research was to explore the reasons for inequity of access to an IIR for adults with type 1 diabetes. The findings of the current study suggest a complex mix of factors influencing individuals' ability to access an IIR involving: the patient; the interface between the patient and the health care system; and communication between the patient and health care professionals. There were 7 key findings from Chapters 3, 5 and 6. These are outlined below with references to the relevant subsections.

Literature review findings (Chapter 3)

- Inequalities in health outcomes, access to health care and diabetes management persist amongst adults with type 1 diabetes and a paucity of research explaining the causal pathways was identified. The primary research in this study was designed to address one aspect of this causal pathway: the accessibility of an IIR.

Thematic analysis findings – gaining access to an IIR (Chapter 5)

- Specialist services are not permeable for individuals of low socioeconomic status and this has an impact on ability to access an IIR (section 7.2.1).
- Issues of alignment and barriers to patient engagement diminish the ability of individuals to assert their candidacy (section 7.2.2).
- Access to diabetes specialist nurses and structured education may facilitate access for vulnerable groups (sections 7.2.3 and 7.2.4).
- Continuity of care may facilitate access to an IIR for vulnerable groups (section 7.2.5).

Conversation analysis findings – maintaining access to an IIR (Chapter 6)

- Patient involvement is a principal influencing factor in the maintenance of access to an IIR. Lack of involvement is likely to compromise patient ability to maintain access (section 7.2.6).

- The multi-disciplinary team can assist vulnerable patients in maintaining access (section 7.2.7).

7.2 Factors Influencing Equitable Access to an IIR

7.2.1 Specialist Services are not Permeable for Patients of Low Socioeconomic Status

A combination of organisational barriers on the supply side, and socioeconomic circumstances and help-seeking behaviour on the demand side appeared to result in barriers to ‘access-entry’. This was significant because although it is recognised that not all patients need to be managed by a specialist team (Sharp et al. 2012), in this sample a prerequisite of gaining access to an IIR was attendance at specialist services. Notable disparities in the utilisation of specialist services appeared to relate to the permeability of services, personal social circumstances and the variable ability of patients to navigate the system.

It appeared that patients of high socioeconomic status placed importance on the expertise found in the hospital setting. This finding on patient preference was not surprising given that the majority of patients were recruited in this setting. However, the finding is in keeping with a previous qualitative study that found that patients believed that their condition was best catered for by consultant led services in hospitals (Somerset et al. 1999). There was a link in this previous study between perceived severity of condition and a lack of trust in the ability of GPs compared with consultant expertise. Patients in the current study also made comparisons between care at the GP practice and the perceived greater expertise encountered within specialist services. Preference for accessing expertise at specialist services appeared to relate to the concept of bi-directional candidacy, discussed by Kovandzic et al. (2011), who observed that some patients may decide which health care professionals are eligible to provide support.

Why some individuals do not access specialist services

Some patients in the sample had previously opted for care at their GP practice for reasons of convenience rather than an expressed preference for these services. This resonates with previous quantitative research linking non-attendance at hospital outpatients’ clinics with deprivation (Hamilton et al. 2002).

In a quantitative study of access to health care for adults with type 1 diabetes Mühlhauser et al. (1998b) postulated that lack of motivation was the root cause of poor attendance amongst individuals of low socioeconomic status. The current study found a more complex and multi-factorial picture than that portrayed in the previous study. In terms of the reasons why

individuals of low socioeconomic status did not attend specialist services the current study found that help seeking behaviour appeared to be influenced by a lack of permeable services on the supply side coupled with demand side factors involving patients with 'chaotic' lives, transport problems and low paid work.

These findings on barriers to attendance in the current study were in line with previous research that suggested that work commitments were amongst the commonest reasons given for non-attendance (Sharp et al. 2001). The current study provided a more nuanced understanding of this barrier since it revealed the financial implications for individuals in low skilled and low paid jobs taking time off work for hospital appointments. The findings on transport concurred with Dixon-Woods et al. (2005) in suggesting that it was a significant barrier for individuals of low socioeconomic status without access to a car.

The current study focused on individuals who, at the time of the interviews, were motivated to attend appointments. However, it was possible to explore potential barriers to attendance because some individuals had experienced difficulties in the past. The findings on barriers to accessing specialist services offer some explanations in relation to the associations of low socioeconomic groups and lack of access to services for adults with type 1 diabetes. It would seem that the way in which outpatient services are organised and structured acts as a barrier for individuals in low socioeconomic groups (Dixon-Woods et al. 2005).

It may be that the way that diabetes care is organised and/or commissioned has an impact on patient ability to access services. A number of significant changes to the provision of diabetes care have occurred in recent years (Gosden et al. 2015). This relates to the separation of commissioners (purchasers) of services and providers of health care and more recently the establishment of Clinical Commissioning Groups in 2013. There have been suggestions that individuals with type 1 diabetes may experience difficulties accessing specialist services (Sharp et al. 2012) due in part to diabetes care increasingly being provided in primary care (Gosden et al. 2015) and concerns that payment by results has led to disincentives for patients to be referred to specialist diabetes care (Rayman et al. 2012; Simmons et al. 2011).

In the current study there was no evidence arising from patient interviews that they had been 'blocked' from attending specialist services; however, this may have been an artefact of the sample since most were recruited within specialist services. The current study findings suggest that issues of permeability appear to be a more important barrier to 'access-entry' for individuals of low socioeconomic status; however, as noted in Chapter 5, an appraisal of the

impact of service commissioning on equitable access to an IIR was beyond the scope of the current study. Nevertheless, in relation to the study findings, access issues relating to the commissioning of services may be important and may exacerbate existing barriers to specialist services for vulnerable groups who lack the 'voice' to demand specialist input to their care.

7.2.2 Issues of Alignment Affect Equitable Access to an IIR

The quality of patient-provider communication was found to be a key influence on access to an IIR. Health care adjudications and patient presentation were interrelated influences on access to an IIR in this study. The key influences were:

- Health care professional adjudications which may exclude potentially eligible candidates.
- Barriers to patient engagement that diminish potential candidacy.

Health care professional adjudications may exclude potentially eligible candidates

In seeking patients suitable for an IIR, in addition to clinical factors, health care professionals selected individuals on the basis of evidence of one or more of the following: motivation; potential ability to use an IIR; and knowledge. This selection process was important in order to ensure that patients were safe, particularly in relation to insulin pumps. Previous research has reported that health care professionals make judgments about patient suitability for insulin pumps based on a number of non-clinical factors including personal and psychological attributes in order to decide which patients will make optimum use of insulin pumps (Lawton et al. 2016). This qualitative study was conducted as part of the Relative Effectiveness of Pumps over MDI and Structured Education (REPOSE) trial. Health care professionals who were interviewed as part of the study acknowledged that during the randomised control trial their assumptions about patient suitability had been challenged, with some patients unexpectedly going on to have success with the insulin pump therapy.

In the current study a key aspect of assessing patient eligibility appeared to be the concept of identifying 'capacity to benefit' (Gask et al. 2012). 'Ideal' patients have a good 'fit' with the health care services on offer since they have 'the exact set of competencies and resources required to make optimal use of the service' (Dixon-Woods et al. 2005, p.53). The concept of the 'ideal user' (p. 53) suggests that there is a match or alignment between patient preferences and services offered by health care professionals. The notion that health care professionals select 'ideal' patients for treatment appeared to resonate with the findings of

the current study. In Chapter 5, the dominant theme in relation to 'in-system' access was patient-provider alignment, defined as the 'goodness of fit' between help-seeking behaviour and the response by health care professionals. The term alignment is used here in a wider sense than 'concordance' since it carries with it connotations of cultural alignment as well as alignment with health care professional goals. It appeared that patients who were able to align with health care professionals were viewed as 'ideal'. In the current study having a 'proactive' or 'collaborative' approach appeared to facilitate access to an IIR because these patients had an ability to engage with health care professionals and build rapport which eased the process of accessing an IIR, even where clinical need for the technology was questionable. Patients who described being engaged in consultations appeared to be articulate, self-confident and often from professional backgrounds. They appeared to be able to assert their claim to candidacy. It has been suggested that middle class patients are better aligned with health care professionals because they can communicate more effectively and consequently are better able to gain access than other patients (Dixon et al. 2003). The findings of the current study would appear to substantiate the claim by Dixon et al. (2003) that the middle classes are able to get a better service than other patients through using their 'voice'.

However, as the discussion in the following sections will identify, this focus on the 'ideal' patient may exclude patients who for a variety of reasons do not conform to health care professional notions of an 'ideal' candidate.

Barriers to patient engagement that diminish potential candidacy

Non-alignment has a negative impact on patient-provider communication

In contrast non-alignment appeared to have a detrimental effect on patient-provider communication and was linked with psychosocial issues, lack of knowledge and inability to manage diabetes. These factors had a detrimental impact on being able to manage the regimens and led in some cases to unwillingness to engage with health care professionals. Patients in this study who were non-aligned with health care professional goals ('support-seekers') described their health care interactions in negative terms. The finding that non-alignment leads to difficulties in patient-provider communication is consistent with a number of studies that highlight the style of communication experienced by individuals who have difficulty managing diabetes (Richards et al. 2006; Snow et al. 2012). In keeping with a study by Wikblad (1991) the current study found that communication with patients was influenced by HbA1c values. Whereas patients with good metabolic control received positive responses from health care professionals, those with unsatisfactory HbA1c results felt both coerced and

unsupported (Wikblad 1991). It would seem that some patients' reports on how they perceived themselves to have been judged resonate with recent research that finds that some health care professionals categorise patients with type 1 diabetes as 'good' or 'bad' depending on their achievement of acceptable HbA1c levels (Brierley et al. 2012).

Patient perceptions of negative communication with health care professionals appeared to affect help-seeking behaviour. This reflected the findings of a study exploring reasons for non-attendance by young adults, in which concerns about receiving negative comments regarding failure to achieve target HbA1c levels influenced decisions to attend appointments (Snow et al. 2012). The findings also resonate with the results of a systematic review of patient non-attendance in chronic care, in which inadequate and paternalistic communication between patients and their health care professionals were identified as contributing factors to missed appointments (Paterson et al. 2010).

Ignoring the subjective experience

Dixon-Woods et al. (2005) discuss the notion of 'threats to identity' identified by Coyle (1999) in a study exploring the impact of negative communication. 'Threats' would include patients feeling that they were being coerced, receiving negative comments or feeling that their subjective experience was being ignored and not being able to assert their own identity. Issues of identity also appear to be relevant to patients who are unable to manage diabetes.

The tendency for patients to feel that their 'subjective experience' (Gask et al. 2012) is being ignored within consultations has been the subject of much research. In a landmark study Mishler (1984) noted the different 'voices' of patients and doctors. Mishler (1984) found that the disparity between the two 'voices', those of medicine and the 'lifeworld' of the patient, led to less satisfaction for patients in their treatment and that this adversely affected adherence with regimens.

In providing a critique of Mishler's (1984) study, Barry et al. (2001) showed that doctor-patient communication was more complex than had been observed in the earlier study. A number of possible combinations were noted: doctor and patient both discussing issues from a purely medical perspective, patient discussing lifeworld issues and being ignored or blocked by the doctor and finally both patient and doctor allowing lifeworld discussions.

In the current study some patients reported that their lifeworld issues were blocked by doctors. They reported that as a consequence of this style of communication they were

dissatisfied with their interactions with medical staff. Patients who felt that they were not being listened to by doctors because their care was too target driven also reported a lack of alignment with doctors. In the study conducted by Barry et al (2001), consultations in which lifeworld issues were blocked tended to result in problematic consultations in which the patient's needs had not been met. In contrast doctor-patient communication was more effective when lifeworld issues (psychological) as well as physical issues were allowed within the consultation (Barry et al. 2001). Health care professionals who listen and empathise with patients have been identified as important to individuals with type 1 diabetes, just as health care professionals who are critical and judgmental have been found to be unhelpful (Richards et al. 2006).

Depression

Among adults with type 1 diabetes, depression is higher than in the general population (Roy et al. 2012). Co-morbidity of depression and type 1 diabetes has been linked with poor outcomes including an increased risk of mortality (van Dooren et al. 2013) and inadequate glycaemic control (Melin et al. 2013). The mechanisms involved in the relationship between depression and diabetes (type 1 and type 2) are not fully understood (Holt et al. 2012) although some pathways have been suggested including the potential of depression to impede self-care adherence and to adversely impact doctor-patient communication (Gask et al. 2011). Previous research suggesting that depression amongst individuals with diabetes may affect both communication with health care professionals and self-care behaviour (Brown et al. 2004) appeared to be substantiated in the current study since some patients who reported having depression also described having an apathetic approach towards self-care activities and a negative appraisal of communication with health care professionals. Some of the issues relating to poor communication reported by individuals who were depressed may have been as a result of an unwillingness to engage with health care professionals' discussions about self-care since a reluctance to discuss self-care has been observed amongst individuals with depressive symptoms (Beverley et al. 2012).

Despite the adverse impact of even mild levels of depression on ability to self-care there is evidence from research into long term conditions that treatment for physical illness often takes precedence over mental illness, although both should be treated together (Holt et al. 2012). In the current study it appeared from the accounts of some patients that depression may well not have been detected by health care professionals. Although depression is associated with poor glycaemic control and its treatment is cost effective, psychological and

psychiatric conditions are largely undetected in patients with diabetes (Nicholson et al. 2009). It may be that time constraints limit the potential for health care professionals to identify and address these co-morbidities (Wikblad 1991). However, there are also issues regarding the stigma surrounding depression which may deter some individuals from seeking help (Kovandzic et al. 2011). Barriers to managing co-morbid depression and long term conditions in primary care include factors involving both the patient and health care professionals. Patients may resist being labelled as depressed and health care professionals may in turn be reluctant to pursue the matter in the face of this reticence (Coventry et al. 2011). Another factor involving both patients and health care professionals, noted by these authors, which appears to impede the treatment of depression, is the perception that depressive symptoms are a normal part of life with a long term condition.

The challenge of addressing these problems has particular relevance in discussions of socioeconomic inequalities since depression is more common amongst individuals with low income (Brown et al. 2004; Roy et al. 2012). Hence it is likely that this group will be disproportionately disadvantaged by the barriers to access caused by mental health issues. Individuals in low socioeconomic groups with depression are less likely to assert their candidacy for treatment of their mental illness (Kovandzic et al. 2011) thus compounding the potential problems of access to an IIR. There was some indication in the current study that individuals from lower socioeconomic groups were less able to obtain help for depression than their counterparts in higher socioeconomic groups.

The integration of diabetes care and mental health care yields improvements in both physical and mental health (Katon et al. 2004; Katon et al. 2010), hence the emphasis placed on detecting depression in long term conditions (National Institute for Health and Care Excellence 2009a). However, although depression screening is part of the primary care QOF diabetes review in England there is some doubt about its effectiveness to detect the condition (Jani et al. 2013; Maxwell et al. 2013). It also appeared that in this study some patients received all of their diabetes care from specialist services. In this scenario it may be that since screening for depression did not take place at specialist services, a diagnosis of depression could be missed. Additionally, the ability of health care professionals in a specialist service to detect depression is likely to be hampered by some of the same issues found in primary care: lack of time in consultations (Chew-Graham et al. 2002); and a reticence by health care professionals to initiate discussions about mood when there are inadequate psychological services available (Coventry et al. 2011). Lack of specialist psychological support for patients with diabetes was reported by health care professionals in this study.

It was noted in Chapter 5 that the focus of the study was not mental health and that the data on co-morbid depression was limited. Although it appears that depression may be an important influence on access to an IIR, no substantive claims can be made by this study. Nonetheless the findings of the current study suggest that depression may be a significant barrier to obtaining access to an IIR through its adverse effects on self-care, motivation and engagement with health care professionals.

7.2.3 Permeable Services: Diabetes Specialist Nurses Facilitate Access to an IIR

An important finding was that the permeability of services provided by diabetes specialist nurses appeared to facilitate access to an IIR. This may be understood by exploring the relationship between permeability, recursivity and continuity of care. Recursivity is a term that has been used to describe the relationship between the way individuals self-manage their chronic conditions and the potentially 'mutually reinforcing' positive contact they experience with health care professionals (Rogers et al. 2005). This concept has been used in relation to health care access previously (Bristow et al. 2011; Hunter et al. (2013); Kovanovic et al. 2011) and it may explain how access to an IIR was enabled by contact with diabetes specialist nurses. For example it may be that the permeability of the diabetes specialist nurse service experienced by patients led to recursive interactions and that continuity of care was established through this process. Kovanovic et al. (2011) describe this aspect of permeability as 'receptivity of services'. In the current study it appeared that patients were encouraged to make contact with diabetes specialist nurses and that this had an influence on future attendance.

Continuity of care in relation to the service provided by diabetes specialist nurses seemed to have had an important influence on gaining access to an IIR. It seemed to enable health care professionals to form an opinion of a patient as a potential candidate for an IIR. It was probable that patients returning to diabetes specialist nurses and who were seen to be working collaboratively with them would be viewed as sufficiently motivated to undertake an IIR. In the current study, the impact of the diabetes specialist nurse service was noteworthy in relation to equitable access to an IIR since their approach appeared particularly important in relation to vulnerable patients. This included patients who described having psychosocial problems and who struggled with their diabetes management. Hence patients unable to access this service may be at a disadvantage in terms of gaining access to an IIR.

The findings of the current study resonate with previous research focusing on specialist nurse services in diabetes care. In terms of communication style a patient-centred approach encompassing interpersonal skills of approachability, empathy, understanding and the provision of clear and understandable advice was previously found in a study exploring patient experiences of specialist nurses in primary care (Stenner et al. 2011). However, this study was conducted within primary care whereas the current study focused on specialist nurses in a secondary care setting. Thus the part played by diabetes specialist nurses in assisting vulnerable groups to achieve access to an IIR in secondary care would appear to be an original research finding of the current study.

Diabetes specialist nurses support patients with psychosocial problems

It appeared from accounts by both health care professionals and patients that diabetes specialist nurses were able to support patients who presented with a number of psychosocial issues. This was reported by patients, the diabetes specialist nurse and doctors. Patients emphasised the importance of receiving a non-judgmental approach to communication when they felt unable to adhere to the regimen. Diabetes specialist nurses appeared to be in tune with other aspects of patients' lives that may impact on their ability to manage diabetes. Therefore although the majority of patients did not have access to specialist psychological services, the support of diabetes specialist nurses appeared to somewhat offset this deficit in care. This empathetic approach to communication appeared to be associated with a tendency for nurses to broaden their discussion with patients to encompass aspects of lifestyle and other health related issues (Stenner et al. 2011).

7.2.4 Diabetes Education Minimises Disparities in Access to an IIR

The current study found that attending a Structured Education Programme was a key influence on accessing an IIR. It appeared that some of the characteristics health care professionals sought in the 'ideal' patient were subject to change through education and gaining knowledge.

The Structured Education Programme appeared to minimise disparities in ability, knowledge and motivation amongst participants. This appears to be in line with a study investigating the role of a Structured Education Programme and associated treatment in type 1 and type 2 diabetes. This study found that socioeconomic differences in HbA1c values were ameliorated by a Structured Education Programme and treatment in specialist services (Bäz et al. 2012).

Acquiring knowledge about diabetes management and alternative regimens seemed to allow individuals to participate more fully in consultations and to manage regimens more effectively. The ability of a Structured Education Programme to empower patients and to lead to a different kind of communication with health care professionals resonates with the findings of a longitudinal study conducted with participants of a DAFNE course (Rankin et al. 2012).

Issues of access to a Structured Education Programme

Despite the important impact of education reported by participants, the current study found that there were issues in terms of being able to access the education. First, amongst participants who had had diabetes for a long time it appeared that education had not been experienced for many years. This finding is in keeping with a longitudinal study conducted with participants of a DAFNE course in which participants had not received education despite having had diabetes for many years (Rankin et al. 2012). Second, amongst those who had recently been diagnosed, education did not appear to have been offered. Lack of opportunity to access a Structured Education Programme appears to be a widespread issue identified by the recent National Diabetes Audit (2011-12). Only 2.2% of newly diagnosed individuals with type 1 diabetes were offered structured education and even fewer attended (0.6%) the course (Health and Social Care Information Centre 2013). Third, it appeared that barriers to accessing education for some groups of patients who had been offered the course such as inability to take time off work and family commitments resonated with the findings of a study investigating the effectiveness of the DAFNE course for adults with type 1 diabetes (Taplin et al. 2013).

Some barriers to attendance were related to patients' resistance and this was also consistent with previous findings. For example a belief that the education had little to offer and that patients were managing their condition effectively has been noted previously (Taplin et al. 2013). The findings of the current study indicated that despite these earlier misgivings, when patients reflected on the impact of the course they recognised the deficits in their own pre-course understanding. This echoed the findings of Murphy et al. (2011) where all the participants attending a DAFNE course lacked knowledge about adjusting insulin dose according to carbohydrate intake.

Health Literacy: impact on engagement and barriers to patient participation

In this study acquiring knowledge about diabetes management and alternative regimens seemed to allow individuals to participate more fully in consultations and to manage regimens

more effectively. The Structured Education Programme seemed to empower patients and facilitate communication with health care professionals. This resonates with the findings of a longitudinal study conducted with participants of a DAFNE course (Rankin et al. 2012).

The findings of the current study also appear to substantiate the view that health literacy may impact on patient engagement (Protheroe et al. 2009). Health literacy refers to the competencies required by individuals in order to interact effectively in the health care setting (Berkman et al. 2011a). These skills involve literacy in relation to: written text; the interpretation of numbers (numeracy); and to aural literacy (the ability to communicate effectively) (Berkman et al. 2011a). Previous research has established links with patient involvement, poor health literacy and socioeconomic deprivation (Docherty et al. 2012). These links with patient involvement were also found in the current study. Patients in the study expressed dissatisfaction with some elements of the service and a feeling that it was not tailored to their needs. These patients were largely but not exclusively from low socioeconomic groups.

Literacy and numeracy skills were described by health care professionals as influential in patients gaining access to an IIR. The application of numeracy skills is a significant part of training in intensive insulin regimens (Kerr 2010). These skills include being able to use fractions, decimals, percentages and ratios (Kerr 2010). According to a recent study up to 47% of participants lacked the necessary numeracy skills; however this was judged to underestimate the true figure because the sample may not have been representative of the local type 1 diabetes population (Marden et al. 2012). Research into the potential impact of poor literacy and numeracy skills has concluded that the latter has an influence on glycaemic levels (Marden et al. 2012). The findings of the current study suggest that, in relation to health care adjudications, individuals of low educational attainment are likely to be disadvantaged. It is also apparent from the literature that individuals with poor literacy skills appear to have problems engaging with health care services.

7.2.5 Continuity of Care is Important for Vulnerable Groups

It was evident in this study that continuity of care was closely related to building trust with health care professionals and that this in turn influenced the uptake of offers for an IIR. The importance of trust and respect in relation to patient-provider communication in chronic disease has been emphasised in a number of studies (Lown et al. 2009; Mechanic et al. 2000) and specifically in relation to decision-making in patients with diabetes (Montori et al. 2006).

However the ability of individuals to experience continuity of care appeared to be distributed variably amongst the sample and appeared to be associated with socioeconomic status. The contrasting ability of patients in different socioeconomic groups to insist on continuity of care resonated with the findings of Protheroe et al. (2013) who found higher socioeconomic groups were more adept at achieving continuity of care than individuals of low socioeconomic status.

Discontinuity of care appears to have a number of disadvantages for individuals of low socioeconomic status. First, there is a tendency for health care professionals to focus on biomedical measures of patient adherence when patients are not known to them (Wikblad 1991). The negative impact of this type of focus for patient-provider communication in relation to individuals who have been unable to achieve target HbA1c levels has already been discussed in section 7.2.2. Second, it would seem that discontinuity of care may have a further detrimental impact on equitable access to an IIR since it has been suggested that lack of continuity of care leads to patients receiving more conservative diabetes treatment in the interests of safety (Lutfey et al. 2005).

7.2.6 Patient Involvement is a Principal Factor in Maintaining Access to an IIR

Across the data sets of interviews and recorded consultations patient alignment was a key influence on patient-provider communication. At the macro level patient-provider alignment was defined as the 'goodness of fit' between help-seeking behaviour carried out by patients and the response to these actions by health care professionals. At the micro level (Chapter 6) patient-provider communication was influenced by alignment with health care professional goals in relation to diabetes management. However, conversation analysis was able to determine that patient involvement was a more important influence on equitable access to an IIR. The key findings were:

- 'High involvement' patients were better able to present themselves as candidates for continued access to an IIR; were able to minimise difficulties associated with non-alignment; and could influence the communication style of the doctor.
- 'Low involvement' patients: received a different style of communication from the doctor; participated less in decision-making; were less able to influence the consultation trajectory; and were consequently less able to present themselves as candidates for continued access to an IIR.
- 'Low involvement' patients in this study were mainly from lower socioeconomic groups.

In the current study 'high involvement/aligned participants' were predominantly from the highest socioeconomic group. In contrast three out of the four 'low involvement' patients were long term unemployed. The significance of these findings is strengthened by the supporting evidence in the literature reporting that involvement in consultations was associated with a number of factors including socioeconomic status (Verlinde et al. 2012).

High patient involvement minimises the difficulties associated with non-alignment

Alignment in terms of biomedical goals was important and it was apparent that the HbA1c result was a key aspect of health care adjudications particularly in relation to continuing eligibility for maintaining access. This finding is in keeping with previous research which indicates that although doctors often acknowledge the importance of non-medical factors in managing diabetes, the evidence is that biomedical markers of adherence are usually given pre-eminence in discussions with patients (Freeman et al. 2000). Additionally, the priority given to discussions about biomedical targets should not be a surprise since guidance on patient eligibility for insulin pumps stipulates the need to demonstrate the continuing benefits of the therapy in relation to reductions in HbA1c and frequency of hypoglycaemia (National Institute for Health and Care Excellence 2008). It would appear that some insulin pump provider services draw up contracts with their patients encompassing their expectations in relation to patient self-care activities for continuing access to insulin pump therapy (Kilvert 2010).

In the current study alignment with health care professional goals led to different communication with the doctor. As previously discussed in section 7.2.2, Wikblad (1991) found that patients who met HbA1c targets received positive communication from health care professionals whereas patients unable to achieve goals received negative comments. In the current study patients not meeting targets did not receive negative comments from the doctor; however, nor did they receive rapport building communication. This appeared to be reserved for patients meeting targets.

The key finding in terms of equitable access and patient alignment was that whereas 'high involvement' patients who were non-aligned were able to give an account of reasons for non-achievement of targets and in some cases proactively pre-empt these discussion with the doctor, 'low involvement' patients, in contrast, were less able to convince the doctor of their commitment to the regimen. Hence, provided patients were actively involved in the consultation, non-alignment was not a problem. In contrast the combination of 'low involvement' and non-alignment was a potential issue in terms of continued access.

Barriers to patient involvement

In the current study it appeared that in consultations characterised by less patient involvement, these patients were of low socioeconomic status and appeared to receive a 'unilateral' style of communication from the doctor. 'Unilateral' and 'bilateral' styles of communication in relation to treatment decision-making have previously been observed in consultations involving diabetes patients (Collins et al. 2005). In the current study, the observation that patients who were non-aligned and 'low involvement' appeared to receive 'unilateral' communication from the doctor raises an important issue in relation to equitable access since, in keeping with previous findings, patients receiving a 'unilateral' style of communication from the doctor were less involved in decision-making (Collins et al. 2005). Hence a 'passive' stance within the consultation appeared to result in a more directive style of communication from the doctor.

Previous research has identified that doctors communicate differently with different patients according to both the patient's own communicative style and their socioeconomic status (Verlinde et al. 2012). The current study concurs with these findings since a 'unilateral' style of communication by the doctor was linked with 'passive' patients of low socioeconomic status. The current study findings also resonate with the literature on 'passive' patients of low socioeconomic status receiving directive communication (Verlinde et al. 2012) and doctors involving them less in treatment decision-making (Kaplan et al. 1995).

The third factor influencing patient-provider communication was the inability of some patients to affect the consultation trajectory as a consequence of being less involved in the interaction. It appears that socioeconomic status influences patient communication within the consultation. This finding agrees with studies reporting that individuals from lower socioeconomic groups are less inclined to engage with health care professionals in decision-making (McKinstry 2000; Protheroe et al. 2013) and are less verbally active in consultations than their counterparts in higher socioeconomic groups (Street et al. 2005). In the current study the majority of 'high involvement' patients were in the middle to higher socioeconomic groups whereas the majority of 'low involvement' patients were in the lowest socioeconomic groups.

This resonates with the review of socioeconomic factors and communication carried out by Verlinde et al. (2012) in which patients of low socioeconomic status appeared to exercise less control over the communication in consultations than their counterparts in the higher socioeconomic groups. This lack of involvement has been partly explained by the social

distance between patient and doctor discouraging verbal assertiveness (Street 1991). However, lack of involvement is also explained, to some extent, by some patients of low socioeconomic status conforming to what they perceive is their expected role as a passive recipient of the doctor's advice (Protheroe et al. 2013). The authors suggest that some patients view negatively the notion of querying the doctor's decisions since this might threaten their standing as 'a good patient' (p. 1053).

In the current study less patient involvement led to less opportunity to discuss treatment in a shared way with the doctor and less opportunity for patients to present themselves as candidates for continued access to an IIR. Additionally, the strong links found in the current study between lack of involvement and socioeconomic status appears to have implications for equitable access, particularly in light of the majority of 'low involvement' patients in the sample having a status of long term unemployed.

7.2.7 The Multi-Disciplinary Team Assists Vulnerable Groups in Maintaining Access

It appeared that some patients were more diffident and less able to communicate with the doctor, although they were able to communicate satisfactorily with other members of the multi-disciplinary team. This finding seems to reflect research which has noted that patients of low socioeconomic status are reticent to communicate with doctors. This interactional asymmetry was not as apparent when the patient communicated with either the nurse or dietitian. This may be explained by the following: use of technical language by the doctor; the doctor's focus on the HbA1c target; and a more patient-centred approach by the nurse and dietitian.

Medical terms versus lay language

The use of 'technical' language appeared to inhibit some patients from engaging with the doctor. It was observed that in one consultation it was necessary for the diabetes specialist nurse to intervene to explain medical terminology to the patient. This barrier to communication echoes previous findings that the use of technical language may deter patient involvement (Dixon-Woods et al. 2005) and may also serve to exacerbate the impact of cultural distance on patient-provider communication (Street 1991).

The biomedical focus versus patient-centred approach

The doctor, nurse and dietitian appeared to have different approaches to communicating with the patient. These findings resonate with a study comparing consecutive doctor and nurse

appointments involving patients with diabetes in a primary care setting. Utilising a conversation analytic approach, Collins (2005) revealed that nurses adopted an approach incorporating an 'everyday' style of communication, and the consultation agenda was influenced by patient responses. In contrast doctor's 'talk' was more 'technical' and tended to be narrowly focused on biomedical assessments and the need to set targets, hence minimising the scope for patient involvement (Collins 2005). This appears to correspond with the current study's findings that the nurse and dietitian adopted a more patient-centred approach whereas the doctor largely adopted a biomedical focus. As in the study by Collins (2005), these communicative styles appeared to relate to the different roles adopted by the nurse and doctor (and the dietitian in the current study). For example, in the current study the doctor had a dominant role in setting HbA1c targets and attending to other medical matters within the consultation whereas the nurse and dietitian were predominantly involved in helping patients to solve problems in relation to the regimen. The presence of the nurse or the dietitian assisted some patients in communicating with the doctor and there were many instances in the data of interventions on behalf of patients. The current study demonstrates the influence that the wider members of the multi-disciplinary team can have in assisting vulnerable patients to maintain access to an IIR and this appears to be a novel finding in relation to issues of equitable access.

7.3 Study Contributions

The primary aim of this thesis was to explain how it is that individuals of low socioeconomic status may experience inequitable access to an IIR. This study has made an original contribution to research in the following areas by the provision of:

- The first systematic review of the literature investigating socioeconomic disparities in health outcomes, diabetes management and access to health care for adults with type 1 diabetes.
- The influences on inequities in access to an IIR for adults with type 1 diabetes.
- Further empirical evidence in support of Candidacy theory.
- A demonstration of the value of conversation analysis in investigating equitable access to health care.
- A further addition to the body of literature on institutional interaction focusing on multi-disciplinary communication.

7.3.1 Systematic Review

The review documented in Chapter 3 identified that inequalities in health outcomes, diabetes management and access to health care were associated with socioeconomic factors for adults with type 1 diabetes. The review identified a paucity of evidence on the causal pathways involved in the persistence of these inequalities. The primary research carried out as part of this study was designed to explain these observed inequalities.

Two main pathways were identified. First, individuals of low socioeconomic status faced barriers to access due to the organisation of specialist services health care services for adults with type 1 diabetes. Second, these patients also faced barriers to access through their interactions with health care professionals.

7.3.2 Candidacy Theory Explains Inequitable Access to an IIR

Candidacy theory was used to frame the findings in relation to gaining and maintaining access. Patient presentation and health care adjudications were common themes across the two data sets. The study has provided further empirical evidence in support of the relevance of Candidacy theory as an explanation for inequitable access to health care by vulnerable groups. In forming their theory Dixon-Woods et al. (2005) focused on a number of vulnerable groups. In relation to accessing an IIR for patients with type 1 diabetes the current study found that the model has relevance for patients from lower socioeconomic groups who face barriers to access relating principally to the permeability of services and to issues of patient-provider alignment.

7.3.3 Patient-Provider Communication Influences Equitable Access

Brown et al. (2004) postulated that patient-provider communication was one of the causal pathways influencing the way that individuals of low socioeconomic status would be disadvantaged in accessing health care. The current study provides evidence of this pathway by explaining how issues relating to patient-provider communication affect equitable access to health care for adults with type 1 diabetes in an English setting.

A key finding in this study was the important influence of communication between patients and health care professionals in terms of selecting individuals who will benefit from intensive regimens. Candidacy theory concepts of patient presentation, health care adjudications and

patient-provider alignment were able to disentangle the complexity of influencing factors involved in barriers to equitable access.

Contributions to conversation analytic and decision-making research

Whilst thematic analysis identified the crucial importance of patient presentation and health care adjudications in relation to accessing an IIR, conversation analytic techniques were able to provide a nuanced understanding of patient-provider communication influencing equitable access. Conversation analysis demonstrated empirically the interrelatedness of patient presentation and health care adjudications. In line with a number of other studies, the current research shows that the asymmetry observed in the dominance of the doctor's agenda was co-constructed with the patient (Street 1991). However, a number of novel findings were identified in relation to conversation analysis and access to an IIR for adults with type 1 diabetes. First, patient alignment, already identified as a key influence in gaining access, was identified as important in maintaining access. Conversation analytic techniques were able to demonstrate how patient alignment influenced communication between the patient and the doctor. Second, patient involvement appeared to be a principal influence in facilitating continued access to an IIR. Observation of the impact of a 'passive' stance in consultations seemed to explain how individuals of low socioeconomic status were less able to assert their candidacy for an IIR. These conversation analytic findings in relation to equitable access to an IIR appear to be an original research contribution.

The study adds to the relatively small body of knowledge concerning treatment decision-making in diabetes care that has utilised conversation analysis. The findings extend previous research that reported 'bilateral' and 'unilateral' approaches in doctor-patient interaction (Collins et al. 2005). The current study findings suggest that these communication styles may be influenced by patient characteristics and hence may have implications for equity of access. In this study patients who were less involved in decisions about their treatment appeared to be at risk of losing access to an IIR.

The study makes a contribution to the body of research focusing on institutional interaction and addresses a relatively under-researched area investigating the way that health care professionals communicate together within the multi-disciplinary team setting in chronic care management (Pilnick et al. 2009). This study provides an original contribution to the investigation of the dynamics of the multi-disciplinary team within an insulin pump clinic setting and demonstrates how the different communicative styles adopted by health care professionals influence opportunities for patient involvement. As the study demonstrates,

these interactions offer examples of 'more complex and variable forms of participation than are exhibited within general practice doctor-patient encounters' (Pilnick et al. 2009, p. 792)

7.4 Strengths and Limitations of the Study

This study explored equity of access to an IIR for adults with type 1 diabetes. There were strengths and limitations of the study and these are discussed in the sections below.

7.4.1 Strengths

The study had five main strengths. First, the study methods succeeded in providing an in-depth exploration of the complex factors involved in accessing an IIR. Second, the study was able to draw on two forms of data collection: interviews with participants and observations of consultations. The interviews provided a method to explore the dynamics of access over time whereas observations of consultations allowed an in-depth investigation of the communication practices within consultations that may influence the maintenance of access. The findings of both interviews and consultations provided a source to illuminate each set of findings. Third, the study addressed a range of perspectives, both patients and health care professionals, from which to explore the pathways involved in accessing an IIR. A fourth strength was the diversity of patient participants involved in the study. This was accomplished through a strategy of purposively sampling a range of participants to take account of socio-demographic and clinical factors. The sample included patients who appeared to be managing their regimens effectively and also those who struggled to achieve optimum outcomes in terms of HbA1c results. This diversity allowed a more nuanced analysis of the impact of socioeconomic factors on access to an IIR. Although the sample had very few participants who were not accessing specialist services at the time of the study, several patients had previously disengaged with these services and hence their earlier experiences provided directly relevant data on issues related to reasons for disengagement. Finally, a key strength was the use of Candidacy theory to frame the findings. This allowed the current study findings to build on previous well established theory in order to gain an understanding of inequity of access to an IIR.

7.4.2 Limitations

Single site in a specialist services setting

There were a number of limitations with the study. The study was undertaken in a single specialist services location in which insulin pump technology was available to patients. It may have been that the influencing factors identified in this study differed according to setting; however, it is not possible to comment on the effects of these differences. The study findings may have been strengthened by the inclusion of another hospital site for comparison purposes. However, choices of sites were limited by the resources available since this was a PhD project.

Limited numbers of health care professionals

The study was also limited by the numbers of health care professionals. For example the sample included one well regarded diabetes specialist nurse. Patient satisfaction with this nurse may have influenced the findings. However, the findings on diabetes specialist nurses were consistently reported by participants in connection with other nurses both at this location and at two other hospitals. In addition, in relation to the recorded consultations it was observed that the diabetes specialist dietitian also had an important role in supporting patients, with or without the presence of the nurse.

Due to the small number of primary care health care professionals the views expressed may not have been representative of a range of primary care health care professionals. For example, other primary care health care professionals may have had different views about care for individuals with type 1 diabetes. However, it was noted that even within this small health care professional group a range of differing views were expressed about where the care of adults with type 1 diabetes should be situated. It was also the case that it was never the intention to undertake a full study in primary care. This aspect of the study was designed to capture the experiences of individuals who had not necessarily engaged with specialist services and to investigate pathways between both specialist services and primary care.

Focus on insulin pump patients

The initial aim of the study was to explore decision-making in relation to gaining access to an insulin pump, hence the focus on this clinic. As the study progressed it was apparent that owing to the very small numbers of new starters on insulin pumps, these decisions would not be captured. Hence the study was widened to look at access more generally. This led to a large

number of insulin pump users in the study. However, it could be argued that an in-depth investigation of this group of participants enabled some important insights into the ways in which individuals had gained access to this technology.

Under-representation of individuals in lower socioeconomic groups

In looking for socioeconomic factors affecting access it is important to have diversity in the sample in terms of socioeconomic background. It would have been preferable to have had more individuals from lower socioeconomic backgrounds participating in the study; however, these individuals appeared not to be well represented at the insulin pump clinic.

Saturation of themes may not have been achieved

The aim of the study was to collect data until a 'saturation point' had been reached (Pope et al. 2006b, p. 66). In terms of the numbers of consultations (25) and interviews (28) diversity of participants and repetition of themes was achieved across both data sets. There were fewer individuals from lower socioeconomic backgrounds than desired, hence the study may have not have achieved complete saturation of themes.

Ideally the study would have given equal weighting to the interactions in primary care and specialist services in order to explore comprehensively the patient pathways involved in gaining access. Since there were limited resources for the study (a single researcher undertaking a PhD) it was necessary to focus on where the key decisions were being made with regard to an IIR; in this geographical context this was specialist services. The data collection in primary care was extremely small and unable to reach any level of data saturation. Therefore no inferences about primary care can be drawn. However, the few interviews in primary care were extremely useful for offering some insight into the wider context in which specialist services operates.

The numbers of health care professionals participating in the study was small because the team offering specialist care in the study hospital was small. There was no data saturation in terms of obtaining the views of health care professionals offering specialist care but since these health care professionals interviewed were responsible for caring for the patients in the sample their input was crucial to understanding the context of the care on offer.

Limitations of observation methods

Recording one consultation provided only a snapshot in time of the patient-provider communication. Several of the patients had previously seen the consultant and therefore they

had had time to get used to each other. It is plausible that their experiences may have been different to those patients seeing the consultant for the first time.

One of the disadvantages of overt observational studies is that being observed may have an effect on the behaviour of study participants (Pope et al. 2006a). The phenomenon known as the Hawthorne effect was first described in a study carried out in the Hawthorne plant of the Western Electricity Company in Chicago during the 1920's and 1930s. A potential threat to the legitimacy of findings could be the effect on participants' behaviour (both patients and health care professionals) of being observed in consultations. As discussed in the methods chapter it was decided for a number of reasons that audio recording would be preferable to video recording. It could be argued that the presence of the recorder may have affected the consultation agenda. However, it was found that consultations were similar in content across the patient group and the study focus was on the moment by moment interactions of participants rather than simply the topic agenda. However, whilst it is not possible in relation to the current study to comment on the possible effect recording the observations had on participant behaviour, the literature suggests that audio recording rather than video recording has less of a negative impact on patients concerns at being observed (Themessl-Huber et al. 2008).

7.4.3 Transferability

Transferability has been suggested as a more appropriate criterion for qualitative research than generalisability (Murphy et al. 2001). Although it is not possible in qualitative research to make direct comparison between settings because the 'phenomena are intimately tied to the times and contexts in which they are found' (Murphy et al. 2001, p. 170) nevertheless it should be possible for the reader to identify from descriptions, that are sufficiently detailed, whether or not similarities exist with other settings. The site for this research was an acute hospital in an area of deprivation and there is no reason to suppose that this hospital differs markedly from other hospitals in similar settings. However, the purpose of the current study was to provide plausible explanations for inequities in access widely observed amongst adults of low socioeconomic status. Hence rather than making claims for generalisability, the aim of the study was to provide insights into aspects of health care organisation and patient-provider interactions that have a bearing on equitable access. The study findings will be more likely to be transferable to other locations in England with a similar organisation of care for adults with type 1 diabetes rather than countries whose health care provision is managed differently or areas of England where services are focused on primary care.

7.4.4 Reflexivity

Reflexivity refers to an attention, by the researcher, to the ways in which through their own input to the study they may have 'shaped' the findings of the research (Murphy et al. 2001, p. 189) and is particularly important when adopting a subtle realist stance. A number of variables may influence the type of data collected by researchers including their gender, age and social class (Murphy et al. 2001). In health care research, whether or not a researcher is a health care professional may also affect what may be reported by participants in interviews (Britten 2006). My background as a non-clinical researcher may have enhanced my ability to converse with patient participants since they would have viewed my stance as neutral. Also it may have been that patients with a similar background to my own revealed more to me owing to the lack of cultural distance between us. However, I believe that largely this was not the case. My stance of empathetic neutrality allowed me to interact with most participants effectively. It is difficult to comment on the two interviews that were much shorter than the others as I do not have access to patients' perceptions about me. However, I detected no discernible differences in the way that the majority of the patient participants interacted with me. I was made welcome in patients' houses and participants were very willing to make time for me. This is probably not something that would have happened if I had not been able to establish a rapport with them.

My status as a non-clinical researcher may not have enhanced my credibility with health care professionals. These participants may have been wary of revealing their views to a non-clinical researcher. Inevitably, there were more data from the patient interviews than the health care professionals' interviews because there were fewer of the latter participants. Therefore, it is likely that there is some bias towards reporting the patient perspective in this thesis. However, this would appear to be appropriate given that the subject of the enquiry is inequitable access to an IIR relating to *patients*. However, to some extent this potential bias was counteracted by having two forms of data collection and the recorded consultations focusing on the interactions between patients and health care professionals.

7.4.5 Reflections on the Study and Methods Used

How the study changed over time

This study used multi-methods to explore access to an IIR from the perspective of equity. The study was able to draw on interviews with patients and health care professionals to explore, using these diverse perspectives, the issues of equity involved in access to an IIR. The aim was to carry out an exploratory study of patient pathways involved in accessing an IIR and to

observe communication in action between patients and health care professionals as part of the diabetes review process. It was noted in Chapter 3 that the study aims changed during the course of the primary research. Initially, the aim was to explore the decision-making processes involved in *gaining* access to an IIR, particularly an insulin pump. Both methods (interviews and recorded consultations) were chosen with this in mind. As the study progressed it became apparent that, in the data collection time frame, there were insufficient patients having consultations about whether or not to have a pump. Consequently the recorded consultations focused on patients who had already adopted an IIR (insulin pump or MDI). However, it became clear that the recorded conversations provided an excellent source of data from which to gain insights into the barriers and facilitators involved in *maintaining* access. This became a new focus of the study.

Reflections on methods

Previous research relating to patient-provider communication has utilised many different approaches (Salmon et al. 2011). Observations and interviews have been used solely or in combination. The ways in which these combined methods have been used has also differed. For example some have used consultation data as a framework for the interviews. Tape-assisted recall (TAR) is a method that has been used to explore participants' reflections on segments of recorded consultations in both primary care (Cape et al. 2010; Chew-Graham et al. 2013) and secondary care settings (Salmon et al. 2011). This approach to communication research has a number of advantages, not least the ability to obtain the participant's thoughts on the consultation whilst reducing recall bias. In the current study the TAR approach may well have yielded interesting insights into the patient and health care professional experience of the consultation. The links between interview data and consultation data may well have been strengthened using TAR, resulting in a more comprehensive understanding of the interaction within the consultation. Nevertheless, for this study the focus was on pathways involved in gaining access to an IIR as well as on interactions within the consultation. The methods used were designed to take account of the wider issues involved in access to an IIR and patient-provider communication since both were important aspects of the study. Hence, the use of TAR would not have fully captured the experience of patients' health care journeys in relation to decisions about insulin regimens.

As a trainee researcher, adopting this multi-methods approach had advantages and disadvantages. The drawbacks were largely those involving both time and resources required to collect and analyse the data. Having never carried out any primary research previously my

aim was to try and become proficient in two forms of data analysis in order to do justice to the time invested in the PhD project by my supervisors and study participants. It has been a challenge within the timescales to accomplish this. Each part of the study (interviews or recorded consultations) could have been the subject of a PhD. However, I believe that combining the two methods has been worthwhile since any disadvantages were outweighed by the insights provided by each method. Triangulation of the different data sources revealed a complex picture of the ways in which patients gained and maintained access to IIR. The findings contributed to an understanding of how and why inequities may occur in relation to access to an IIR for disadvantaged individuals.

Patient and public involvement in research

There are two key drivers to patient and public involvement (PPI) in research (INVOLVE 2012). First, user involvement is widely thought to ensure the quality and relevance of health care research for users and communities and second, people should have a say in publicly funded research which may affect them. PPI has become an important part of health and social care research both in the UK and internationally (Brett et al. 2014). In the UK, PPI has been supported through INVOLVE (the organisation who promote PPI in the UK) and encouraged by the need to demonstrate PPI in order to achieve successful grant applications (NIHR 2014).

More recently the growing interest in PPI has been strengthened by an international systematic review providing evidence of the benefits accruing to research using the approach; that is, PPI has a beneficial effect on the design, implementation and dissemination of health and social care research (Brett et al. 2012). Although PPI is recognised to have benefits for those involved in the process (service users, the community and researchers) difficulties integrating PPI have also been reported by researchers in relation to deficits in time and money available (Brett et al. 2014).

PPI may comprise a number of activities including for example: assisting in the identification of research priorities; helping to develop patient leaflets; assisting with data collection; and participating in advisory groups (INVOLVE 2012). INVOLVE describe three approaches to PPI in research: consultation; collaboration; and user controlled (INVOLVE 2012). Each approach has benefits and challenges.

In the current study I involved patients at the very beginning, to elicit their input on the relevance of the research and to obtain their help in the design of the study. Hence the involvement of patients in this study may be categorised as 'consultation'. As noted in Chapter

4, patient involvement played an important part in the early stages of the study design. INVOLVE suggest that when researchers are new to PPI, a small scale approach is acceptable, for example, involving people in one stage of the research. This experience can be used to build expertise for future research (INVOLVE 2012). As this was both my first project and the first time that I had involved people in my research it seemed appropriate to undertake a modest start to public involvement.

In some studies patients are involved in the data collection process and data analysis phase and in the current study this approach may well have yielded benefits. However, it should be noted that more extensive public involvement also requires a degree of expertise by the researcher. As this was a PhD both time and resources were limited and hence the level of patient involvement was commensurate with these factors. In future research I intend to maximise the use of PPI in order to optimise its potential benefits.

PPI is also important at the dissemination stage where user involvement can help to ensure that the study findings are communicated in a way that is relevant to both patients and policy makers. It is likely that patients involved in relevant groups (for example Diabetes UK) will have suggestions about how and where to disseminate the study findings so that they are accessible to a lay audience (NIHR 2014). I intend to involve relevant groups in the dissemination stage of this research.

7.5 Implications for Policy and Practice

In terms of facilitating equitable access to an IIR, the findings of this thesis add weight to policy in two key areas:

- Providing more accessible services
- Improving patient-provider communication

7.5.1 Improving Access to Care for Vulnerable Groups with Type 1 Diabetes

Access to a specialist services

There are considerable challenges facing the NHS in England in terms of diabetes care. Key areas of concern are: variation in care both in primary and secondary care services; a feeling amongst individuals with diabetes that their care is fragmented; poor uptake of and access to structured education; and for adults with type 1 diabetes, the evidence suggests that large numbers with poor glycaemic control will result in avoidable complications (NHS diabetes

2013). In addition, despite the known benefits of near-normal glycaemia, the data from a recent National Diabetes Audit shows that there has been little improvement in glycaemic control for adults with type 1 diabetes in recent years (Health and Social Care Information Centre 2013).

There is recognition that most adults with type 1 diabetes require specialist care (Royal College of Physicians 2013), although some patients may be managed satisfactorily in primary care (Sharp et al. 2012). However, concerns have been expressed that the growing prevalence of type 2 diabetes may lead to less attention being paid to adults with type 1 diabetes since these patients will represent a very small proportion of the total diabetes patients in a given GP practice (Sharp et al. 2012). There are estimates that 15% to 20% of people with type 1 diabetes do not attend specialist services (Sharp et al. 2012) and 30% of individuals participating in a recent survey reported not being referred to specialist care when needed (Diabetes UK 2013). Concerns have also been expressed that in relation to commissioning services there is no distinction made between type 1 and type 2 diabetes and hence no proper consideration of the different needs of both conditions (Sharp et al. 2012).

The current study adds to the debate by suggesting that vulnerable groups of patients face additional barriers in terms of attending specialist services. The findings support the opinion that commissioners of services should focus on the health needs of patients with complex needs since ultimately poor metabolic control will result in both poorer outcomes for these individuals and ultimately greater consumption of health care resources (Goenka et al. 2011).

The current findings support the promotion of better ways to commission diabetes services that incorporate a whole systems ethos rather than the current piecemeal approach which results in fragmentation of care (NHS diabetes 2013). The concept of eroding boundaries between primary and secondary care with specialist service providers working within the community setting is an approach endorsed in 'Teams without Walls' (Royal College of Physicians et al. 2008). Hence specialist services need not be limited to the hospital environment and patients can receive services closer to their homes. The re-design of services for vulnerable groups is necessary in order to 're-focus on care delivery to patients who all too often are on the fringes of health care and do not fit in with established norms for service

provision' (Future Hospital Commission 2013, p. 19). Integration of diabetes services³³ in order to provide seamless health care for adults with type 1 diabetes appears to offer a solution to the fragmentation and duplication of services currently experienced by some patients. The current study endorses the calls for patients to be treated closer to home where possible. This is particularly important for vulnerable groups who find attending specialist services difficult due to transport issues or have problems taking time off for appointments due to low paid work.

Insulin pumps are offered in specialist services; therefore helping individuals from low socioeconomic groups to access specialist services, by reducing their transport and time off work difficulties, will address socioeconomic disparities in access to insulin pumps. Insulin pump usage remains low in the UK compared with the USA (40%) and other European countries (>15%) (White et al. 2014) so further efforts to address the barriers to uptake of this technology and to ensure that uptake is equitable will also reduce international variation in access.

Access to a Structured Education Programme

In the current study health literacy appeared to influence the ways that individuals navigated the health care system, processed health information, presented themselves as candidates for services and engaged with health care professionals. Low levels of health literacy found amongst individuals of low socioeconomic status in this research resonate with previous findings associating low health literacy with low socioeconomic status (Paasche-Orlow et al. 2005). Diabetes education and knowledge were found to be strongly linked to an ability to gain access to an IIR in this study. There were also indications that the Structured Education Programme could ameliorate some of the disparities associated with barriers to access by improving health literacy. However, the national picture suggests that access to Structured Education Programmes remains difficult. A particularly crucial time to receive offers of education would seem to be at diagnosis. The National Diabetes Audit (2011-12) reported that only 2.2% of newly diagnosed individuals with type 1 diabetes are offered structured education and even fewer attend (0.6%) the course (Health and Social Care Information Centre 2013). Some of the same barriers to accessing specialist services, relating to socioeconomic

³³ Integration of care is defined as 'an approach that seeks to improve the quality of care for individual patients, service users and carers by ensuring that services are well co-ordinated around their needs'. (The King's Fund et al. 2012)

factors, also apply to the Structured Education Programme in that people in lower socioeconomic groups experience similar difficulties in travelling to the course and managing to take time off if they are in low paid work. The findings of the study endorse the integration of services accomplished in some parts of England resulting in diabetes education being made available in a community as well as hospital setting (Rea et al. 2011). The current study recommendations go further in suggesting that provision should include evenings and weekends in order to facilitate attendance by those who experience difficulty taking time off due to low paid work. This would both reduce barriers to undertaking the Structured Education Programme for people in low socioeconomic groups and facilitate access to an IIR by improving health literacy levels.

7.5.2 Patient-Provider Communication

Patient-centred communication

Despite the known benefits of effective communication in terms of improved health outcomes (Greenfield et al. 1988), this study found a number of barriers to good quality patient-provider interactions. In relation to health care disparities, patients from low socioeconomic groups reported dissatisfaction with some health care interactions. They perceived that they were not 'heard', that they were being 'judged' and that they lacked involvement in key decisions. Many of the findings on patient-provider communication in this study resonate with previous research. For example dissatisfaction with provider communication has been found to be more commonly experienced amongst individuals of low socioeconomic status. (Verlinde et al. 2012) and poor patient-provider communication has been found to negatively impact on the ability of individuals with diabetes (type 1 and type 2) to self-care (Wilkinson et al. 2014). In terms of equitable access, therefore, it seems imperative that communication practices by both patients and health care professionals are addressed. This relates to patient-provider communication more generally within the consultation and also to decision-making processes.

Within the current study patients in low socioeconomic groups described variation in the way they experienced communication with some doctors and nurses, preferring, in general, the patient-centred approach of the latter. Vulnerable patients in the sample valued health care professionals who listened to them although they reported that this was not always their experience. The current study endorses previous research that finds that patients are more likely to engage with health care professionals if they perceive that the latter are listening to them (Gao et al. 2009).

One of the key tenets for successful patient-centred communication is the recommendation that doctors engage in 'active listening' (Matusitz et al. 2014) or 'attentive listening' (Jagosh et al. 2011; Silverman et al. 2005). 'Active listening' requires an approach that includes open ended questions, regular summaries, clarification and negotiation. An advantage of 'active listening' or 'attentive listening' is that the approach gives patients permission to speak (Jagosh et al. 2011; Matusitz et al. 2014). This is important because low socioeconomic patients do not always feel able to participate (Protheroe et al. 2013).

The Calgary-Cambridge guide is currently used to educate trainee health care professionals in the skills required for effective communication and provides excellent evidence-based guidelines in relation to a patient-centred approach to communication (Kurtz et al. 2003; Silverman et al. 2005). Training in communication skills, however, should not cease at the qualification stage; learning the skills involved in effective communication should form an important part of continuous professional development (Maguire et al. 2002). More recently the need for training in communication skills was identified as an important requirement by health care professionals themselves in a study involving a specialist team caring for young people with type 1 diabetes (Brierley et al. 2012). Yet despite communication skills training being a well developed and integrated element of the undergraduate medical curricula, with some exceptions, 'communication training so often disappears into a black hole after doctors qualify especially in hospital based specialities' (Silverman 2011).

For qualified health care professionals, education and refresher training should focus on what constitutes good communication from the patient perspective. In this study, it was noted across both data sets that doctor-patient communication had a predominantly biomedical focus. Patient-provider communication will be more equal when patients perceive it to be centred on their requirements and for some patients focusing on targets may not be helpful. Ideally the consultation agenda should be negotiated jointly at the outset with both the patient and the doctor agreeing on the parameters for the review (Silverman et al. 2005). A review that begins with the patient's experience of living with diabetes may reveal patient problems with the regimen much earlier in the consultation. Previous research has shown that a patient-centred approach to communication does not necessarily lead to lengthier consultations (Levinson et al. 2010; Street et al. 2005) although time pressures have been identified as a major concern for some health care professionals (Pooley et al. 2001). Additionally, a patient-centred approach is an important precursor to shared decision-making since it is only through listening attentively to patients that health care professionals will be able to determine the level of involvement desired by patients.

Promoting shared decision-making

Shared decision-making appears to offer a way to lessen health inequalities (Durand et al. 2014); however, in the current study it was not always experienced by individuals of low socioeconomic status. In this study patients who were less involved in decision-making were also less able to influence the consultation trajectory and were less able to present themselves as candidates for continued access to an IIR. This study supports previous research reporting that the way decisions are framed may influence patient involvement and that generally a 'unilateral' style of communication excludes patients from involvement in decision-making (Collins et al. 2005).

The drive to involve patients in decisions about their care assumes that all patients want to participate in decision-making (Protheroe et al. 2013). Although it is recognised that not all patients want to be involved in decision-making to the same extent (Bensing et al. 2003) and preference for involvement appears to be related to socioeconomic status (McKinstry 2000; Protheroe et al. 2013) the current study demonstrates the implications for inequitable access when patients are unable to participate effectively. Inability to share decisions is likely to exacerbate existing health inequalities particularly when disadvantaged groups are the least knowledgeable, least healthy and least engaged (McCaffery et al. 2010).

Shared decision-making appears to offer the potential to engage patients of low socioeconomic status thus improving outcomes for this group and reducing health inequalities (Durand et al. 2014). Hence every effort should be made to involve these patients. This will entail adopting an approach most likely to engage these patients. Strategies to improve doctor-patient communication with low socioeconomic status patients include having a greater awareness of their needs within the consultation and the potential impact of particular styles of communication (Verlinde et al. 2012). Interventions have already provided an evidence base in relation to the benefits of involving patients from all backgrounds (Durand et al. 2014). These need to be implemented more widely.

However, health care professionals should be careful about assuming that everyone wants to be involved in decision-making (Verlinde et al. 2012). Although it appears to be important to empower the 'passive' patient and encourage greater involvement, for patients who do not want this level of interaction, respect for patients as individuals and the need to gauge the level of involvement desired by the patient is of greater importance (Verlinde et al. 2012). Empathetic and supportive health care professionals are valued by patients with diabetes (Entwistle et al. 2008; Richards et al. 2006); however, it would appear that an empathetic

approach that also attends to the patient's personal situation is particularly important for individuals of low socioeconomic status with chronic conditions (Smith et al. 2009).

Patients may be unwilling to engage in discussions with health care professionals for a variety of reasons. Unfortunately assumptions may be made about lack of patient engagement and these may disproportionately disadvantage individuals including those from lower socioeconomic groups, those suffering from psychosocial problems and patients struggling with diabetes. A heightened awareness of the possible reasons for lack of involvement coupled with a patient-centred approach would assist in addressing these communication barriers.

Addressing health literacy issues in patient-provider communication

In the current study socioeconomic variation in health literacy was identified in both data sets. For example high levels of health literacy appeared to facilitate good communication with health care professionals (section 5.6.2) whereas poor health literacy appeared to disrupt the flow of communication (section 6.5.5). In this study those with lower levels of health literacy were in lower socioeconomic groups. Despite a growing body of research from the US, relatively little health literacy research been conducted in the UK (Protheroe et al. 2009). However, more recently there appears to be a growing interest in the implications of health literacy (Royal College of General Practitioners 2014) and in addressing inequalities in health arising from poor health literacy (Public Health England and UCL Institute of Health Equity 2015).

Low health literacy poses a challenge to the goal of increasing patient participation in health care (Protheroe et al. 2009), however, there are, a number of ways to improve communication amongst individuals with low health literacy and to promote patient involvement. As a first step health care professionals should consider the health literacy of their patients. For example health care professionals should be 'sensitised' to the difficulties faced by patients and avoid communicating in technical terminology; instead wherever possible lay language should be used (Protheroe et al. 2009). The current study endorses recommendations to raise awareness of health literacy issues amongst health care professionals, training providers, commissioners and NHS trusts (Royal College of General Practitioners 2014).

It is known that patients recall or comprehend approximately half of what doctors communicate in a given encounter and that although this is the case, assessing patient understanding is rarely carried out (Schillinger et al. 2003). Techniques for improving communication have used the 'teach-back' strategy which is designed to assist patients with

low health literacy to recall and comprehend their communication with health care professionals (Nath 2007). The approach involves explaining concepts and instructions in a simple and clear way and then asking patients to repeat back to the health care professional, in their own words, what they have just heard. The interactive nature of the approach facilitates patient involvement and the strategy has been found to improve outcomes amongst low health literacy individuals with diabetes (Rothman et al. 2004). This approach has the advantage that misunderstandings may be addressed immediately with the patient.

Continuity of care

The current study identified the importance of continuity of care both as an aspect of service valued by patients and also in relation to the important influence it appeared to have on gaining access to an IIR. Continuity of care should be viewed as an essential aspect of care for individuals with type 1 diabetes and is particularly important for vulnerable groups. Continuity of contact with health care professionals allows the fostering of mutual trust and respect, an aspect of patient-provider relationships valued by patients with long terms conditions (Entwistle et al. 2008), and considered important to the success of shared decision-making (Lown et al. 2009). A patient-provider relationship based on trust and mutual respect is key to enabling patients with diabetes to self-manage their condition (Montori et al. 2006).

Role of the diabetes specialist nurse

The findings of this study endorse the calls for diabetes specialist nurses to play an increasingly important role in the management of adults with type 1 diabetes. In the current study diabetes specialist nurses appeared to bridge a communication gap between some patients and their doctors. Their role appeared to be particularly influential in facilitating access to treatment for vulnerable patients. The current study found that the patient-centred approach adopted by diabetes specialist nurses appeared to be very important for patients who struggled with diabetes management. In addition diabetes specialist nurses have an important role to play in assisting patients in lower socioeconomic groups who struggle to be heard by other health care professionals. This study adds weight to the concerns that diabetes specialist nurse posts have been frozen and that cuts to services have not taken into account the long-term implications of terminating services (National Audit Office 2012).

7.6 Summary of Key Recommendations

The following summarises the key recommendations that would assist in improving access to an IIR for vulnerable groups:

- Commissioners and health care professionals involved in designing services should consider ways of improving access to specialist health care services for adults with type 1 diabetes. For example, specialist services could be provided closer to patients' homes to facilitate attendance for those who face difficulties due to transport or to low paid work.
- Structured Education Programmes should be made available at places convenient for the patient, for example, in the community setting and not just hospitals in order to overcome barriers to access experienced by low socioeconomic groups. It is important that a Structured Education Programme is offered to patients at diagnosis.
- Communication practices and interventions designed to encourage patient involvement amongst low socioeconomic groups and those with low health literacy should be adopted by health care professionals (including the 'teach-back' method). Promoting patient involvement requires raised awareness amongst health care professionals that some low socioeconomic patients do not feel as able as their counterparts in higher socioeconomic groups to participate in patient-provider communication.
- Continuous professional development should encompass training to improve communication skills in 'active listening', since by hearing the patient's story, self-care problems including psychosocial issues will be elicited and the patient will be given a 'voice'. This is particularly important for patients in low socioeconomic groups who struggle to be 'heard'. This approach will assist in reducing health care access disparities to an IIR by enabling health care professionals to view people in lower socioeconomic groups as candidates for an IIR.
- Recognition should be given to the expertise of the diabetes specialist nurse in assisting vulnerable groups of patients to access an IIR. Commissioners of services should ensure that diabetes specialist nurse posts continue to be funded. Continuity of

care should be a priority and would be facilitated by assigning each patient with type 1 diabetes a diabetes specialist nurse.

7.7 Future Research

This study has been exploratory. It has identified that patients may experience inequitable access to an IIR. Further research could focus predominantly on hard to reach groups and individuals not currently accessing specialist services. The focus of this study was socioeconomic inequity; however, it appeared that older participants were an under-represented group amongst insulin pump users. In addition, most of the participants were white British. Inequity of access involving age and ethnicity could be the subject of future research. A longitudinal design would offer a more comprehensive investigation so that patient experiences could be captured over time. Owing to the limitations of PhD resources this was not an option in the current study.

Quantitative research has been carried out in the United States and has focused on children in relation to socioeconomic inequalities in access to insulin pumps. These results cannot be applied to the UK since the United States does not have a universal health care system. Replication of these studies in the UK for both adults and children would quantify progress towards equal access to technology for all groups.

Psychosocial issues were a key barrier to access and further research could explore the impact of depression and other mental health problems on gaining access to an IIR.

The importance of health literacy in relation to health inequalities is an area that is gaining interest in the UK. The current study has identified health literacy as an influencing factor in relation to gaining and maintaining access to an IIR. Further research is needed to assess the impact of interventions designed to improve low health literacy amongst adults with type 1 diabetes.

7.8 Conclusions

The aim of this study was to explain how and why adults with type 1 diabetes from low socioeconomic groups experienced inequitable access to health care. The study has made an original contribution to the evidence base for inequity in access to health care for adults with type 1 diabetes, using complementary qualitative methods to generate new insights into the underlying inequalities observed.

First, this study has produced the first comprehensive systematic review of health outcomes, access to diabetes care and diabetes management for adults with type 1 diabetes. Second, the study has provided plausible explanations for inequitable access to specialist services and an IIR in adults with type 1 diabetes. The study has provided a detailed and to my knowledge original exploration of the influencing factors involved in equitable access to an IIR. Third, the study provides further empirical evidence to support the value of Candidacy theory in explaining inequitable access. Fourth, the study has made an original contribution to the body of literature using conversation analysis in relation to institutional interactions. Finally, the study has made a contribution to the literature on patient-provider decision-making and has demonstrated the potential of conversation analysis to offer new insights into inequitable access and the dynamics of the multi-disciplinary team.

Equitable access to intensive regimens was impeded for people from lower socioeconomic groups by a complex mix of factors relating to patients, their interactions with the health care system and patient-provider communication. Permeability of access was influenced by personal social circumstances including low paid work and transport difficulties. Factors diminishing candidacy for an IIR were low health literacy, non-alignment with health care professional goals, psychosocial problems and poor quality patient-provider communication. Some of the barriers associated with access were modifiable through contact with diabetes specialist nurses, a structured education programme and continuity of care.

Conversation analysis identified that patient involvement was important for maintaining access to an IIR and that the multi-disciplinary team approach was advantageous for vulnerable patients. Efforts to improve the quality of communication with these patients could lessen inequities in access to intensive regimens.

Appendix 1: Example Search Strategy

Medline via Ovid (final search up to March week 1 2014 – no date limit)

No	Search	Result
1	Type 1 diabet*.mp [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	25580
2	Diabetes Mellitus, Type 1/or type 1 diabetes.mp	65868
3	Insulin dependent diabet*.mp [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	24325
4	1 or 2 or 3	78907
5	Socioeconomic Factors/ or socioeconomic.mp	143387
6	Socio-economic.mp	18501
7	Social class*.mp [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	36204
8	Social class.mp or Social Class/	35630
9	Social status.mp	3924
10	Poverty/ or Impoverished.mp	29809
11	Inequit*.mp [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	4438
12	Inequity.mp or Health Status Disparities/ or Healthcare Disparities/	14296
13	Health status disparit*.mp [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	7142
14	Healthcare disparit*.mp [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	7166
15	Equity.mp or Health Services Accessibility/	55766
16	Access.mp [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	175351
17	Access*.mp [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	325611
18	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17	513350
19	4 and 18	1474
20	Limit 19 to (English language and humans)	1291
21	Limit 20 to "all adults"	698

Appendix 2: Data Extraction Checklist

Author:		
Title:		
Journal:		
Year:	Volume:	Pages:
Study Aims:		
Correct population?		
Study design:		
Study location:		
Total number of participants:	Male:	Female:
Age of participants:		
Ethnicity if given:		
Inclusion criteria:		
Exclusion criteria:		
Clinical variables:		
Non-clinical variables or SES Variables:		
Analysis – statistical techniques used:		
Quality assessment carried out?		
Results:		

Appendix 3: Study Appraisal Form

Author:				
Title:				
Journal:				
Year:	Volume:	Pages:		
Study Appraisal checklist based on CASP (Critical Appraisal Skills Program (CASP) 2006)	Yes	No	Unclear	Not applicable
1. Did the study address a clearly focused issue?				
2. Was an appropriate method used to answer the question?				
3. Were inclusion/exclusion criteria reported?				
4. Were participants recruited to minimise selection bias?				
5. Were objective measures used?				
6. Did measures used minimise bias?				
7. Did the study take account of the confounding factors in the design and analysis?				
8. Was the follow up of subjects complete enough?				
9. Was the follow up long enough?				
10. Are the results reported adequately?				
11. Can the results be believed?				
12. Can the results be applied to the local population?				
13. Do the results of this study fit with other available evidence?				

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Anderson et al. (2014) <u>Morbidity</u>	UK	Cross sectional	1621 (42.3% women)	Type 1 diabetes adults aged 16-92 years (mean 47.6 years)	HbA1c, blood pressure, medication for neuropathic pain, estimated glomerular filtration rate, cholesterol, BMI, diagnosis of depression/anxiety disorder	Age, sex, Townsend score for deprivation
Butalia et al. (2013) <u>Morbidity</u>	Canada	Cross sectional	1994 (255 individuals with admission for diabetic ketoacidosis)	Type 1 diabetes adults ≥18 years of age, diabetes duration less than 6 months excluded	Diabetes duration, BMI, care type, blood pressure medication, statin medication, self- report: retinopathy, neuropathy, gastroparesis, other specified conditions, psychiatric conditions, eating disorder, HbA1c (median) and median estimated glomerular filtration rate	Age, sex, Statistics Canada was used to obtain median household income and education by small geographic area: family income mean, proportion with university degree, certificate or diploma
Chaturvedi et al. (1996) <u>Morbidity</u> <u>Diabetes</u> <u>Management</u>	31 European countries	Cross sectional	1217 men 1170 women	Type 1 diabetes Onset <30 Continuous need for insulin 1 year after diagnosis Aged ≥25 years	Diabetes duration, blood pressure, height, weight, hip and waist circumference, ECG, HbA1c (previous 8), cholesterol, fasting triglyceride, urinary albumin, retinopathy, heart disease -H/O myocardial infarction	Age, sex, education (measured by age of completion). Primary up to 14 years, secondary 15- 18, college after age 19, social class (UK Registrar General Classifications of Occupations) smoking, exercise and diet

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Connolly and Kesson (1996) <u>Morbidity</u>	Scotland	Cross sectional	1553 (402 type 1)	Type 1 and type 2 diabetes. Type 1 diabetes defined as requiring insulin within 3 months of diagnosis	Diabetes duration, diabetes type, blood pressure, cholesterol, height and weight	Age, sex, deprivation measured using Carstairs index, smoking status.
Forssas et al. (2010) <u>Mortality</u>	Finland	Cohort	1,407,025 person years 59,917 deaths	Type 1 and type 2 age 30-79 . Type 1 defined by medication usage/ or onset <30 years of age	Mortality	Age, sex, occupation, defined by Statistics Finland
Forssas et al. (2003) <u>Mortality</u>	Finland	Cohort	All people aged 30-74 in 1980 and 1990 census	Type 1 and type 2 Type 1: reimbursement for medication < 30 Type 2: onset > 40 Mortality comparison 40-59	Mortality	Age, sex, occupation defined by Statistics Finland
Forssas et al. (2012) <u>Mortality</u>	Finland	Cohort	528,734 person years 18,841 deaths	Type 1 and type 2 Diabetes patients aged 30-79 at the end of 1999 Type 1: if insulin the only drug used all others type 2 or if no medication information type 1 : age at onset <30, type 2: >40	Mortality	Age, sex, occupation defined by Statistics Finland education, disposable income, employment status, living alone, municipality

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Gnavi et al. (2004) <u>Mortality</u>	Italy	Cohort Follow up from recruitment (1991 onwards) to 1999	31,264 diabetes patients 874,801 general population	Type 1 and type 2 Type 1: based on diagnosis ≤ 35 years Type 2: > 35 years Age ≥ 20 years in 1991	Mortality	Age, sex, education, area of birth
Harris et al. (1993) <u>Diabetes Management</u>	USA	Cross sectional survey	2405 (124 type 1 patients)	Adults with type 1 or type 2 diabetes ≥ 18 years of age. Type 1 defined by BMI, < 30 years at diabetes onset	Diabetes duration, Structured interview BMI, attendance on course, frequency of physician visits	Age, sex, ethnicity, education, household income
Hepburn et al. (1994) <u>Diabetes Management</u>	Scotland	Cross sectional	121	Type 1 patients (in study 1) 18-50 years of age	Diabetes duration, age at onset, personality, intelligence, self-forgetfulness, self-report compliance, HbA1c	Age, sex, occupation (Office of Population Censuses and Surveys 1980) and number of years in full time education
Johansen (1986) <u>Diabetes Management</u>	Denmark	Cross sectional	37 (Study 1) 20 (study 2)	Insulin dependent diabetes	Diabetes duration, age at onset, HbA1c, questionnaire on self-care and diabetes knowledge	Social status (occupation)
Karter et al. (2000) <u>Diabetes Management</u>	USA	Cross sectional survey	44,181 (2818 type 1)	Type 1 and type 2. Type 1 based on an algorithm	Diabetes duration, BMI, Number of daily injections, self-reported monitoring of blood glucose levels	Age, sex, ethnicity, educational attainment, income, (group level) alcohol and smoking status, expenditure on glucometer strips

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Kibbey et al. (2013) <u>Diabetes Management</u>	Australia	Cross sectional survey	86 (response 24%)	Type 1 diabetes Target sample Aged 18-30	Diabetes duration , age at onset of diabetes, BMI, HbA1c Questionnaires relating to depression, diabetes and illness perception	Age, sex, education, income, alcohol and smoking status
Leese et al. (2003) <u>Morbidity</u>	Scotland	Cohort 12 month follow up	69 adults with 112 events (Type 1 diabetes)	Type 1 and type 2 Type 1 if diagnosed <35 years with a requirement for insulin or evidence of ketonuria and insulin requirements with 28 days	Diabetes duration, severe hypoglycaemia HbA1c	Age, sex, Carstairs index of social deprivation based on postcode (Carstairs et al. 1991)
Lievre et al. (2005) <u>Morbidity</u>	France	Cross sectional	562 children 1691 adults	Type 1 diabetes Children <16 years of age . Adults aged 16-45	Diabetes duration, weight, height, HbA1c, blood pressure. Complications: retinal, renal, cardiovascular, lower limb, ketoacidosis, severe hypoglycaemia	Age, sex, aggregate score based on employment status, occupation and education, smoking status
Lloyd et al. (1993) <u>Diabetes Management</u>	USA	Cohort	592	Type 1 diabetes ≥ 18 years < 17 years at diagnosis and to be on insulin therapy at discharge 2% non-white	Diabetes duration, HbA1c, BMI, questionnaires on self-care health behaviour , neuropathy, cardiovascular and peripheral vascular disease, renal function, retinopathy	Age, sex, education, household income

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Matsushima et al. (1996) <u>Mortality</u>	Japan	Case control	180	Insulin dependent diabetes Onset of diabetes <18 Years Placed on insulin at diagnosis Exclusions: diabetes secondary to other causes	Age at diabetes onset, insulin dose/regimen, frequency of clinic attendance, number of times doctor changed, hospital admissions, complications/coma, psychiatric disease, school phobia, emotional instability, mortality	Age, sex, education (years of), patient income, household income, marital status, living alone, smoking/alcohol status, access time required for hospital visit
Mühlhauser et al. (1998a) <u>Morbidity</u>	Germany	Cohort Mean follow up 19 months	684 adults (41% women)	Type 1 diabetes ≥18 years Initiation of insulin before 31 years of age 684 out of 932 participated (73%)	Diabetes duration, HbA1c, C-peptide, protein in urine, body weight, blood pressure, foot examination, renal parameters, questionnaire about treatment goals, structured interview about hypoglycaemia	Age, sex, baseline: social class based on aggregate score of education, occupation and income, smoking history
Mühlhauser et al. (1998b) <u>Diabetes Management</u> <u>Morbidity</u>	Germany	Cross sectional	684 adults (41% women)	Type 1 diabetes ≥18 years Initiation of insulin before 31 years of age 684 out of 932 participated (73%) Mean age 36 (range 18-77)	Diabetes duration, HbA1c, C-peptide, Protein in urine, body weight, blood pressure, foot examination, renal parameters, eye examination for retinopathy, diabetes quality of life	Age, sex, baseline: social class based on aggregate score of education, occupation and income, smoking history

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Mühlhauser et al. (2000) <u>Mortality</u>	Germany	Cohort Followed up after 10±3 (mean ±SD) years	3674	Type 1 patients attending a 5 day course on intensive therapy Exclusion: diabetes resulting from disease of exocrine pancreas Gestational diabetes	Diabetes duration, HbA1c, Nephropathy, Foot complications Retinopathy, BMI, cholesterol, Hypertension, Smoking and alcohol status, mortality	Age, sex, social class score based on educational attainment and present or last occupation
Nadas et al. (2009) <u>Diabetes Management</u> <u>Morbidity</u>	Hungary	Cross sectional	209 men 228 women	Type 1 diabetes ≥25 years Diabetes onset before 30 years of age, insulin within 1 year Ethnicity Caucasian	HbA1c, Albumin, blood pressure, waist circumference, serum triglycerides, cholesterol	Age, sex, education, diet and smoking status
Pederson-Bjergaard et al. (2004) <u>Morbidity</u>	Denmark and UK	Cross sectional	1076	Type 1 diabetes Adults (< 18 years of age), diagnosis before the age of 40 and insulin at the time of diagnosis. Exclusions : end-stage renal disease, malignant disease, pregnancy or inability to complete questionnaire	Diabetes duration, episodes of severe hypoglycaemia for the preceding one year, awareness of hypoglycaemia, history of diabetes and complications, HbA1c	Age, sex, education (primary school, high school, university), alcohol consumption and smoking status, marital status

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Perros et al. (1998) <u>Diabetes</u> <u>Management</u>	Scotland	Cross sectional	60 (men 40)	Type 1 diabetes. Age ≥ 18 years. Exclusion age > 55 , diabetes duration < 3 years, duration of current insulin regimen < 1 year. Type 1 diabetes clinically determined	Diabetes duration, age at onset, insulin regimen, frequency of self-monitoring of blood glucose levels, HbA1c	Age, sex, smoking status, occupation (% professional), marital status, education measured in years
Robinson et al. (1984) <u>Morbidity</u>	UK	Case control	95 type 1 79 type 2 155 controls	Type 1 and type 2 diabetes Aged between 35-59	Cardiovascular disease or past history of possible myocardial infarction. Body mass index, retinopathy, fasting bold glucose concentration, cholesterol and serum triglyceride	Age, sex, social class based on occupation (Registrar General's classification for England and Wales), smoking status and alcohol consumption
Robinson et al. (1998) <u>Mortality</u>	UK	Cross sectional	2104	Type 1 and type 2 adults (17-65) Type 1 defined as diagnosed prior to age 36 and treated with insulin. Type 2 all others	Diabetes duration, glycaemic control (poor vs fair) complications, hospital admissions, mortality	Age, sex, occupation defined by the British Registrar General Classifications of Occupation. education, housing, employment status
Rossing et al. (1996) <u>Mortality</u>	Denmark	Cohort	939	Insulin dependent diabetes, aged ≥ 18 years, diabetes duration ≥ 5 years, aged ≤ 40 at onset of diabetes	Diabetes duration, height, urinary albumin, blood pressure, HbA1c, smoking status, retinopathy status mortality	Age, sex, occupation defined by classification of Danish National Institute of Social Research (Class I-IV)

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Rossing et al (2002) <u>Morbidity</u>	Denmark	Cohort Follow up ≥10 years (median 9 years)	537 adults	Type 1 diabetes ≥ 18 years, diabetes duration ≥5 years Age ≤40 at onset normoalbuminuria and not taking anti- hypertensive drugs	Urinary albumin, blood pressure, annual HbA1c Retinopathy	Age, sex, social class based on aggregate of education and occupation, smoking history
Sastre et al. (2012) <u>Diabetes Management</u> <u>Morbidity</u>	Spain	Cross sectional	1465	Type 1 diabetes aged ≥ 16 years with diabetes for at least 5 years. Type 1 diabetes clinically determined. Mean age 39 (range 16-83)	Diabetes duration, age at onset, presence of cardiovascular risk factors, blood pressure, cholesterol, BMI, HbA1c, insulin therapy type, hypoglycaemia, creatinine, urea	Age, sex, ethnicity, educational level, smoking status
Secrest et al. (2011a) <u>Mortality</u>	USA	Cohort	317 adults (10.7% deaths during follow up)	Type 1 (childhood onset < 17) Assessed as close to age 28 as possible ± 4 years	Diabetes duration, HbA1c, cholesterol, hypertension, BMI, serum and urinary albumin, creatinine, complications, depression intensive insulin therapy, mortality	Age, sex, occupation (Hollingshead Index of social position) Education, household income, smoking status

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Secrest et al. (2011b) <u>Diabetes Management</u> <u>Morbidity</u>	USA	Cohort Median 8-12 years follow up after age 28 depending on complication	317	Type 1 (childhood onset < 17) Assessed as close to age 28 as possible ± 4 years	Diabetes duration, blood pressure, depressive symptoms, HbA1c, cholesterol, triglycerides, intensity of insulin regimen, coronary artery disease, end stage renal disease, autonomic neuropathy, proliferative retinopathy, lower extremity arterial disease	Age, sex, occupation (Hollingshead Index of social position), education, household income, smoking status
Swaminthan et al. (2004) <u>Morbidity</u>	Scotland	Cohort Follow up period varied by disease	2228 adults	Type 1 diabetes Age ≤35 years at diagnosis Insulin treated Ethnicity : >98 white	Diabetes duration, blood pressure, albumin, HbA1c, cholesterol Hospital admission with macrovascular disease or death from macrovascular disease or registered with severe retinal disease	Age, sex, Carstairs index (Carstairs et al. 1991), smoking status
Unwin et al. (1996) <u>Diabetes Management</u> <u>Morbidity</u>	UK	Cross sectional	1246 (296 type 1)	Type 1 and type 2 diabetes Aged 20-69	Body mass index, serum cholesterol, proteinurea	Age, sex, deprivation, smoking status

Appendix 4: Study Characteristics – Systematic Review

Author/Date/ Review scope	Country	Study type	N	Study sample	Clinical variables	Non-clinical/SES variables
Weinstock et al. (2013) <u>Morbidity</u>	USA	Cross sectional	7012	Type 1 diabetes age at least 26 years old with type 1 diabetes for ≥2 years, 54% female 91% non-Hispanic white	Diabetes duration, information on severe hypoglycaemia and diabetes ketoacidosis in previous 12 months (from records and self- report)	Age, sex, ethnicity, education, household income, private insurance or non-private/no insurance
Wolf et al. (2011) <u>Morbidity</u>	Germany	Cohort	174	Type 1 and type 2 diabetes Caucasian	Diabetes duration, creatinine, albumin, chronic kidney disease categories, HbA1c, blood pressure	Age, sex, socioeconomic status measured using an aggregate of occupation, education and household net income, smoking status
Zgibor et al. (2000) <u>Diabetes</u> <u>Management</u>	USA	Cross sectional analysis of data provided as part of 10 year follow up cohort study	429	Type 1 diabetes Childhood onset (<17 years of age)	Diabetes duration, questionnaire relating to self-care, specialist non-specialist care, HbA1c, retinopathy, nephropathy, renal failure/transplant, coronary artery disease (medical records), lower extremity arterial disease, blood pressure	Age, sex, education and income

Appendix 5: Socioeconomic Status and Mortality in Type 1 Diabetes

Author/ Date	Study aims	Study findings reported for adults with type 1 diabetes
Matsushima et al. (1996)	To evaluate the social and behavioural risk factors of mortality in patients with insulin dependent diabetes.	Education: Deceased cases were more likely to have lower educational attainment (RR 2.5 (CI 0.9-7.2)). Income: No association found. Living alone: No association found.
Rossing et al. (1996)	To evaluate risk factors for cardiovascular and all-cause mortality in insulin dependent diabetes.	Clinical factors as well as socioeconomic group predict mortality: Microalbuminuria was an independent predictor of all cause and cardiovascular mortality. Smoking, hypertension, male sex, age, height and low socioeconomic group were associated with increased mortality. Social class V versus social class IV RR 1.70 95% CI: 1.25-2.31, p <0.001. Poor glycaemic control was an independent risk factor. HbA1c (RR 1.11, 95% CI: 1.03-1.20, p <0.02).
Robinson et al. (1998)	To investigate deprivation in relation to mortality in adults with diabetes.	Occupation: Mortality rates higher for those of lower vs higher social class (OR 1.34, CI: 0.61-2.96). This was more pronounced in type 2 patients. Education: Mortality rates higher for those who left school >16 years compared to those who left at 16 or later (OR 4.0, CI 1.96-8.06, p<0.05). Unemployed: Higher mortality rate than those employed (OR 3.10, CI 1.67-5.79, p<0.001). Unemployed for over a year OR 6.8, 95% CI 1.47-31.77 p<0.001. Those who were unemployed were significantly more likely to be of low social class, living in rented accommodation, to have left school prior to 16 and to be registered disabled. Housing: Those living in council houses had higher mortality than those living in other accommodation (OR 2.57, CI 1.35-4.91, p<0.01).
Mühlhauser et al. (2000)	To assess predictors of mortality and end stage diabetic complications for patients with type 1 diabetes on intensified regimens.	Clinical factors as well as socioeconomic group predict mortality: Nephropathy (HR 3.85, 95% CI: 2.6-5.6) is the most important predictor of mortality together with the following: Smoking 1.9 (1.4-2.6) Diabetes duration 1.5 (1.2-1.8) for a difference of 10 years Serum cholesterol 1.1 (1.0-1.2) for a difference of 1mmol/l Lower social status 1.4 (1.1-1.8), Age 1.3 (1.1-1.16), Male sex 1.4 (1.1-1.9), Systolic blood pressure 1.1 (1-1.2). Conventional risk factors similar to general population. HbA1c predicted complications but not mortality.

Appendix 5: Socioeconomic Status and Mortality in Type 1 Diabetes

Author/ Date	Study aims	Study findings reported for adults with type 1 diabetes
Forssas et al. (2003)	To explore socioeconomic differences in the diabetic population in Finland in 1991-1996 and carry out a comparison with findings from the early 1980s.	<p>Occupation: In the 1980's no major socioeconomic differences in mortality for people with diabetes were found, whereas there were in the general population. In the 1990's substantial socioeconomic differentials emerged due to a reduction in mortality in the higher groups and very little progress in lower socioeconomic groups.</p> <p>Disease contribution to mortality disparities: For type 1 men circulatory diseases contributed 48% and diabetes 34% of the mortality disparities between blue and white collar workers. Among women with type 1 the socioeconomic gradient was mainly due to diabetes 42%.</p>
Gnavi et al. (2004)	To compare diabetes and non-diabetes populations in terms of mortality and socioeconomic differences.	<p>Comparisons with general population: Risk of death for men with type 1 diabetes was double that of non-diabetic population SMR 197.7 (95% CI: 155.7, 247.4). Risk of death for women with type 1 diabetes was triple that of non-diabetic population SMR 336 (95% CI: 259.3, 428.2).</p> <p>Education: Among men disparities relating to education and mortality were more evident amongst type 1 and in the youngest age group. Among women compared to type 2 where no statistically significant educational inequalities were found, there were significant disadvantages amongst the youngest and least educated.</p>
Forssas et al. (2010)	To investigate the socioeconomic gradient in Finland amongst people with diabetes in the period from the 1980's to 2003.	<p>Changes in disparities over time: From 1991-94 to 1995-1999 socioeconomic disparity among people with diabetes increased in almost all major causes of death.</p> <p>Disease contribution to mortality disparities: The relative increase was largest in deaths strongly related to smoking alcohol and cardiovascular disease. This was due to a decrease in rates amongst higher socioeconomic groups.</p>
Secrest et al. (2011a)	To examine the role of socioeconomic status and all-cause mortality in childhood-onset type 1 diabetes.	<p>Comparisons with general population (by income and education): Individuals in the highest income and education group had similar mortality rates to local general population. Individuals with lower income and education had rates of mortality that were five times higher than the general population.</p> <p>Univariate analysis: Individuals without a college degree were three times more likely to die than those without a college degree HR 3.0, 95% CI: 1.2-7.8, p = 0.02.</p>

Appendix 5: Socioeconomic Status and Mortality in Type 1 Diabetes

Author/ Date	Study aims	Study findings reported for adults with type 1 diabetes
Forssas et al. (2012)	To examine the role of six socioeconomic factors (income, occupational position, education, unemployment, living alone and type of residential area) in relation to all-cause mortality and specific causes of death (for example alcohol disease).	<p>Five aspects of socioeconomic position were related to mortality: Occupation, education, income, employment and living alone.</p> <p>Unemployment and income for men: Among type 1 men mortality differences largest for long term unemployed (aged 30-64). RR 3.85 (3.00-4.94) compared with employed and for low versus high income RR 1.96 (1.78-2.17). Findings similar for type 2.</p> <p>Unemployment and education for women: For women mortality differences largest for unemployment RR 3.32 (1.88-5.88) and education; RR 2.35 (1.84-3.00).</p> <p>Municipality: No significant mortality differences were found for type of municipality of residence.</p>

Appendix 6: Socioeconomic Status and Morbidity in Type 1 Diabetes

Author/Date	Study aims	Study findings reported for adults with type 1 diabetes
Robinson et al. (1984)	To study the risk factors for microvascular and macrovascular complications in type 1 and type 2 diabetes.	Microvascular and Macrovascular: There were no significant socioeconomic differences found in men with type 1 diabetes in relation to risk factors for large or small vessel disease complications. Women with type 1 diabetes smoked more and had higher mean triglyceride levels.
Chaturvedi et al. (1996)	To explore the relationship between socioeconomic factors and diabetes control and complications in adults with type 1 diabetes.	Microvascular: Significantly lower rates of microalbuminuria and proliferative retinopathy for college educated men versus primary educated men. Little difference in rates of microvascular complications except for proliferative retinopathy which appeared to be more in college educated versus primary educated women. Macrovascular: No differences for men found with regard to heart disease. Risk factors for coronary artery disease: College educated men had lower smoking rates, exercise rates were higher, more favourable diet and lipid profile than primary educated men. Heart disease prevalence was lower for college educated women versus primary educated women. Education was the socioeconomic variable of choice however similar results were obtained by social class but not tabulated.
Connolly et al. (1996)	To examine the relationship of socioeconomic status and risk factors for cardiovascular disease in individuals with diabetes.	Cardiovascular disease risk factors: The proportion of patients with three or more risk factors was higher in the most deprived groups ($p < 0.001$). The most affluent categories had the highest proportion of patients without additional risk factors. The proportion of patients with no cardiac risk factors fell by 30.6% (comparing category 1 to 7) $p < 0.001$. 34% of individuals in deprived categories smoked compared with 13% in the affluent categories ($p < 0.001$).
Unwin et al. (1996)	To investigate the relationship between cardiovascular risk factors and socio-economic status in people with diabetes.	Cardiovascular disease risk factors: Increasing deprivation was significantly associated with both mean serum cholesterol and the proportion smoking ($p < 0.01$ and $p < 0.01$ respectively).
Mühlhauser et al. (1998a)	To identify the risk factors for severe hypoglycaemia in adults with type 1 diabetes.	Hypoglycaemia: Multivariate analysis - Social status (aggregate of education, income, occupation) was a statistically significant predictor of severe hypoglycaemia HR: 0.78 95% CI: 0.63-0.96 ($p = 0.0162$) for every 5 social levels (0 = lowest to 24 = highest).

Appendix 6: Socioeconomic Status and Morbidity in Type 1 Diabetes

Author/Date	Study aims	Study findings reported for adults with type 1 diabetes
Mühlhauser et al. (1998b)	To investigate diabetes care and education in association with socioeconomic status in adults with type 1 diabetes.	<p>Nephropathy: Social status (higher) was associated with a lower risk of nephropathy even when adjustments were made for blood pressure and smoking status. Prevalence of overt nephropathy 7 vs 20% for highest vs lowest quintiles of social class (OR 3.5, 95% CI: 1.6-7.5, p = 0.002).</p> <p>Foot complications: Fewer adults of higher social status had foot complications (OR 0.69, CI 0.55-0.86, p = 0.001).</p> <p>Macrovascular: Fewer adults of higher social status had macrovascular complications (OR 0.56, CI: 0.739-0.79 p = 0.0013).</p> <p>Retinopathy: No association found for risk of retinopathy.</p>
Mühlhauser et al. (2000)	To assess predictors of mortality and end stage diabetic complications for patients with type 1 diabetes on intensified regimens.	<p>Complications: Low socioeconomic status was a significantly predictive of complications (a combination of blindness or amputations or renal replacement therapy). Other predictors were nephropathy, foot complications, HbA1c, smoking, cholesterol, systolic blood pressure, retinopathy, and hypertension.</p>
Rossing et al. (2002)	To evaluate risk factors for micro-albuminuria and macro-albuminuria.	<p>Microalbuminuria/ macroalbuminuria: In normoalbuminuric patients social class did not predict the development of microalbuminuria or macroalbuminuria.</p>
Leese et al. (2003)	To determine the incidence, risk factors and costs of hypo-glycaemia in adults with type 1 and type 2 diabetes.	<p>Hypoglycaemia: Increasing deprivation measured by Carstairs index (Carstairs et al. 1991) was associated with severe hypoglycaemia in type 1 diabetes (p < 0.001).</p>
Swaminathan et al. (2004)	To explore socio-economic status and cardiovascular risk factors/micro-vascular and macro-vascular disease.	<p>Microvascular /macrovascular: No association found between socioeconomic deprivation and either microvascular or macrovascular disease.</p>
Pederson-Bjergaard et al. (2004)	To assess the rate and distribution of severe hypoglycaemia in a specialist secondary care setting.	<p>Hypoglycaemia: Univariate analyses: Primary school education was associated with higher rate of severe hypoglycaemia (RR = 0.57 (0.38-0.85, p = 0.00162)). University education compared to primary school education was not found to be associated with severe hypoglycaemia. Individuals consuming both alcohol and smoking compared with those who did neither were significantly at higher risk of severe hypoglycaemia (RR = 2.1 (1.4-3.2, p = 0.0004)). Multivariate analyses: Education was no longer associated with severe hypoglycaemia. The remaining risk markers were reduced awareness, symptomatic neuropathy and smoking.</p>

Appendix 6: Socioeconomic Status and Morbidity in Type 1 Diabetes

Author/Date	Study aims	Study findings reported for adults with type 1 diabetes
Lievre et al. (2005)	To study the relationship between clinical and socioeconomic variables on disease management and complications in young French adults.	<p>Complications: The risk of having at least one complication was increased by 16% 95% CI: (0%; 29%) for each decrease in the socioeconomic score by 1 point, by 13.5% (11.1%;16.0%) for five years of diabetes duration, and by 25% (12.7%; 38.8%) for each 1% increase in HbA1c.</p> <p>Ketoacidosis: was associated with socioeconomic score (OR= 0.71 95% CI (0.51-0.97) for a 1% increase)</p> <p>Smoking inversely correlated with socioeconomic score ($p < 0.006$)</p> <p>Hypoglycaemia: Severe hypoglycaemia in the year prior to the study adults (18.7%) was not related to any study parameters.</p> <p>Increase in HbA1c significantly and independently linked with prevalence of complications.</p>
Nadas et al. (2009)	To investigate the association between educational level and cardiometabolic risk.	<p>Metabolic syndrome: Prevalence of metabolic syndrome was higher in patients with low (primary) compared with high (university) educational levels 42.9% versus 21.5%, ($p = 0.0006$). Treatment for hypertension and cardiovascular disease was more prevalent in patients with low versus high educational level (46.4% versus 26.2%, $p = 0.01$, 12.5% versus 2.3%; $P = 0.02$ respectively). Smoking associated with low versus high educational level (smokers: 28.6% versus 11.6%, $p = 0.01$) and regular physical activity (5.4% versus 33.1%; $p = 0.0001$).</p>
Secrest et al. (2011b)	To explore the relationship between socioeconomic status and risk of complications.	<p>Complications: All complications significantly associated with at least one socioeconomic measure.</p> <p>At age 28 prevalence of overt nephropathy did not differ by SES status. At age 28 coronary artery disease (CAD) and lower extremity arterial disease (LEAD) prevalence was low as was autonomic neuropathy (AN) and proliferative retinopathy (PR). Smoking was less prevalent in the top three Socioeconomic groups ($p < 0.01$ for all).</p> <p>At baseline:</p> <p>Education at age 28 was the only significant SES measure associated with end stage renal disease (ESRD) ($p = 0.01$) or CAD ($p = 0.002$).</p> <p>Income at age 28 associated with LEAD ($p = 0.04$), but not with education or occupation.</p> <p>Low income and non-professional status associated with AN $p = 0.02$ and 0.03 respectively).</p> <p>No SES measure associated with proliferative retinopathy.</p> <p>After adjustments for other key variables:</p> <p>low Income and association with LEAD persisted.</p> <p>Income continued to show association with AN after adjustment.</p> <p>Income but not education was persistently associated with ESRD and Lead after adjustment for other risk factors.</p>

Appendix 6: Socioeconomic Status and Morbidity in Type 1 Diabetes

Author/Date	Study aims	Study findings reported for adults with type 1 diabetes
Wolf et al. (2011)	To investigate socioeconomic status associations and renal function.	Renal function: Socioeconomic status was not an independent factor for low renal function in type 1 diabetes.
Sastre et al. (2012)	To assess glycaemic control, cardiovascular risk factors and treatment regimens in type 1 diabetes.	Cardiovascular risk factors: In univariate analysis low educational level (or no primary education was associated with a greater prevalence of cardiovascular risk factors. Patients with a greater number of risk factors had higher HbA1c levels (7.8% for one factor versus 8.5% for four factors, $p < 0.001$).
Butalia et al. (2013)	To identify the clinical and socio-demographic factors associated with hospitalization for diabetic ketoacidosis.	Diabetic ketoacidosis: (DKA) No association between hospitalization for DKA and income. Associations found with DKA : longer duration of diabetes, associated with lowered odds (OR 0.96 per year, 95% CI: 0.95-0.98), gastroparesis (OR 4.13 95% CI 1.82-9.35) and psychiatric disorders (OR 1.98, 95% CI: 1.22-3.19) and higher HbA1c (OR 1.25, 95% CI: 1.16-1.35).
Weinstock et al. (2013)	To determine the frequency and factors associated with severe hypoglycaemia and diabetic ketoacidosis.	Hypoglycaemia: Lower socioeconomic status was associated with higher frequency in both severe hypoglycaemia and diabetic ketoacidosis. Severe hypoglycaemia was more likely in those with low education ($p = 0.003$), lower household income ($p < 0.001$) and those that did not have private insurance ($p < 0.001$). Severe hypoglycaemia was associated with diabetes duration ($p < .001$)(with 18.6% of those having diabetes for ≥ 40 years having an event in the last 12 months), was less frequent in those whose HbA1c levels were in the range 7.0% (53 mmol/mol) - 7.5% (58 mmol/mol) and more frequent in those whose HbA1c levels were $< 7.0\%$ (< 53 mmol/mol) or $> 7.0\%$ (> 58 mmol/mol). Diabetic ketoacidosis was associated with lower education level, lower income and insurance status ($p > 0.001$ for each). Diabetic ketoacidosis was associated with higher HbA1c levels ($p < 0.001$), particularly those with HbA1c $\geq 10.0\%$ (≥ 86 mmol/mol).
Anderson et al. (2014)	To investigate the association of socioeconomic factors and prescribing for painful neuropathy.	Neuropathic pain: In univariate analysis each unit increase in Townsend score was associated with 11.5% increased risk of being prescribed medication for neuropathic pain (OR 1.11 95% CI: 1.06-1.17). In multivariate analysis each unit increase in Townsend score was associated with an 11% increased odds of requiring pain treatment (OR 1.11 95% CI: 1.05-1.17, $p < 0.001$), independent of age, male gender, systolic blood pressure and estimated glomerular filtration rate.

Appendix 7: Study Documents

Appendix 7.1: Ethics Approval Letter

Appendix 7.2: Information Sheet for Staff (Parts One and Two)

Appendix 7.3: Patient Information Sheet (Parts One and Two)

Appendix 7.4: Information Sheet for Accompanying Individuals (Part One)

Appendix 7.5: Information Sheet for Staff (Part Three)

Appendix 7.6: Information Sheet for Patients (Part Three)

Appendix 7.7: Letter of Invitation to Patient (Parts One and Two)

Appendix 7.8: letter of Invitation to Patient (Part Three)

Appendix 7.9: Reply Form All Study Parts

Appendix 7.10: Consent Form for Staff (Part One)

Appendix 7.11: Consent Form for Patients (Part One)

Appendix 7.12: Consent Form for Accompanying Individuals (Part One)

Appendix 7.13: Consent Form for Staff Interviews (Parts Two and Three)

Appendix 7.14: Consent Form for Patient Interviews (Parts Two and Three)

Appendix 7.15: Example Topic Guide for Patients

Appendix 7.16: Example Topic Guide for Staff

Appendix 7.17: Field Notes Form

Appendix 7.1: Ethics Approval Letter



National Research Ethics Service

NRES Committee East Midlands - Nottingham 2
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839428
Facsimile: 0115 9123300

16 November 2011

Mrs Anne Scott
Postgraduate Research Student
University of Sheffield
SchARR, University of Sheffield, Regent Court, 30 Regent St
Sheffield
S1 4DA

Dear Mrs Scott

Study title: Decision making processes in the use of technology for
Type 1 diabetes: Lay and Clinician Perspectives: Impact
on Access and Allocation
REC reference: 11/EM/0381

Thank you for your email of 8th November 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

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

Conditions of the favourable opinion

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

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

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

This Research Ethics Committee is an advisory committee to the East Midlands Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		07 October 2011
Investigator CV	Anne Scott	06 October 2011
Investigator CV	Alicia O'Cathain	03 October 2011
Letter of invitation to participant	1 - Study parts 1 and 2	04 October 2011
Letter of invitation to participant	1 - study part 3	04 October 2011
Other: ESRC+3 Postgraduate Studentship		02 August 2010
Other: Outline Topic Guide - decision making processes in the use of technology for type 1 diabetes	1	04 October 2011
Other: Reply form research study - Study parts 1, 2 and 3	1	04 October 2011
Participant Consent Form: Patients - Interviews - Study parts 2 and 3	2	07 November 2011
Participant Consent Form: Patients - Clinic 5 - Study part 1	2	07 November 2011
Participant Consent Form: Staff interviews - Study parts 2 and 3	2	07 November 2011
Participant Consent Form: Staff - Clinic 5 - Study part 1	2	07 November 2011
Participant Consent Form: Individuals accompanying patients - Clinic 5	2	07 November 2011
Participant Information Sheet: Information for staff - clinic 5 - Study parts 1 and 2	1	04 October 2011
Participant Information Sheet: Information for GP practice staff - study part 3	1	04 October 2011
Participant Information Sheet: Individuals accompanying patients - Clinic 5 - Study part 1	2	07 November 2011
Participant Information Sheet: Patients - Clinic 5 - Study parts 1 and 2	2	07 November 2011
Participant Information Sheet: Patients - GP practice - Study Part 3	2	07 November 2011
Protocol	1	04 October 2011
REC application	85473/255111/1/257	06 October 2011
Referees or other scientific critique report	Reviewers checklist 1	
Referees or other scientific critique report	Scientific Reviewers Comments 1 - Maxine Johnson	29 September 2011

Referees or other scientific critique report	Scientific reviewers checklist 2	
Referees or other scientific critique report	Scientific reviewers comments 2 - Annette Haywood	27 September 2011
Response to Request for Further Information		08 November 2011
Summary/Synopsis	1	04 October 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

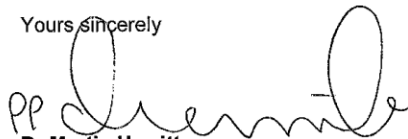
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/EM/0381	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely


Dr Martin Hewitt
Chair

E-mail: heather.harrison@nottspct.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Printed on headed notepaper

INFORMATION FOR STAFF – CLINIC X

Decision making processes in the use of technology for Type 1 diabetes

This leaflet tells you about a study looking at how decisions are made regarding different insulin treatments for Type 1 diabetes.

We are asking individuals with Type 1 diabetes who attend Clinic X to take part in a study.

We would like to study how decisions are made about insulin treatments when individuals attend clinic appointments.

To do this a researcher would like to record patient consultations with medical staff.

You are being invited because your patients are being selected to take part in this study.

We require your consent to audio digitally record these consultations.

We would also like to invite you to participate in an interview with a researcher to discuss your input into the decision making process.

Introduction

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The study aims to find out about how decisions are made regarding insulin regimens and what influences these decisions. To carry out the research we would like to record consultations in diabetic clinics (Clinic X). We would also like to invite you to participate in a follow up interview.

Why have I been chosen?

You are being invited because your patients are being invited to take part in this study. We will be selecting patients who attend Clinic X appointments and who have had diabetes for at least one year.

Do I have to take part?

It is up to you to decide. You will be asked at clinic if you would be interested in taking part in the study. We will go through this information sheet and answer any questions you may have. You will be given time to consider if you want to take part. If you want further information, please telephone us (the number is at the end of the information sheet). If you decide to take part you can withdraw at any time without giving a reason.

What will happen if I take part?

If you decide to take part, the researcher will ask you to sign a consent form to show you have agreed. Consent will be for the duration of the study.

During the appointment

The researcher will sit in on the consultation and record what is said (using an audio digital recorder). The researcher will make other brief notes about the consultation including: who is present and details about the patient's current insulin regimen. The researcher will ask the medical staff for details about the patient's last recorded HbA1c test but will not have access to the patient's medical record.

Follow up interview

The researcher will invite you to take part in an interview to discuss the decision making processes involved in allocating different treatment regimens and influences on these choices. If you agree, the researcher will arrange to interview at Clinic X on a different day. The interview will last approximately 40-50 minutes.

What are the possible benefits of taking part?

We do not anticipate immediate benefits to the research participants involved in this study. However, the research findings have the potential to inform improvements in the allocation of technology. The findings will be disseminated to staff and this may inform future patient/clinician interactions. Participating in the study may lead to improved patient awareness about their condition.

What are the possible disadvantages and risks of taking part?

We do not expect that there will be any disadvantages or risks to you taking part. At any time during the course of the consultation you may ask the researcher to leave, for example if you or the patient would prefer to speak privately. If the patient becomes upset at any point during your consultation, the researcher will leave without needing to be asked. In this last case the researcher will turn off and erase the recording.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal requirements to ensure that all information about you is stored securely. All information stored about you will be kept strictly confidential. We will keep your name separate from any information collected. This information will be identified by a study number. Your information will only be viewed by the researcher and her academic supervisors.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time, (including during the consultation or interview) but data will be used up to the point that you withdraw unless you request that data collected is excluded.

What will happen to the results of the research study?

The findings will be written up as a thesis for a PhD. A shorter report will be written and disseminated to staff involved in the study. This will also be shared with Diabetes UK. The results will also be written up and submitted to academic journals.

Who is organising and funding the research?

The study is being organised by the University of Sheffield. The research is being undertaken as part of a PhD project funded by the Economic and Social Research Council.

Who has reviewed the study?

All research in the NHS is looked at by independent Research Ethics Committees. This is to protect your safety, rights, wellbeing and dignity. This study has been reviewed by Nottingham Local Research Ethics Committee 2.

Further information and contact details

If you have any questions about the study, wish to discuss taking part or have any concerns, please contact the researcher leading the study:

Anne Scott
University of Sheffield
ScHARR, Regent Court, 30 Regent St
Sheffield, S1 4DA
Tel: 07785 230725 Email: anne.scott@sheffield.ac.uk

The Academic Supervisor for the project is:
Professor Alicia O'Cathain
University of Sheffield
ScHARR, Regent Court, 30 Regent St
Sheffield, S1 4DA
Tel: 0114 2220770 Email: a.ocathain@sheffield.ac.uk

Finally, thank you for reading this leaflet.

Appendix 7.3: Patient Information Sheet (Parts One and Two)

Printed on headed notepaper

PATIENT INFORMATION SHEET – CLINIC

Decision making processes in the use of technology for Type 1 diabetes

This leaflet tells you about a study looking at how decisions are made regarding different insulin treatments for Type 1 diabetes.

We are asking individuals with Type 1 diabetes who attend Clinic 5 to take part in a study.

We would like to study how decisions are made about insulin treatments when individuals attend clinic appointments.

To do this a researcher would like to record your appointment conversation with medical staff.

We may also invite you to participate in an interview with a researcher to discuss your treatment choices in the past as well as the present.

If you would like to find out more, please read the rest of this leaflet. A larger type version of this leaflet is available.

Introduction

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk about the study with others if you wish, for example a friend, relative, nurse or doctor. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The study aims to find out about how decisions are made regarding insulin regimens and what influences these decisions. To carry out the research we would like to record your consultation. We may also ask you to participate in a follow up interview.

Why have I been chosen?

You have been chosen because you have type 1 diabetes and you attend a specialist diabetes clinic as part of your care. We will be selecting patients who attend Clinic 5 appointments and who have had diabetes for at least one year. Your consultant or specialist diabetes nurse has helped us to identify who to invite to take part. We need a range of individuals on different insulin regimens. In total we need about 40 people to help with this study.

Do I have to take part?

It is up to you to decide. You may be contacted by letter or asked at clinic if you would be interested in taking part in the study. You will be given time to consider if you want to take part. If you decide that you would like to take part, please return the reply form (in postage paid envelope). Alternatively if you prefer you may telephone clinic 5 (contact details are on the attached letter). If you want further information, please telephone or e-mail us (the details are at the end of the information sheet). At your clinic appointment we will go through this information sheet and answer any questions you may have. If you decide to take part you can withdraw at any time without giving a reason. This would not affect the standard of care you receive.

What will happen if I take part?

If you decide to take part, the researcher will arrange to meet you at your next clinic appointment. The researcher will check that you still want to be involved in the study. The researcher will ask you to sign a consent form to show you have agreed. If you are accompanied by a friend or family member and they will be sitting in on your appointment we will also ask them to sign a consent form as well. If you have to stay longer at the hospital because of the research (talking to the researcher before and after your appointment) we will reimburse your car parking charges.

Before the appointment

We will ask you for some background details such as your age and how long you have had diabetes.

During the appointment

The researcher will sit in on your appointment with the doctor or nurse and record what is said (using an audio digital recorder). This will record the conversation. The researcher will make other brief notes about your consultation including: who is present and details about your current insulin regimen. The researcher will ask the medical staff for details about your last recorded HbA_{1c} test but will not have access to your medical record.

After the appointment

The researcher may invite you to take part in an interview to discuss the consultation and the types of treatment you have had since being diagnosed. If you agree the researcher will arrange to meet you at a place of your choosing (for example at home or hospital) on a different day. The interview will last approximately 60 minutes. If you attend the hospital for the purposes of the interview you will be reimbursed car parking and travel expenses.

What are the possible benefits of taking part?

We do not anticipate immediate benefits to the research participants involved in this study. However, the research findings have the potential to inform improvements in the allocation of technology. The findings will be disseminated to staff and this may inform future patient/clinician interactions. Participating in the study may lead to improved patient awareness about their condition.

What are the possible disadvantages and risks of taking part?

We do not expect that there will be any disadvantages or risks to you taking part. At any time during the course of the consultation you may ask the researcher to leave, for example if you would prefer to speak privately with the doctor or nurse. If you become upset at any point during your consultation the researcher will leave without you needing to ask. In this last case the researcher will turn off and erase the recording. Sensitive issues will not be included in the interview, however, if you become distressed or worried for any reason during the conversation, the researcher will ask if you want to continue. If you decide not to proceed, the researcher will stop the recording and end the interview. Any concerns that cannot be resolved with the researcher will be referred to the clinical care team.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal requirements to ensure that all information about you is stored securely. All information stored about you will be kept strictly confidential. We will keep your name separate from any information collected. This information will be identified by a study number. Your information will only be viewed by the researcher and her academic supervisors.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time, (including during the consultation or interview) but data will be used up to the point that you withdraw unless you request that data collected is excluded.

What will happen to the results of the research study?

The findings will be written up as a thesis for a PhD. A shorter report will be written and to be disseminated to staff involved in the study. This will also be shared with Diabetes UK. The results will also be written up and submitted to academic journals.

Who is organising and funding the research?

The study is being organised by the University of Sheffield. The research is being undertaken as part of a PhD project funded by the Economic and Social Research Council.

Who has reviewed the study?

All research in the NHS is looked at by independent Research Ethics Committees. This is to protect your safety, rights, wellbeing and dignity. This study has been reviewed by Nottingham Local Research Ethics Committee 2.

Further information and contact details

If you have any questions about the study, wish to discuss taking part or have any concerns, please contact the researcher leading the study:

Anne Scott
University of Sheffield
ScHARR, Regent Court, 30 Regent St
Sheffield, S1 4DA
Tel: 07785 230725 Email: anne.scott@sheffield.ac.uk

If you have any queries about participating in research or complaints you can contact the hospital's Patient Advice and Liaison Service (PALS) (contact details are on the bottom of this page).

The Academic Supervisor for the project is:
Professor Alicia O'Cathain
University of Sheffield
ScHARR, Regent Court, 30 Regent St
Sheffield, S1 4DA
Tel: 0114 2220770 Email: a.ocathain@sheffield.ac.uk

Finally, thank you for reading this leaflet.

Version 3 – 05/01/2012 – Study Parts One and Two

Appendix 7.4: Information Sheet for Accompanying Individuals (Part One)

Printed on headed notepaper

INFORMATION SHEET - INDIVIDUALS ACCOMPANYING PATIENTS – CLINIC X

Decision making processes in the use of technology for Type 1 diabetes

Introduction

We are conducting a study in Clinic X looking at how decisions are made regarding insulin treatments for type 1 diabetes. To carry out the research we would like to record a number of consultations in Clinic X. You are accompanying a patient who has been invited to participate in the study. If you are accompanying the patient during their consultation we will need your consent as well as that of the patient. This is because we will be recording the conversations during the consultation and you may be involved in these discussions.

The researcher will sit in on the appointment with the doctor or nurse and record what is said (using an audio digital recorder). You or the patient can choose to withdraw from the study at any time. If the patient becomes upset at any point during the consultation the researcher will leave without needing to be asked. In this last case the researcher will turn off and erase the recording.

The study is being organised by the University of Sheffield. The research is being undertaken as part of a PhD project funded by the Economic and Social Research Council.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal requirements to ensure that all information about you is stored securely. All information stored about you will be kept strictly confidential.

Further information and contact details

If you have any questions about the study, or have any concerns, please contact the researcher leading the study:

Anne Scott, University of Sheffield, ScHARR, Regent Court, 30 Regent St, Sheffield, S1 4DA
Tel: 07785 230725 Email: anne.scott@sheffield.ac.uk

If you have any queries about participating in research or complaints you can contact the hospital's Patient Advice and Liaison Service (PALS) (contact details are on the bottom of this page).

The Academic Supervisor for the project is:

Professor Alicia O'Cathain, University of Sheffield, ScHARR, Regent Court, 30 Regent St
Sheffield, S1 4DA, Tel: 0114 2220770 Email: a.ocathain@sheffield.ac.uk

Version 3 – 05/01//2012 – Study Part One

Printed on headed notepaper with patient's address

INFORMATION FOR GP PRACTICE STAFF

Decision making processes in the use of technology for Type 1 diabetes

This leaflet tells you about a study looking at how decisions are made regarding different insulin treatments for Type 1 diabetes.

We are asking individuals with Type 1 diabetes who attend a specialist diabetes clinic to take part in a study.

In this part of the study we would like to explore how decisions are made about insulin treatments when individuals attend clinic appointments.

We would also like to interview patients registered at your practice who do not currently access specialist diabetes services.

We would like to invite you to participate in an interview with a researcher to discuss your input into the decision making processes involved in treatment for these patients.

Introduction

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The study aims to find out about how decisions are made regarding insulin regimens and what influences these choices. The study is in two parts. Part one focuses on patients attending a specialist diabetes clinic and involves both observations of consultations as well as follow up interviews. We would also like to interview patients who do not currently access specialist diabetes services as well as clinicians who provide their diabetes care.

Why have I been chosen?

You have been chosen because we are inviting patients in your practice to take part in the study who have type 1 diabetes and who do not currently attend specialist diabetes services.

Do I have to take part?

It is up to you to decide. We will go through this information sheet and answer any questions you may have. You will be given time to consider if you want to take part. If you want further information, please telephone us (the number is at the end of the information sheet). If you decide to take part you can withdraw at any time without giving a reason.

What will happen if I take part?

If you decide to take part in the interview, the researcher will ask you to sign a consent form to show you have agreed. The interview will last approximately 40-50 minutes.

What are the possible benefits of taking part?

We do not anticipate immediate benefits to the research participants involved in this study. However, the research findings have the potential to inform improvements in the allocation of technology. The findings will be disseminated to staff and this may inform future patient/clinician interactions. Participating in the study may lead to improved patient awareness about their condition.

What are the possible disadvantages and risks of taking part?

We do not expect that there will be any disadvantages or risks to you taking part.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal requirements to ensure that all information about you is stored securely. All information stored about you will be kept strictly confidential. We will keep your name separate from any information collected. This information will be identified by a study number. Your information will only be viewed by the researcher and her academic supervisors.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time, (including during the interview) but data will be used up to the point that you withdraw unless you request that data collected is excluded.

What will happen to the results of the research study?

The findings will be written up as a thesis for a PhD. A shorter report will be written and disseminated to staff involved in the study. This will also be shared with Diabetes UK. The results will also be written up and submitted to academic journals.

Who is organising and funding the research?

The study is being organised by the University of Sheffield. The research is being undertaken as part of a PhD project funded by the Economic and Social Research Council.

Who has reviewed the study?

All research in the NHS is looked at by independent Research Ethics Committees. This is to protect your safety, rights, wellbeing and dignity. This study has been reviewed by Nottingham Local Research Ethics Committee 2.

Further information and contact details

If you have any questions about the study, wish to discuss taking part or have any concerns, please contact the researcher leading the study:

Anne Scott
University of Sheffield
ScHARR, Regent Court, 30 Regent St
Sheffield, S1 4DA
Tel: 07785 230725

The Academic Supervisor for the project is:
Professor Alicia O’Cathain
University of Sheffield
ScHARR, Regent Court, 30 Regent St
Sheffield, S1 4DA
Tel: 0114 2220770

Finally, thank you for reading this leaflet.

Version 1 – 04/10/2011 – Study Part Three

Printed on headed notepaper with patient's address

PATIENT INFORMATION SHEET – GP PRACTICE

Decision making processes in the use of technology for Type 1 diabetes

This leaflet tells you about a study looking at how decisions are made regarding different insulin treatments for Type 1 diabetes.

We are asking individuals with Type 1 diabetes who attend different clinics to take part in this study.

The aim of the study is to look at the decision making processes involved in treatment for Type 1 diabetes.

You have been chosen because your care is currently being managed by your GP surgery.

We would like to invite you to take part in an interview with a researcher to discuss your insulin treatment (in the past as well as the present).

If you would like to find out more, please read the rest of this leaflet.

A larger type version of this leaflet is available.

Introduction

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk about the study with others if you wish, for example a friend, relative, nurse or doctor. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The study aims to find out about how decisions are made regarding insulin regimens and what influences these decisions. We would like to invite you to take part in an interview with a researcher.

Why have I been chosen?

You have been chosen because you have type 1 diabetes and your care is currently being managed by the GP surgery. We will be selecting a number of individuals with Type 1 diabetes on a range of different insulin treatments. In total we need about 40 people to help with this study.

Do I have to take part?

It is up to you to decide. If you decide that you would like to take part, please return the reply form (in the postage paid envelope). A researcher will telephone you to discuss the study and if you are in agreement will arrange to interview you. If you want further information, please telephone us (the number is at the end of the information sheet). If you decide to take part you can withdraw at any time without giving a reason. This would not affect the standard of care you receive.

What will happen if I take part?

If you decide to take part, the researcher will arrange to interview you at a place of your choosing (for example at home or GP surgery). The interview will last approximately 60 minutes.

Before the interview

The researcher will check that you still want to be involved in the study. The researcher will ask you to sign a consent form to show you have agreed. We will ask you for some background details such as your age and how long you have had diabetes.

The interview

The researcher will discuss the types of treatment you have had since being diagnosed, how these were chosen and the clinics you have attended.

After the interview

The researcher will ask the GP surgery for details about your last recorded HbA_{1c} test but will not have access to your medical record.

What are the possible benefits of taking part?

We do not anticipate immediate benefits to the research participants involved in this study. However, the research findings have the potential to inform improvements in the allocation of technology. The findings will be disseminated to staff and this may inform future patient/clinician interactions. Participating in the study may lead to improved patient awareness about their condition.

What are the possible disadvantages and risks of taking part?

We do not expect that there will be any disadvantages or risks to you taking part. You may stop the interview at any time. In addition, you may decline to answer specific questions.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal requirements to ensure that all information about you is stored securely. All information stored about you will be kept strictly confidential. We will keep your name separate from any information collected. This information will be identified by a study number. Your information will only be viewed by the researcher and her academic supervisors.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time, (including during the interview) but data will be used up to the point that you withdraw unless you request that data collected is excluded. Sensitive issues will not be included in the interview, however, If you become distressed or worried for any reason during the conversation, the researcher will ask if you want to continue. If you decide not to proceed, the researcher will stop the recording and end the interview. Any concerns that cannot be resolved with the researcher will be referred to the clinical care team.

What will happen to the results of the research study?

The findings will be written up as a thesis for a PhD. A shorter report will be written and disseminated to staff involved in the study. This will also be shared with Diabetes UK. The results will also be written up and submitted to academic journals.

Who is organising and funding the research?

The study is being organised by the University of Sheffield. The research is being undertaken as part of a PhD project funded by the Economic and Social Research Council.

Who has reviewed the study?

All research in the NHS is looked at by independent Research Ethics Committees. This is to protect your safety, rights, wellbeing and dignity. This study has been reviewed by Nottingham Local Research Ethics Committee 2.

Further information and contact details

If you have any questions about the study, wish to discuss taking part or have any concerns, please contact the researcher leading the study:

Anne Scott
University of Sheffield
SchARR, Regent Court, 30 Regent St
Sheffield, S1 4DA
Tel: 07785 230725

If you have any queries about participating in research or complaints you can contact the Patient Advice and Liaison Service (PALS) Phone number given.

The Academic Supervisor for the project is:
Professor Alicia O’Cathain
University of Sheffield
SchARR, Regent Court, 30 Regent St
Sheffield, S1 4DA
Tel: 0114 2220770

Finally, thank you for reading this leaflet.

Version 2 – 07/11/2011 – Study Part Three

Appendix 7.7: Letter of Invitation to Patient (Parts One and Two)

Printed on headed notepaper with patient's address

Dear

We are collaborating in a study being organised by the University of Sheffield. You have been invited to take part because you attend Clinic X as part of the management of your Type 1 diabetes care.

The aim of the study is to look at the decision making processes involved in the treatment of Type 1 diabetes. To do this we would like to audio digitally record your next appointment at Clinic X. A researcher would be present at this appointment and would make notes about the conversation you have with medical staff. The researcher would ask medical staff for your last HbA1c result but would not have access to your medical record.

Some patients will also be asked to participate in a follow up interview with the researcher. This would be arranged at a time to suit you either at the hospital or your home whichever you would prefer. The interview would take about an hour.

If you are interested in the study please read the attached information sheet which provides more details. If having read the leaflet you are still interested, please sign, date and return the attached form to me (giving a contact telephone number). Alternatively, if you would prefer, please phone my secretary with your details on (insert phone number).

This will allow us to give your phone number to the researcher who will then contact you to discuss the study and if you are in agreement will make arrangements to meet you at your next appointment.

Your car parking charges will be reimbursed if your stay at the hospital is longer due to your involvement in the research.

The study is being undertaken as part of a PhD and is funded by an Economic and Social Research Council grant.

Thank you for taking the time to read this letter.

Yours sincerely

Diabetes Consultant

Version 2 – 05/01/2012 – Study Parts One and Two

Appendix 7.8: letter of Invitation to Patient (Part Three)

Printed on headed notepaper with patient's address

Dear

We are collaborating in a study being organised by the University of Sheffield. The aim of the study is to look at the decision making processes involved in the treatment of Type 1 diabetes. You have been chosen to take part because your care is currently being managed by the team at the Surgery.

We would like to invite you to take part in an interview with a researcher. This would be arranged at a time to suit you either at the Surgery or your home whichever you would prefer. The interview would take about an hour.

If you are interested in the study please read the attached information sheet which provides more details. If having read the leaflet you are still interested please sign, date and return the attached form to me (giving a contact telephone number). This will allow us to give your phone number to the researcher who will then contact you to discuss the study and if you are in agreement will make arrangements to interview you.

Thank you for taking the time to read this letter.

Yours sincerely

General Practitioner

Version 1 – 04/10/2011 – Study Part Three

Appendix 7.9: Reply Form all Study Parts

Printed on headed notepaper

REPLY FORM RESEARCH STUDY:

DECISION MAKING PROCESSES IN THE USE OF TECHNOLOGY FOR TYPE 1 DIABETES

I consent to my phone number being given to the researcher who will then be able to contact me about the above study.

My phone number is _____

Name of Participant

Date

Signature

Please return this form in the reply paid envelope

Appendix 7.10: Consent Form for Staff (Part One)

Printed on headed notepaper

CONSENT FORM – STAFF – CLINIC X

Title of Research Project: Decision making processes in the use of technology for Type 1 diabetes

Name of Researcher: Anne Scott

Sponsor: University of Sheffield

Participant Identification Number for this Project:

Please Initial Box

- | | |
|--|--------------------------|
| 1. I confirm that I have read and understand the information sheet Final Version dated (insert date) explaining the above research project and I have had the opportunity to ask questions. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences (Data will be used up to the point that I withdraw unless I request that data collected is excluded). | <input type="checkbox"/> |
| 3. I understand that the clinic appointment will be audio digitally recorded. The recording will be written out word-for-word and anonymous quotes may be used in reports, publications and journals. | <input type="checkbox"/> |
| 4. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. | <input type="checkbox"/> |
| 5. I understand that data collected during the study may be looked at by authorised individuals from the University of Sheffield, regulatory authorities or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my study data. | <input type="checkbox"/> |
| 6. I agree for the anonymised data collected from me to be used in future research. | <input type="checkbox"/> |
| 7. I agree to take part in the above research project. | <input type="checkbox"/> |

Name of Participant
(or legal representative)

Date

Signature

Name of person taking consent
(Lead Researcher)

Date

Signature

To be signed and dated in presence of the participant

2 Copies: 1 copy for participant (with letter and/or information sheet), 1 copy for the project file
Version 3 – 01/03/2012 – Study Part One

Appendix 7.11: Consent Form for Patients (Part One)

Printed on headed notepaper

CONSENT FORM – PATIENTS – CLINIC X

Title of Research Project: Decision making processes in the use of technology for Type 1 diabetes		
Name of Researcher: Anne Scott		
Sponsor: University of Sheffield		
Participant Identification Number for this Project:		Please Initial Box
1. I confirm that I have read (had read to me) and understand the information sheet Final Version dated (insert date) explaining the above research project and I have had the opportunity to ask questions.		<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences (Data will be used up to the point that I withdraw unless I request that data collected is excluded).		<input type="checkbox"/>
3. I understand that the clinic appointment will be audio digitally recorded. The recording will be written out word-for-word and anonymous quotes may be used in reports, publications and journals.		<input type="checkbox"/>
4. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.		<input type="checkbox"/>
5. I understand that data collected during the study may be looked at by authorised individuals from the University of Sheffield, regulatory authorities or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my study data.		<input type="checkbox"/>
6. I agree for the anonymised data collected from me to be used in future research.		<input type="checkbox"/>
7. I agree to take part in the above research project.		<input type="checkbox"/>
_____ Name of Participant (or legal representative)	_____ Date	_____ Signature
_____ Name of person taking consent (Lead Researcher) <i>To be signed and dated in presence of the participant</i>	_____ Date	_____ Signature
3 Copies: 1 copy for participant (with letter and/or information sheet), 1 copy for the project file 1 copy to be placed in the patient's medical record (with letter and/or information sheet)		
Version 3 – 01/03/2012 – Study Part One		

Appendix 7.12: Consent Form for Accompanying Individuals (Part One)

Printed on headed notepaper

CONSENT FORM – INDIVIDUALS ACCOMPANYING PATIENTS – CLINIC X

Title of Research Project: Decision making processes in the use of technology for Type 1 diabetes

Name of Researcher: Anne Scott

Sponsor: University of Sheffield

Participant Identification Number for this Project:

Please Initial Box

1. I confirm that I have read (had read to me) and understand the information sheet Final Version (insert date) explaining the above research project and I have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences (Data will be used up to the point that I withdraw unless I request that data collected is excluded).
3. I understand that the clinic appointment will be audio digitally recorded. The recording will be written out word-for-word and anonymous quotes may be used in reports, publications and journals.
4. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
5. I understand that data collected during the study may be looked at by authorised individuals from the University of Sheffield, regulatory authorities or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my study data.
6. I agree for the anonymised data collected from me to be used in future research.
7. I agree to take part in the above research project.

Name of Participant
(or legal representative)

Date

Signature

Name of person taking consent
(Lead Researcher)

Date

Signature

To be signed and dated in presence of the participant

2 Copies: 1 copy for participant (with letter and/or information sheet), 1 copy for the project file
Version 3 – 01/03/2012 – Study Part One

Appendix 7.13: Consent Form for Staff Interviews (Parts Two and Three)

Printed on headed notepaper

CONSENT FORM – STAFF INTERVIEWS

Title of Research Project: Decision making processes in the use of technology for Type 1 diabetes		
Name of Researcher: Anne Scott		
Sponsor: University of Sheffield		
Participant Identification Number for this Project:	Please Initial Box	
1. I confirm that I have read and understand the information sheet Final Version dated (insert date) explaining the above research project and I have had the opportunity to ask questions.	<input type="checkbox"/>	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences (Data will be used up to the point that I withdraw unless I request that data collected is excluded). In addition, should I not wish to answer any particular question, I am free to decline.	<input type="checkbox"/>	
3. I understand that the interview will be audio digitally recorded. The recording will be written out word-for-word and anonymous quotes may be used in reports, publications and journals.	<input type="checkbox"/>	
4. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	<input type="checkbox"/>	
5. I understand that data collected during the study may be looked at by authorised individuals from the University of Sheffield, regulatory authorities or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my study data.	<input type="checkbox"/>	
6. I agree for the anonymised data collected from me to be used in future research.	<input type="checkbox"/>	
7. I agree to take part in the above research project.	<input type="checkbox"/>	
_____	_____	_____
Name of Participant (or legal representative)	Date	Signature
_____	_____	_____
Name of person taking consent (Lead Researcher)	Date	Signature
<i>To be signed and dated in presence of the participant</i>		
2 Copies: 1 copy for participant (with letter and/or information sheet), 1 copy for the project file		
Version 3 – 01/03/2012 – Study Parts Two and Three		

Appendix 7.14: Consent Form for Patient Interviews (Parts Two and Three)

Printed on headed notepaper

CONSENT FORM – PATIENTS – INTERVIEWS

Title of Research Project: Decision making processes in the use of technology for Type 1 diabetes		
Name of Researcher: Anne Scott		
Sponsor: University of Sheffield		
Participant Identification Number for this Project:	Please Initial Box	
1. I confirm that I have read (had read to me) and understand the information sheet Final Version dated (insert date) explaining the above research project and I have had the opportunity to ask questions.	<input type="checkbox"/>	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences (Data will be used up to the point that I withdraw unless I request that data collected is excluded). In addition, should I not wish to answer any particular question, I am free to decline.	<input type="checkbox"/>	
3. I understand that the interview will be audio digitally recorded. The recording will be written out word-for-word and anonymous quotes may be used in reports, publications and journals.	<input type="checkbox"/>	
4. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	<input type="checkbox"/>	
5. I understand that data collected during the study may be looked at by authorised individuals from the University of Sheffield, regulatory authorities or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my study data.	<input type="checkbox"/>	
6. I agree for the anonymised data collected from me to be used in future research.	<input type="checkbox"/>	
7. I agree to take part in the above research project.	<input type="checkbox"/>	
_____	_____	_____
Name of Participant (or legal representative)	Date	Signature
_____	_____	_____
Name of person taking consent (Lead Researcher)	Date	Signature
<i>To be signed and dated in presence of the participant</i>		
2 Copies: 1 copy for participant (with letter and/or information sheet), 1 copy for the project file		
Version 3 – 01/03//2012 – Study Parts Two and Three		

Appendix 7.15: Example Topic Guide for Patients

Outline Topic Guide-Decision Making Processes in the use of Technology for Type 1 Diabetes
<i>Individuals with Diabetes</i>
Demographics Just to get started it would be really helpful to know a little bit about you. This is useful for the research I know a little about you already from the consultation. Can you just start by letting me know who you live with: Cover education and occupation since leaving school So if we can move onto the diabetes can you think about when you were diagnosed? Can you tell me what happened?
If we can move onto the diabetes can you think back to when you were first diagnosed. What happened
Firstly how long ago is since you were diagnosed <ul style="list-style-type: none">• History of the patient's diabetes symptoms how it was diagnosed• Impact on life• Key events in disease trajectory• Long and short term complications
I want to ask about the various regimens you have been on
First/Previous regimens <ul style="list-style-type: none">• What were you started on• Who was involved (GP specialist clinic)• Why was this chosen• What part did you play in the decision• What part did others play• impact on daily life
Current regimen <ul style="list-style-type: none">• when did current regimen start• why did the regimen change• who was involved in changing the regimen• what part did you play in the decision• what were the key influences on the change• describe current daily regimen• how does it compare• Impact on daily life• Carb counting – what's involved• Blood glucose monitoring – how often and what are the results• HbA1c have there been any changes since being on the new regimen• How often do you get blood checked• Comparison with previous regimen
Clinic Consultations in general Have you attended the specialist clinic in the past for your diabetes care <ul style="list-style-type: none">• How did you get to clinic• What's involved in attending – time off work etc• What clinics did you attend• How frequently

- **How** do you feel about frequency
- **How** long were the clinics

Last clinic consultation

- **Who** referred you to the clinic
- **Do you recall your last visit**
- **What** do you think about how that consultation went
- **What** did you want to discuss
- **Did** you feel you were able to discuss
- **What** were you expecting would happen
- **Did** you ask all your questions
- **What** were your feelings about the outcome of the consultation
- **What** part did you feel you played in the consultation decisions

Compare consultant clinics and nurse clinics

Decision making

- **What** part do you feel you play in deciding what treatments to have for managing the diabetes

Continuity and support

- **How** often have you seen this consultant /team
- **How would you describe the** relationship you with staff in the clinic
- **What** help and support have you had:
 - From clinic staff and other clinical staff
 - Family members
 - Courses/other sources

GP

- **How** often do you see your GP
- **How** long does it take to get to GP
- **How** do you get there
- **What** support do you get from the GP
- **What** kind of relationship do you have with the GP

Information

- **Where** do you get information about diabetes from

Before closing is there anything you would like to mention

We could talk for a long time and I could ask many more questions but we will have to draw this to a close now. Is there anything that you would like to mention to me that has occurred to you during this interview

I am really grateful to you for giving up your time today and inviting me into your home

Just to say again everything you have said will be treated in strictest confidence. Please contact us if you want to ask any questions our contact details are on the leaflet.

Do you have any questions about anything we have talked about
Thank you for taking part in the study

26/09/2012

Appendix 7.16: Example Topic Guide for Staff

Outline Topic Guide-Decision Making Processes in the use of Technology for Type 1 Diabetes
<i>Clinicians</i>
Clinic Background <ul style="list-style-type: none">• How long has clinician worked in this setting and as a clinician• How long involved with diabetes care• What is the role of the clinician in this setting• Do you sit in on any other clinics
Pump technology - I would like to start with asking about access to pump technology <ul style="list-style-type: none">• How do patients access pump technology in this hospital• Who refers patients to the pump clinic<ul style="list-style-type: none">○ is there a system or is at the discretion of clinicians○ Would some be more likely to refer• Other than clinical characteristics what would influence the decision to refer<ul style="list-style-type: none">○ What assessments would staff undertake before referring• I have heard that other hospitals utilise a panel approach to allocating pump technology – this seems a more formal approach than here can you give me your thoughts on that• Where would you say the decision to allocate pump technology is made• In terms of who gets pumps how fair do you think the system is in terms of who gets a pump or who might be referred for consideration for a pump<ul style="list-style-type: none">○ What part do non clinical factors play○ Is it luck of the draw who you see in terms of doctors and nurses○ Are some people more likely to be seen as potential candidates for a pump due to non clinical factors - have a lot of health related people or professional people in my sample is this typical<ul style="list-style-type: none">▪ Are the right people getting the pumps now and in the past• What influences the number of pumps that can be issued<ul style="list-style-type: none">○ Is there a limit
Pump technology other influences to access <ul style="list-style-type: none">• What impact can a change of consultants have on access to pumps<ul style="list-style-type: none">○ Changes over recent years○ Policy on discharging patients to GP• Who is eligible to attend a course<ul style="list-style-type: none">○ Are enough type 1 patients attending courses○ If not why not○ What is the impact of education on patients with type 1 diabetes
Consultation – referring to the pump clinic <ul style="list-style-type: none">• What is the objective of the pump clinic consultation<ul style="list-style-type: none">○ what is the team trying to achieve in 15 mins○ What do you feel about the appointment slot of 15 mins• What are the respective roles of staff present<ul style="list-style-type: none">○ How does the MDT approach work

- How do you feel your clinic is running now
 - What changes have you made - why
 - What problems have you encountered associated with the clinic
- Can you tell me about the approach to individuals who are struggling to manage their diabetes
 - Ideally on a pump HbA1c would improve what if it doesn't
 - HbA1c is deteriorating over time – how is this managed
- To what extent is withdrawal of pump an option
 - What part does quality of life play in these decisions
- Can you tell me about the system you have instigated where patients e-mail their results
 - Why was instigated - how is it working
 - How do patients feel about it

Decision making

- What is your approach to treatment decision making regarding the different insulin regimens
- what part do you play and what part is played by the patient
- What influences patients to take up the offer of a change of regimen
- What do you feel helps patients to make decisions in the consultation

Accessing Specialist Care – more generally

- What are the barriers/difficulties for patients in accessing specialist services
- The hospital is situated in an area of deprivation are these people represented amongst pump users
For people with Type 1 diabetes there is an obvious trend with the mortality rate increasing as the level of deprivation rises (national diabetes audit 2011)
- What are the challenges your service faces for this population in terms of access and their management of diabetes
- What services or support are available to patients who cannot attend the hospital clinic
- Describe the type of patient who is invited to attend clinic but does not attend
 - What about pump patients who do not attend
- What kinds of regimens are people on who have not attended clinic for several years

The role of Primary and Secondary Care in type 1 diabetes

- What are your views on the split care received by type 1 patients between GPs and hospital
 - does it work
- Are there any disadvantages to patients in being seen only by the GP
- How could the management of type 1 patients be improved
 - what is your vision for diabetes care in the coming years in this hospital

Just to say again everything you have said will be treated in strictest confidence. Please contact us if you want to ask any questions our contact details are on the leaflet. Thank you for taking part in the study.

19/03/213

Appendix 7.17: Field Notes Form

Field Notes				
Participant No		Participant No(s) (Staff):		
Other attendees:				
Clinic ¹ :	Date:	Clinic Duration:		
Socio-Demographic Details				
Sex:	Age:	Ethnic Origin:	Occupation:	Post Code:
Background Diabetes				
			HBA _{1c}	
Complications: None				
Treatment:				
Past Treatment:			Current Treatment:	
Consultation (Scope)				
<p>The researcher will record notes to aid analysis of transcribed consultations</p>				
08/09/2011			Page 1 of 2	

Field Notes (Cont)	
Consultation (Outcome)	
Appointment under 6 weeks	Appointment over 6 weeks -
Referral to other clinic:	
Discharge (reasons):	
¹ Clinic Codes: General Diabetes (A), Under 25's (B), Insulin Intensification Clinic (C), Nurse Led (D)	
08/09/2011	Page 2 of 2

Appendix 8: Conversation Analysis - Transcription Conventions

Speaker identifier: Patient (P); Doctor (D); Diabetes specialist nurse (N); Diabetes specialist dietitian (A); Partner (B).	
Characteristics of speech including timings and delivery adapted from Heritage and Maynard (2006b)	
Use of brackets	
[]	Overlapping speech
()	Empty brackets or words in single brackets denotes lack of clarity in recording or name of participant omitted
(())	Either an aspects of the recording is not straight forward to transcribe, for example coughing, or actions by participants, for example 'looking up records on a computer'
Timing of utterances	
(0.0)	Intervals in speech timed in tenths of a second
(.)	Timings that are less than 0.2 of a second
=	No pause between utterances
Speech delivery	
.	Period indicates a fall in intonation
↑↓	A marked rise or fall in pitch
<u>Underlined</u> words	Increased volume in relation to other utterances
::	Colons indicate stretching of words
◦word◦, ◦◦word◦◦	Use of degree sign indicates softly spoken words. Two degrees very softly spoken
> <	Speech speeded up
< >	Speech slowed down
.hhh	Audible inbreath
hhh	Audible outbreath
Hah hah	Laughter
-	Word cut-off or self-interruption

Appendix 9: Individual Characteristics of Patient Participants

Code	Regimen	Gender	Age	HbA1c %	HbA1c m/mol	Diabetes years/ Months	SEC-2010 [#]
P1	MDI	Male	26	11.2	99	16 months	3
P2	Pump	Female	49	8.80	73	24 years	3
P3	Pump	Female	35	7.30	56	22 years	1
P4	Pump	Female	54	6.80	51	21 years	1
P5	Pump	Male	49	7.80	62	17 years	3
P6	Pump	Female	37	7.60	60	30 years	3
P7	Pump	Female	56	6.80	51	33 years	1
P8	Pump	Male	39	7.80	62	32 years	1
P9	Pump	Male	65	6.20	44	12 years	2
P10	Pump	Male	21	9.40	79	12 years	3
P11	Pump	Female	54	7.10	54	41 years	1
P12	Pump	Male	40	8.10	65	20 years	1
P13	Basal/Bolus	Male	34	8.50	69	7 years	2
P14	Pump	Male	79	6.70	50	57 years	1
P15	MDI	Female	31	9.70	83	14 years	2
P16	Pump	Female	46	8.30	68	37 years	1
P17	Pump	Male	44	9.90	85	14 years	3
P18	Pump	Female	38	9.70	83	3 years	1
P19	Pump	Female	49	8.60	70	26 years	2
P20	MDI	Male	47	14.00	130	6 years	3
P21	MDI	Female	21	15.20	143	8 years	2
P22	Pump	Male	44	7.50	58	33 years	1
P23	Pump	Female	20	7.80	62	14 months	N
P24	MDI	Female	60	8.10	65	19 years	1
P25	MDI	Female	55	9.70	83	16 years	2
P26	MDI	Female	39	7.50	58	12 years	2
P27	Basal/Bolus	Male	48	7.50	58	36 years	3
P28	MDI	Male	48	7.00	53	37 years	3

[#] Socioeconomic status – Standard Occupation Classification

Three classes: 1 = Higher Managerial and Professional; 2 = Intermediate; 3 = Routine and Manual; N = Not Classified (Office for National Statistics 2010b).

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